Advocating for HIV Prevention and Care: A Critical Role for Older Women Living With HIV in Rural Kenya

Peninnah M. Kako1, Jennifer W. Kibicho1, Lucy Mkandawire-Valhmu1, Patricia E. Stevens1, and Anne K. Karani2

Abstract
The number of older women living with HIV in Kenya is increasing. However, there are little empirical data available about their role in HIV prevention. The purpose of this study was to understand the nuanced role of older women in HIV prevention. We engaged 54 HIV-positive women in three narrative-eliciting interviews between 2009 and 2010 over a period of 6 months to understand their role in HIV prevention. In this article, we focus on a sample subset of 7 rural women 50 years and older living with HIV. From narrative analysis of 19 interviews from 7 women who were 50 years and older, four themes emerged: promoting HIV transmission risk reduction, promoting HIV testing, educating others about HIV, and protecting children from HIV infection. HIV-positive older women are engaged in helping mitigate HIV in their communities and should be central to meaningful HIV-related interventions especially in rural communities.

Keywords
HIV and AIDS, women 50 years and older, rural, advocacy role, qualitative

Background
HIV continues to be a major public health problem in sub-Saharan Africa, home to 70% of persons living with HIV globally with women bearing the most HIV burden (UNAIDS, 2010). In Kenya, as more people access life-saving antiretroviral drugs and live longer, there is an urgent need to find ways of preventing HIV transmission including the role of older persons living with HIV. Although there remains limited information about challenges faced by older HIV-positive women living in sub-Saharan Africa, there is a greater paucity of research related to the advocacy role of HIV-positive older women in curtailing HIV infection in their communities (Gavazzi, Herrmann, & Krause, 2004). For instance, since the 1996 launching of the Joint UNAIDS to strengthen the UN response to the pandemic, HIV/AIDS reporting has focused on 15 to 49 years. Only in 2006 did this reporting shift to 15 years and older, and even then, there was no specific prevalence reporting for persons 50 and older (Gillett & Parr, 2010). Similarly, in Kenya, where the overall HIV prevalence rate was 6.3% in 2009, previous population

1University of Wisconsin–Milwaukee College of Nursing, WI, USA
2University of Nairobi, Kenya

Corresponding Author:
Peninnah M. Kako, University of Wisconsin–Milwaukee, College of Nursing, P.O. Box 413, 1921 E. Hartford Avenue, Milwaukee, WI 53201, USA.
Email: pmkako@uwm.edu
surveys have targeted respondents of reproductive age, and only until recently did the national HIV prevalence surveys include persons 50 years and older (Turan, Miller, Bukusi, Sande, & Cohen, 2008; Van Damme, Kober, & Kegeles, 2008; World Health Organization [WHO], 2007). Increasingly, HIV-positive peers are taking part in the task shifting to support HIV-related treatment, care, and support (Tenthani et al., 2012). However, HIV-positive older women’s role as advocates for HIV prevention remains underexplored.

It is imperative that clinicians, researchers, and policy makers no longer overlook the growing population of older persons, especially the role of older women living with HIV (National AIDS STI Control Programme and Ministry of Health Kenya, 2008; Negin & Cumming, 2010). As global advocacy for zero discrimination, zero new HIV infections, and zero AIDS-related deaths through universal access to effective HIV prevention, treatment, care, and support (UNAIDS, 2010), creative approaches that engage HIV-positive older women will be critical. To be effective in countries like Kenya, where the cultural context is focused on a collective perspective versus a more individualistic perspective that is more endemic to Western societies, HIV-prevention programs need to consider locally held beliefs and practices as well as the family and communal context of the women (Ngula & Miller, 2010). Although initial efforts were based on an individualistic Western worldview, there is hope that emerging interventions are beginning to pay attention to local contextual factors (Rasool, Syed, & Siddiqi, 2011).

In Kenya, and especially in rural Eastern Kenya, gender power inequities that favor men persist. In particular, although the rate of traditional marriages is decreasing, in some areas of Kenya, especially in the rural areas, polygamy persists, in which older men marry young girls as second, third, or even fourth wives (KNBS and ICF Macro, 2010). Traditionally, polygamy was meant to be protective and supportive of children (Mbiti, 1990) but favored men. Generally, the position of women and girls in sub-Saharan Africa is that of subservient one, usually present at birth and nurtured through adolescence and into adulthood until marriage (Hattori & DeRose, 2008). Capturing the role of older women in the era of HIV could highlight cultural practices that put women at risk of HIV and could help facilitate HIV prevention.

Much of the research on HIV-positive older women has been conducted in developed countries (Centers for Disease Control and Prevention, 2009; Hillman, 2007; Levy-Dweck, 2005; Plach, Stevens, & Keigher, 2005). In sub-Saharan Africa, the HIV-related studies that have included older women have focused mostly on their role as grandparents and caretakers, particularly of orphaned children (Horwitz, Yogo, Juma, & Ice, 2009; Kyobutungi, Egondi, & Ezeh, 2010). The advocacy role of HIV-positive older women has so far not been well articulated in Kenya (Kyobutungi, Ezeh, Zulu, & Falkingham, 2009; Muturi & Mwangi, 2011). To design locally applicable HIV-prevention interventions, women voices are critical, given that women, in particular older women, are involved in day-to-day family and community activities (Njue, Rombo, & Ngige, 2007). As more people know their HIV status in resource-limited rural areas, studies designed to harness the power and wisdom of older women living with HIV are needed.

Method
Postcolonial Feminism and Narrative Inquiry Framework

In this longitudinal qualitative study, we utilized postcolonial feminist perspective and narrative inquiry to elicit older women’s voices about their role in preventing HIV. In utilizing a postcolonial feminist lens, we ascribe that Kenyan women, although they live in oppressive patriarchal societies, as is the case with most societies around the world, are not victims but active participants in planning their health (Anderson, 2004). A postcolonial feminist perspective acknowledges not only the colonial impact on formal education (Mweti, 2008) but also the persistent effect of that colonialism. Our postcolonial feminist perspective enabled us to analyze women narratives with the understanding that gender roles are socially constructed and that women occupy marginalized spaces in society, which place them at greater risk of HIV infection (Gortner, 1993). Given the older women’s experiences with HIV infection and the respect and wisdom that are culturally awarded to the elders (Mbiti, 1990), HIV-positive older women have strategic ability to influence others in their communities and contribute to development of culturally meaningful HIV-prevention interventions and programming. In this article, we provide a forum where older women share their knowledge using empowering modes of telling (Spivak, 1988).

Using a narrative inquiry methodology to collect data offered a platform for women to tell their stories in a way that was meaningful to them. In rural Kenya where we conducted our study, narratives have played an important role in the history and culture of local rural women from the pre-colonial era onward (Mbiti, 1990). Eliciting narratives from older women living with HIV afforded a platform from which silenced voices of women could be heard. Riessman (2008) has defined narrative inquiry as storytelling whereby the narrator chooses to tell their story in a manner that is meaningful to them. Narrative inquiry then is an amalgam of analytic lenses and methods that revolve around an interest in biographical particulars communicated from the narrator’s point of view (Chase, 2005). Storytelling breaks abstract concepts into concrete, meaningful concepts for local women (Mweti, 2008). To elicit women narratives, we used open-ended questions to help guide the women’s stories. Verbal and nonverbal statements of affirmation were given to communicate to the women that we were listening and that we...
wanted them to continue telling the story in their own way. By using postcolonial feminism and narrative inquiry, we acknowledge the need for self-reflection (Racine, 2003). We used self-reflection throughout the data collection and analysis by continually examining our values, assumptions, and motivations to identify how they might affect interpretation of the data (Riessman, 2008).

Recruitment

We used purposive sampling to recruit a total sample of 7 women who were 50 years and older from the original larger sample of 54 women. Women were included in the study if they were (a) conversant in English, KiSwahili, or Kikamba; (b) self-reported as HIV-positive; and (c) accessing HIV-related health care at three rural clinics (Nyblade, Singh, Ashburn, Brady, & Olenja, 2011). Women were excluded if they did not meet the criteria, were not willing to be interviewed, or were too ill to participate in interviews. The Institutional Review Board at the University of Wisconsin–Milwaukee; the Kenyatta National Hospital (KNH) Ethics Committee; and the Ministry of Education, Science, and Technology approved the research prior to our commencing the study. Women attending rural health clinic were approached by clinic staff or volunteer peer educators and offered initial information about the study. Those interested in the study were directed to the first author who reviewed the research in detail with potential participants. Those women willing to voluntary participate gave oral informed consent prior to beginning the interview and gave written permission to audiotape the interview prior to our commencing digital audio recording. To ensure privacy, interviews were conducted in a private room at the clinic or at subgroup meeting center based on the participant’s preference.

Data Collection and Analysis

We conducted individual in-depth interviews between July 2009 and March 2010, beginning with an initial interview, followed by interviews at 1-month and 6-month intervals, for a series of three interviews. All participants consented to the study and granted permission for the first author to digitally audio record prior to initiating interviews. Each woman received a nominal incentive of 2 kg of wheat flour and a half liter of cooking oil as a thank-you token for participating. Women were aware that they would receive the token even if they did not complete the interview.

After initial demographic data collection, using open-ended questions, the first author explored questions about the circumstances around their discovery of their HIV diagnosis and subsequent events, their experiences with HIV transmission risk, and self-care management. Subsequent interviews sought to determine how women managed their HIV illness, including how they helped other women access HIV testing. We also asked questions about how they would help other women if they had a chance. For instance, we asked questions such as “If you had a chance to talk to other women who did not know their status, what would you tell them?” (Figure 1). Women often told long stories about how they had helped other women. Interviews lasted 45 min to 2 hr and were digitally recorded. Before conducting the subsequent interviews, initial interviews were transcribed and reviewed to determine the need for clarification on any of the points initially discussed. To foster confidentiality and protect participants’ privacy, transcriptions and field notes that could be traced to participants were stored in a locked file cabinet accessible only to the investigators and pseudonyms were used to avoid indentifying the women and audio recordings were erased after transcription, translation, and data verification. Six of the seven women completed all three interviews, and one of the women completed one interview. By using narrative-eliciting interviews of women 50 years and older who participated in our study, we were able to achieve data saturation.

A research assistant proficient in Kikamba, KiSwahili, and English simultaneously transcribed and translated interviews into English. The first author, a native of Kenya and familiar with the local language, first checked the transcripts

Figure 1. Narrative Eliciting Interview Guide.

| How did you find out you had HIV? |
| How did you contract HIV? |
| What has happened since you found out you had HIV? |
| How has HIV affected you and your family? |
| How have others reacted to you in the time since you have had HIV? |
| What do you do to keep yourself healthy? |
| What are some of the hardest things that have happened since the HIV? |
| What helps you the most to live with HIV? |
| If you had the chance to talk to another woman who just found out she had HIV, what would you tell her? |
| How best can persons living with HIV take care of themselves? What are some of the things you would recommend a person living with HIV should do? |
| How is it like living with HIV in this community? |
against the original recordings for inconsistencies before analysis by reading the transcripts and comparing them with field notes. We then read each woman’s narrative and completed within-case analysis identifying thematic narratives in relation to their advocacy role. After within-case analysis, we compared themes across women and identified the common emerging themes on advocacy. The first two authors independently coded the transcripts and compared final themes for inter-coder congruency. All authors read and compared the final themes and made adjustments as needed. Data were managed using NVivo 8 data management software, which allowed for thematic narrative coding (Richards, 2005).

**Sample Description**

The mean age of the seven women who were 50 years and above was 55 years ($SD = 6.30$). The majority 71% ($n = 5$) were widowed; two women were married. Of the widowed women, four of the five women lost their husbands to AIDS-related illnesses. The highest formal educational level was seventh grade; four of the women had never attended formal schooling. Average time since HIV diagnosis was 9 years ($SD = 5.5$). All seven women participating in this study were living in rural Eastern Kenya in relatively poor conditions on less than US$1 dollar a day, reported support group attendance, and self-identified with Christian religion. For details on sample demographics, see Table 1.

**Results**

Using a postcolonial feminism perspective and narrative inquiry methodology to elicit older women’s stories during data analysis, we documented the advocacy role experiences of older HIV-positive women living in rural Eastern Kenya. Older HIV-positive women’s stories show that they face difficult challenges related to HIV illness and family responsibilities, yet are assertive about the advocacy role they play in their families and local communities challenging the notions of victimization. While older HIV-positive women attempt to make sense of their own HIV illness, they are also concerned about HIV prevention for other women and children. In the narratives, they shared strategies for mitigating HIV. We present these strategies in the following four themes: promoting condom use; promoting HIV testing; educating others about HIV; and protecting children from HIV infection. In the following section, we provide women’s narratives that exemplify these themes. Original transcriptions of the data presented in this article can be made available as needed.

**Promoting HIV Transmission Risk Reduction**

The women in our study shared how they encouraged others to use condoms or abstain from sexual relations. Women spoke of how they deliberately utilized their age to influence other women. For instance, older women spoke of how they had helped other women by giving them advice on how to keep themselves from engaging in casual relations with men by refusing to accept gifts from men for sex. To meet their family economic needs, some women in rural areas are often coerced by area men to do sexual favors in exchange for financial support. As Mrs. Betty exemplifies, women spoke of their role in helping other women to say no to such advances that put them at risk of HIV transmission:

> Women have many thoughts like they may desire to move [have sexual relations] with men but this should not be the case. Women should not think of getting money from men and obeying their bodily desires but they should do things positively.

For instance, Mrs. Emma spoke of how she supported women in her community by encouraging them to use condoms if they were not able to abstain:

> I counsel them and tell them to keep on trusting the Almighty God. I tell them to abstain from sex and not transmit it [HIV]. Yes those who cannot stay like that [abstain], we give them condoms. They take it well, and we normally explain to them how to use them [condoms].

Not all women endorsed condom use; some who had had negative past experiences of their own or of someone else shared their reservations about condom use with others. Mrs. Agnes expressed her concerns:

| Participant | Age | Marital status | Number of years in formal schooling | Number of children | Number of years since HIV diagnosis |
|-------------|-----|----------------|-----------------------------------|-------------------|-----------------------------------|
| Rachael     | 56  | Widow          | 6                                 | 7                 | 17                                |
| Emma        | 51  | Widow          | 7                                 | 5                 | 11                                |
| Beth        | 51  | Married        | 4                                 | 6                 | 9                                 |
| Rosinda     | 61  | Widow          | 0                                 | 10                | 8                                 |
| Agnes       | 67  | Married        | 0                                 | 6                 | 2                                 |
| Pauline     | 50  | Widow          | 0                                 | 4                 | 15                                |
| Betty       | 50  | Widow          | 0                                 | 9                 | 2                                 |

Table 1. Participants Demographics.
Promoting HIV Testing

Women spoke of utilizing every opportunity to help other women by encouraging them to go for testing, counseling them about HIV, and encouraging them to find a way of having their husbands tested. Older women spoke extensively of how they routinely advocated for other women by encouraging HIV testing and providing support after a woman tested positive for HIV. Women encouraged others at risk of HIV, including those with HIV symptoms, or with husbands rumored to be having extramarital affairs, to be tested for HIV. By sharing their wisdom and personal stories, and acting as role models, they provided tangible support to those who needed it, as Mrs. Emma explained:

We tell them [those looking ill] to go for HIV Voluntary Counseling and testing (VCT) [to test for HIV], depending on how often a person gets sick. If this person is willing, then she will take action to do that. However, some do not [go] and, with time, they die.

Older women shared how they used their wise communication skills to persuade the younger women to go for testing, as Mrs. Rachael shared,

I like those ones [the younger women], since I do sweet talk with them. They are helped, and they continue with life. Those women I have ever helped look so good that you cannot imagine them being sick.

Mrs. Beth spoke of how she welcomed other women to talk privately as needed after they tested HIV-positive,

I tell them not to worry about testing HIV-positive or about anything if they are found to be positive; if anyone has got some problems if they test positive, they can see me later. There are so many things that people need to cope with HIV.

Older women were willing to recruit the assistance of health care providers and use their own experience to help others learn their status.

Educating Others About HIV

Women educated others about how to determine their HIV status by being tested and about the importance of engaging in safe sex, including abstinence and condom use. They spoke of helping others reduce risk by educating them about common HIV risk factors. These HIV-positive older women also educated their caregivers and explained how to protect themselves from infection by using gloves to avoid exposure to body fluids in open wounds, as Mrs. Agnes explained:

“When cutting nails using the same razor blade, you get a wound and go to wash another person with a wound; then you get the disease. It is not only through sex.” Women also spoke of how they help educate women on using gloves while helping others to deliver their babies at home, as Mrs. Agnes shared further:

When you are delivering a baby and you have not worn gloves, you can easily get it [HIV] through this process. At our place, there are many women [who give birth at home] and the people do not wear gloves.

HIV-positive older women spoke of providing social support to younger women at risk of HIV infection by encouraging them to enroll and participate in women’s HIV support groups, and by creating safe, nurturing, and supportive environments where women at risk of HIV can come to them to get help. Women who had received help before being diagnosed and after testing positive for HIV felt compelled to pass on the favor by actively reaching out to and supporting other women they identified as at risk of HIV. Often, older women spoke of how they used their own experiences in offering guidance to other women, as Mrs. Rosinda explained:

I can tell her [a newly diagnosed HIV-positive women] to have courage and join a support group. I can show her what she can do, just the way I do things, and show her ways of surviving.

Educating women about HIV and contacting them with services brought a sense of accomplishment for the older women, as Mrs. Agnes shared, “I have brought five people, here at homecare, those that I have convinced. And I feel I am doing well and satisfied with myself.” Women felt satisfied in helping others understand the importance of knowing their HIV status so that they could start caring for themselves. Older women reported working with health care providers, religious leaders, and civic leaders to educate women and spread awareness about the importance of testing and treatment in curtailing the spread of HIV in their communities.

Protecting the Children From HIV Infection

The women in our study were also concerned about protecting children, including grandchildren from contracting HIV, and shared with the children in their lives ways to decrease HIV risk. As Mrs. Agnes said,

I tell them not to joke around [not to have casual sex], since these days things are bad. Especially my grandchildren, I tell them not to play [have sex] with others, to keep distance from bad company, and to finish school first [before getting to sexual relations].

Mrs. Rachael talked about how she had decided to abstain from sexual relations with local men so that she can keep a
good example and positive role model for the children in her life. She explained,

I am old enough to keep respect to both the young and the old and set a good example. I take care of them. When I am sick, they use gloves to attend to me. Even those body fluids can transmit the disease, so I really take a lot of care.

In a society with minimal formal institutional orphan care, the responsibility for caring for orphaned children is left with the community, as Mrs. Pauline pointed out:

In our area there are many children who have been orphaned; the neighbors usually pull together and just help as they can. The father died, the mother died, and the children are left there with no one to care for them.

Older women in this study took responsibility for taking care of children and protecting orphaned children in their villages. They believed it was their role to advocate for and support orphaned children left after their parents had died from AIDS.

**Discussion**

In this study, we examined the unique advocacy role of older HIV-positive women in their efforts to stem HIV in their communities. The findings suggest that HIV-positive women 50 years and older living in rural Eastern Kenya may have untapped skills that have great potential for affecting HIV-prevention interventions. The women in our study spoke of their ongoing advocacy role in the community and gave examples of lives changed because of their influence. Women spoke of how they helped others reduce HIV transmission risk by promoting HIV testing, encouraging abstinence or use of condoms, and educating others about HIV.

Although women spoke of abstinence and condom use, they did not bring up the issue of faithfulness in marital relationships. Although being faithful may be a critical method for reducing HIV risk transmission, in the context of rural living, women do not always have control of their partner’s faithfulness (UNAIDS, 2010). Studies have shown that being faithful is dependent on the decisions of men. Although women might be faithful, they do not have an influence on the multiple sexual partners their men or their co-wives might have (Kako, Stevens, Karani, Mkandawire, & Banda, 2012; Ragnarsson et al., 2011).

In addition, our findings show that older HIV-positive women have a vital influence on younger women and children. Older women took responsibility in protecting children from HIV infection by openly talking about HIV, modeling behavior, and taking on the responsibilities to care for orphaned children in the community. Our findings on the roles of HIV-positive older women are consistent with other studies that examined the caregiver role that older women play in the lives of orphaned children in Kenya (Nyasani, Sterberg, & Smith, 2009). However, there is an urgent need to scale up efforts to equip older women—with or without HIV—with accurate knowledge about HIV and its impact on the young. Their relationship with their grandchildren is an important conduit for reaching the young with the message of HIV transmission risk reduction. Women in our study were greatly concerned about the young and described how they utilized knowledge acquired from support groups to educate others. Utilizing older persons can add to peer-based HIV-prevention interventions for the young (Van Der Heijden & Swartz, 2010). Health care providers, researchers, and policy makers can maximize older women’s ability to advocate, engage, and educate future generations about HIV risk. Older women in our study were creative in reaching others whom they thought were at risk or showed signs of HIV infection. Cultivating older women’s knowledge and role in the community could reduce HIV risk.

In this era of global austerity, grassroots efforts such as support groups, especially in rural areas in Kenya, will become an even more important forum where women obtain HIV education. Because rural women tend to be less formally educated, they rely on verbal education received from their support groups to gain the knowledge needed to protect themselves and their families (Gillet & Parr, 2010). The marginalized voices of women must be included moving forward with HIV-prevention interventions and programming. In rural areas, older women could be enlisted to help build community-based support for the increasing numbers of women being diagnosed with HIV. This approach would rely on the strength of older women and their agency to pass on knowledge, thereby aiding in HIV prevention and care. Historically, older women have been the bearers of traditional or local knowledge that is passed down to younger generations during teachable moments, through oral reports in the form of stories (Mbitt, 1990; Mweti, 2008). Older women often serve as the community’s local knowledge reservoir. There is therefore a need for researchers to reflect on their own position, depart from colonizing roles as experts, and embrace women’s perspectives as a legitimate source of knowledge to inform current HIV-related interventions and programs (Racine, 2003).

We recognize that older women living with HIV represent a vulnerable population themselves who need particular attention, especially because of age-related co-morbidities and other age-related challenges (Smith, Delpch, Brown, & Rice, 2010). The special positions elders occupy in rural areas in Kenya reinforce the need to address these special needs to support older women in their crucial advocacy role in families and communities (Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011). Programming that includes older women must consider the additional needs of aging women who are living with HIV. Studies about older women living with HIV are needed to highlight how to meet the specific needs of these elders while engaging them in locally meaningful interventions for HIV prevention and care.
Our study contributes to the body of literature by emphasizing the critical advocacy role older women who are living with HIV can play in HIV-prevention interventions in East Africa. The community leadership roles of advocacy demonstrated by women in our study should be encouraged. Such encouragement might come from policy makers considering the agenda of the elders living with HIV as an important one.

**Study Limitations**

Our study was of a small sample, utilized purposive sampling technique that sought women already living with HIV, and focused on women living in rural Eastern Kenya limiting the generalization of the results. However, women shared important insights into their advocacy role that could be translated to HIV-prevention interventions in similar settings. It is also possible that women in the study only shared their views that they felt were important to the study and might have selectively eliminated stories that they might have deemed not socially desirable. Subsequent research and interventions that place older women at the center are warranted, particularly with older women as the interventionists in community-based participatory research and programming.

**Conclusion**

We assert that HIV-prevention interventions and programs should evaluate and address prevailing myths if they are going to be successful. Although older women attempt to apply previously prescribed methods of reducing HIV transmission risk, our study shows that older women have made local adaptations such as HIV status self-disclosure to encourage others to seek testing for HIV risk reduction (Gillett & Parr, 2010).

There is a need to ensure that women aged 50 and older living with HIV have accurate information to avoid misinforming their communities. Health care providers and policy makers need to be aware of and evaluate local myths, in particular, personal negative condom use messages passed on to other women and accepted as truth that could be detrimental to HIV-prevention efforts if passed to other women in the community. Highlighting the significant role that elders play in society could be an important strategy in winning the fight against HIV/AIDS in Kenya. Because of the influential spaces older women occupy in Kenyan local communities, clinicians should readily elicit what women already know about HIV prevention, so that any misconceptions are identified and clarified in partnership with the women.

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**Author Biographies**

**Peninnah M. Kako** is an Associate Professor in the College of Nursing at University of Wisconsin-Milwaukee. She obtained her PhD in Nursing from University of Wisconsin-Milwaukee. Dr. Kako is a certified Family Nurse Practitioner. Her research expertise and interests include health care access, vulnerable populations, Global health research, and women and HIV/AIDS in sub-Saharan Africa.

**Jennifer W. Kibicho** is an Assistant Professor in the College of Nursing at the University of Wisconsin-Milwaukee. Dr. Kibicho has a PhD in Economics from Wayne State University and a post-doctoral fellowship in HIV Prevention Research from the Center for AIDS Intervention Research, the Medical College of Wisconsin. Her research interests include the evaluations of structural-level interventions that address poverty, gender-based violence, and other structural factors that place individuals at elevated risk for HIV infection in sub-Saharan Africa.

**Lucy Mkandawire-Valhmu** is an Associate Professor in the College of Nursing at the University of Wisconsin-Milwaukee. She obtained her PhD in Nursing from University of Wisconsin-Madison. Her areas of research and expertise include violence in the lives of women in Southern Africa, health care of immigrants and refugees, community health nursing and utilization and
application of feminist methodology particularly in research with third world women.

**Patricia E. Stevens** is a Professor in the College of Nursing at University of Wisconsin-Milwaukee and a Center Scientist at the Center for Urban Population Health, a partnership between University of Wisconsin-Milwaukee, University of Wisconsin-Madison, and Aurora Health Care. Dr. Stevens obtained her PhD from University of California and is a Fellow in the American Academy of Nursing. She has done extensive research in the area of HIV/AIDS and is expert in qualitative research methods and community based participatory research.

**Anna K. Karani** is a Professor of Nursing Education at University of Nairobi, Kenya. She obtained her PhD from University of Nairobi. Dr. Karani has a wide experience in clinical work in hospital and in community work as well as extensive experience in teaching and community-based research in Kenya. She also serves as the Chief Editor of the *Kenya Nursing Journal*. 