Article

The Struggle for Recognition by People Living With HIV/AIDS in Sudan

Jocelyn DeJong[1] and Iman Mortagy[2]

Abstract
In settings with high HIV/AIDS-related stigma and where HIV is at low prevalence, the political space is often not conducive to making the epidemic more visible to public debate. In the Middle East and North Africa people living with HIV are only beginning to be prominent players in the policy planning in response to the epidemic. We conducted a qualitative case study analyzing an emerging nongovernmental support group association of people living with HIV/AIDS in Sudan. The study consisted of 16 interviews, with 15 HIV-positive members and the president of the association. We also conducted eight interviews with leaders of HIV-related institutions in Khartoum and reviewed relevant published and unpublished literature. We document the challenges faced by the association's members and illustrate the potential for community mobilization to counter HIV-related stigma. We also point out the need to create the political space for addressing the needs of people living with HIV.

Worldwide, groups formed by people living with HIV/AIDS have played major roles in challenging and shaping the response to HIV. However, most of the research on such movements is drawn from the experience of developed or developing countries with high HIV prevalence. In low-prevalence contexts, there is often a strong stigma associated with HIV and with the behaviors that increase exposure to it (such as commercial sex work, injecting drug use, and men having sex with men). In such contexts, the epidemic is typically hidden from public view and therefore absent from public debate. Such a situation exists in the Middle East and North Africa region,[1] where meaningful involvement of people living with HIV/AIDS in response to the epidemic is still at a nascent stage.

In the Middle East and North Africa region, few countries have a generalized epidemic; rather, the epidemic is largely concentrated among at-risk populations (Abu-Raddad et al., 2010). However, before prevention and treatment efforts can be scaled up, there is a need for what Charles Taylor (1994) called "the politics of recognition" (p. 25), which in this case would involve opening up of the political space to build the confidence among those infected with HIV to articulate their sociopolitical demands. Once they have done so, health and social policy makers will be more likely to implement HIV-related policies.

Such a process is beginning to occur in the Middle East and North Africa region, with the emergence of the first nongovernmental associations of people living with HIV where the disease is highly stigmatized. We report in this article on a case study of one such organization, The Sudanese People Living with HIV/AIDS Care Association (hereafter referred to as the "Association"). Sudan is a country that has been governed by an Islamist government since 1989, and HIV remains highly stigmatized and at relatively low prevalence. In consultation with the Joint United Nations Program on AIDS (UNAIDS), we chose Sudan as a site for this study because the Association, unlike many in the Middle East and North Africa region at that time, had become a vocal and public advocate on behalf of people with HIV.

The objective of the study was to explore the Association members' views, as well as those of AIDS-related organizations in Khartoum, concerning the potential for such an association to address HIV-related stigma and the rights of people living with HIV. In particular, we aimed to trace the history of establishing and operationalizing the Association and its role in the overall HIV response as viewed by its members and other

[1]American University of Beirut, Beirut, Lebanon
[2]Colchester, Essex, United Kingdom

Corresponding Author:
Jocelyn DeJong, Faculty of Health Sciences, American University of Beirut, P.O. Box 11-0236, Riad El Solh, 1107-2020 Beirut, Lebanon.
Email: jd16@aub.edu.lb

HIV-related organizations. We use Shamos, Hartwig, and Zindela's (2009) definition of stigma as a "social process conducted in a relative power structure that allows labeling and separation and that leads to status loss or discrimination" (p. 1679).

Background

Associations of People Living With HIV/AIDS in the Middle East and North Africa Region

Intense stigma and discrimination around HIV and the behaviors that increase the risk of exposure to it have been a major challenge to AIDS-prevention efforts in the Middle East and North Africa region (Abu-Raddad et al., 2010; Akala & Jenkins, 2005). A number of countries in this region, including Algeria, Egypt, Jordan, Lebanon, Morocco, and Sudan have witnessed the recent formation of associations of people living with HIV/AIDS. However, little published literature is available on the role and impact of such organizations,[2] which vary in size, legal registration, and visibility. To improve health policy and services, as well as to reduce AIDS-related stigma, some organizations are initiating a transition from offering mutual support to playing a more collective and public role as advocates on behalf of people with HIV. Beginning in a meeting that took place in Algeria in 2005 (Algiers Declaration, 2005), UNAIDS held a series of meetings to increase the involvement of people living with HIV/AIDS. In general, however, groups from the region are only beginning to be well represented in global networks of people living with HIV.

In the Middle East and North Africa region there has been relatively little published research on HIV-related stigma. Some recent exceptions are studies on attitudes about HIV among industrial and tourist workers in Egypt (El Sayyed, Kabbash, & El-Gueniedy, 2008), coping mechanisms of individuals living with HIV in Egypt (Kabbash, El-Gueniedy, Sharaf, Hassan, & Al-Nawawy, 2008), the quality of life of individuals with HIV in Lebanon (Abboud, Noureddine, Abu Saad Huijer, DeJong, & Mokhbat, 2010), stigma and HIV among university students in Yemen (Badahdah & Sayen, 2010), and HIV-related attitudes among women college students in Kuwait, Bahrain, and Jordan (Badahdah & Foote, 2010). In a review of the scientific peer-reviewed literature on HIV-related stigma published through 2007, of 390 articles, none focused on the Middle East and North Africa region (Mahajan et al., 2008). The majority of articles—including those on that region—focused on stigma-assessment studies, which explore the stigma that people living with HIV perceive.

Mahajan et al. pointed to the need to develop "new models of advocacy and social change in response to HIV/AIDS stigma" (2008, p. 575) and to "implement community-based interventions that are designed to mobilize people living with HIV as well as other social actors, such as opinion leaders and clergy, to address maladaptive, self-stigmatizing behavior and to advocate against discrimination in the wider community" (p. 577). In this article we analyze an example of one such community-based movement in northern Sudan.

The Sudanese Context

An Islamist regime has been in power in Khartoum since 1989. In 2005, the war between the government of Sudan and the Sudan People's Liberation Movement based in the south of the country ended with the signing of the Comprehensive Peace Agreement (United Nations Mission in the Sudan, n.d.). Under this agreement, a Government of National Unity was established, with more autonomy delegated to the Government of Southern Sudan. Results of a 2011 referendum indicated overwhelming support of the separation of the north and south, and South Sudan was declared an independent country in July 2011. Before partition, Sudan had a population of some 45 million (including more than 8 million in southern Sudan) that was ethnically and religiously diverse. In total, about 70% of the population was estimated to be Sunni Muslim (in the north); Christians comprised about 5% of the population (mostly living in the south and in Khartoum); whereas those espousing indigenous or animist beliefs comprised 25% of the population (Index Mundi, 2011).

The United Nations Development Program's (UNDP, 2006) Human Development report ranked Sudan 141st among 177 countries in terms of human development. Based on Sudan's 2010 MDG progress report, 47% of the population in the north and 51% in the south were estimated to be living below the poverty level of less than $1US a day (Republic of Sudan National Population Council Ministry of Welfare and Social Security, 2010). It is estimated that only 61% of the population is literate (71.8% of men and 50.5% of women; Index Mundi, 2011). Sudan has the second highest adult HIV/AIDS prevalence in the Middle East and North Africa region, but the available information, which is constrained by years of civil conflict, indicates that only South Sudan has a generalized epidemic (Abu-Raddad et al., 2010).

In northern Sudan (now Sudan), there is evidence of a possible concentrated epidemic among injecting drug users and among men who have sex with men; however, there is no evidence of a concentrated epidemic among female sex workers (Abu-Raddad et al., 2010). In 2009

the Sudan National AIDS Control Program (SNAP) estimated the overall HIV prevalence at 1.1% overall and 0.67% in the north (SNAP, 2010). Also in 2009, the total number of adults and children living with HIV was about 122,216 in north Sudan (SNAP, 2010). SNAP reported in its 2006–2007 report on north Sudan to the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS that only 1,759 individuals were on antiretroviral treatment for HIV (SNAP, 2008).

Prolonged civil war, which included warfare in Darfur, as well as poverty and displacement have severely limited both surveillance of and the response to the epidemic. At the same time, high-level political commitment as well as foreign funding for HIV, particularly from the Global Fund for AIDS, Tuberculosis and Malaria, have boosted action. A draft law to protect the rights of people living with HIV/AIDS was developed in 2005 but awaits final approval from the Ministry of Justice before being forwarded to the Cabinet for approval (SNAP, 2010). Delays in the process are because of procedural matters rather than substantive issues, indicating that there is support for the draft law, according to the former deputy of SNAP (T. El Mansour, personal communication, July 20, 2009). Despite high-level policy statements, only 3.8% of the government's health budget was allocated to HIV programs in 2008 (Christian Aid, 2008).

There is no published literature on HIV-related stigma in northern Sudan, although existing unpublished literature attests to a pervasive stigma: A survey of more than 400 health care providers found that more than 50% harbored negative feelings toward people with HIV (Hassan, 2008). In a 2006 needs assessment SNAP and UNAIDS found that the main difficulties expressed by people living with HIV were low socioeconomic status, stigma, lack of education, rights violations, limited access to medical care, and poor psychological well-being (SNAP, 2008).

In a qualitative unpublished study on the experience of people with HIV, Christian Aid (2008) interviewed 38 HIV-infected individuals in Khartoum. It found that the stigma they experienced resulted in their reluctance to seek the available counseling services, thus "creating and increasing an invisible population with HIV who are unable or unwilling to access treatment and care" (p. 5). Moreover, individuals with HIV reported extensive discrimination from medical providers, which led to many concealing their HIV status from providers. Researchers in another study conducted in South Sudan (Machine, Ross, & McCurdy, 2011) also found that HIV-related stigma was a major barrier to HIV testing, treatment, and care. The authors noted the scarcity of research on how people with HIV/AIDS, or those suspected of being infected, are perceived and treated in Sudan.

Conceptual Framework on AIDS-Related Stigma, Recognition, and Redistribution

Studies on stigma in public health owe their roots to the work of Erving Goffman, who described stigma as an "attribute that is deeply discrediting" (Goffman, as cited in Shamos et al., 2009, p. 1679). Goffman drew attention to the social processes and relationships that create stigma (Castro & Farmer, 2005). HIV has attributes that make it, and the behaviors that increase exposure to it, highly susceptible to stigma (Parker & Aggleton, 2003). Over the last decade, writers on HIV-related stigma have tried to shift attention away from attributing stigma to a static, individual level and more toward the social processes and power relations that generate stigma (Mahajan et al., 2008; Parker & Aggleton). In calling for greater attention to the structural roots of AIDS-related stigma, these writers underscored the importance of community mobilization and activism by those stigmatized. They acknowledged that there has been relatively little documentation of collective processes for reducing stigma, at least in the context of developing countries.

Campbell, Foulis, Maimane, and Sibiya (2005) have categorized strategies to reduce stigma into three types: (a) information-based awareness programs, (b) the institution of legal safeguarding, and (c) the participation of local community members in antistigma efforts. They argued that the first two have limitations. In the first it is assumed that stigma is largely caused by ignorance, and that providing information about how HIV is or is not transmitted is the best approach. They noted, however, that this has not proven to be successful in reducing stigma. The second strategy does not address the subtle forms of stigma, which relate more to social norms that cannot be changed through legal means alone. The authors thus argued for collective discussion and action on the part of community members, who should "engage in critical thinking about the wider webs of representation and practice that feed into stigmatization of people with AIDS" (p. 813).

There is a substantial literature on the role of support groups and associations of people living with HIV/AIDS in developed countries (Crook, Browne, Roberts, & Gafni, 2005; Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996; Sandstrom, 1996; Spirig, 1998). Analysts of movements in developing countries have understandably tended to focus on relatively high AIDS prevalence settings and on individual nongovernmental organizations (NGOs) in such settings, such as Uganda's The AIDS Support Organization (TASO; Kaleeba et al., 1997) or South Africa's Treatment Action Campaign (TAC; Robins, 2006). These organizations have moved from supporting individual members to being politically active on a national and even global level in an effort to

widen access to treatment and promote the rights of those with HIV. Research on the Thai Network for People Living with HIV/AIDS (TNP+) has shown how the organization has helped in the "social normalization of being HIV-positive" (Lyttleton, 2004, p. 3) and has expanded access to antiretroviral therapies (Liamputtong, Haritavorn & Kiatying-Angsulee, 2009; Lyttleton; Lyttleton, Beesey, & Sitthikriengkrai, 2007).

Little has been written about the role of organizations run by people living with HIV in tackling stigma, where HIV is both at low prevalence but also highly stigmatized. In low-prevalence settings, the general population is often minimally exposed to discussion about HIV and is less likely to have encountered HIV-positive individuals than in higher-prevalence settings. Although studies on stigma have been focused on individual perceptions and experience of stigma, in this article we aim to characterize the institutional level and the social mobilization process required to create a collective identity among people living with HIV, as exemplified by the Sudanese Association.

Beyond health and within the realm of political philosophy, researchers on the "politics of recognition," beginning with Charles Taylor (1994), have drawn attention to the cultural processes that prevent some groups from being recognized and from participating in society. The social movements underlying the currently preeminent "identity politics" are said to engage in such a process of recognition, which aims at attributing value to cultural difference. However, Nancy Fraser (1996) has argued persuasively that because the obstacles to such participation are usually both cultural and economic, redressing the injustice of their exclusion requires not only social processes of recognition but also economic processes of redistribution. Fraser's conceptual approach is particularly relevant in Sudan, where poverty is widespread, and where HIV exacerbates both social and economic exclusion.

Methods

We designed a qualitative case study on the Association, and Iman Mortagy conducted the field study in Khartoum. She interviewed 15 HIV-positive men and women who were members of the Association, as well as its HIV-negative president and leaders of eight HIV-related organizations (international agencies, NGOs, and faith-based groups) in Khartoum in late 2005. Staff at both UNAIDS and SNAP reviewed the study instruments and ethical aspects of the study and gave helpful comments on the study design. After the president of the Association introduced her briefly to members, Mortagy recruited a convenience sample of members on its premises; those members then referred her to other members through snowballing.

Recruitment of the sample of HIV-positive members of the Association proved challenging. Although they were members of the Association, and therefore in a sense public about their condition, most did not disclose their serostatus publicly and did not need to do so because the Association includes both infected and noninfected individuals. However, all members we approached to participate in the study agreed to be interviewed except for one. For the interviews with AIDS-related organizations, we asked both SNAP and UNAIDS, as well as all of the Association's participants, about relevant AIDS organizations that had interacted with the Association. Because of resource constraints, we selected only organizations with representatives in Khartoum.

We explained the study carefully to the participants, assured confidentiality by not requesting names or identifiers, made clear that the participant could refuse to be interviewed or to answer any questions, and could withdraw from the study. Verbal informed consent was obtained and a private space was ensured. Three HIV-positive women requested that their counselor attend the interview. Mortagy conducted three interviews in English and the rest in Arabic, for a duration of 1 to 2 hours each, at venues chosen by the participants.

After we translated study materials into Arabic, staff at SNAP reviewed and modified them for the Sudanese dialect. We then pilot tested the interview guide for HIV-positive members with one HIV-positive woman member. After conducting and transcribing the interview, Mortagy met with the same participant to obtain her feedback on the questions. The topic guide was refined and added to based on her comments. Interviews with Association members were guided by key topics related to mode of infection, disclosure, treatment seeking, history of the Association, their personal involvement in and expectations of the Association, as well as their views on the contribution of the Association in addressing HIV-related stigma.

We focused the interviews with representatives of AIDS-related organizations on the history of the Association, their own institution's involvement with the Association, their perceptions of the Association's work, and its contribution to addressing stigma. Interviews lasted between 45 and 70 minutes and were held in locations that were convenient for the participants. We conducted these interviews in English except for two, which were conducted in Arabic at the participants' requests. We conducted interviews until data saturation on key themes was reached.

Mortagy recorded interviews with a digital recorder (with the consent of the participants), transcribed them verbatim, and translated Arabic interviews into English. We transliterated Arabic words that have no exact translation into English (both authors understand Arabic).

We analyzed the transcribed interviews separately and arrived at themes for analysis independently. We then consolidated a list of themes. We analyzed the retrieved segments using content analysis, which helped to identify recurring themes. Data analysis remained linked to the context in which we had generated the themes and concepts. The data were coded and analyzed using the qualitative analysis software MAXQDA version 2. We validated the initial analysis of the findings through two separate, open meetings with NGOs and the Association, and held a second meeting with AIDS-related funding organizations in Sudan, including UNAIDS. At the first meeting, HIV-positive members of the Association who had been interviewed were invited to attend and most did so.

Description of the Sample

HIV-Positive Members of Association

We interviewed people who were either receiving support from the Association or were involved in its activities. We selected the sample purposively to reflect differences in religious background between Muslims and Christians, a distinction that might have affected experiences of stigma. The sample of HIV-positive members included 8 HIV-positive women (5 Christian, 3 Muslim) and 7 HIV-positive men (6 Muslim, 1 Christian). We also interviewed the (then current) president, who was HIV negative.

Participants, all of whom lived in Khartoum, came from different places of origin including south, east, central, and north Sudan. They ranged in age from 25 to 65 years. Five women were HIV widows. Some had HIV-negative partners and others had HIV-positive partners. The sample included 2 single people and 1 divorcee. It included older and newer members of the Association, likely reflecting how long they had known they were infected by HIV. The individuals' knowledge of their infection ranged from 3 months to 10 years. Most participants were in good health apart from 4 women, who suffered from general fatigue, weight loss, and problems with their eyes and feet. Most participants reported the mode of infection to be heterosexual sex; 1 believed it was through blood transfusion; the rest were not sure. Most of the participants were from economically disadvantaged backgrounds and often faced employment-related discrimination. Losing or maintaining their livelihoods was a preeminent concern.

AIDS-Related Organizations

We conducted eight additional interviews with representatives of AIDS-related organizations that had been involved in some capacity with the Association. These included faith-based organizations that had been involved in the formation of the Association, international organizations with local offices in Sudan, and Sudanese NGOs involved in HIV-related activities.

Results

According to participants, the Association grew from many sources, including an initiative sponsored by SNAP and encouraged by UNAIDS, some faith-based organizations, and NGOs active in HIV/AIDS. Formally registered in 2003, it began renting its own premises as of 2005. The initial impetus for the formation of the Association was an HIV-positive individual who had died before we conducted this research and whom participants described as a highly charismatic figure. Quite exceptional for the time in Sudan, this former president of the Association spoke publically about his HIV status. He mobilized a small support group of infected and affected individuals and counselors; they met monthly and called themselves the Association of Patients' Friends. Having a strong vision for the Association, he was able to lobby the government to register it legally. He had been completely rejected by his family. As one participant described, even after he died, when a delegation of his friends went to pay condolences to his family, they were not welcomed. Because he was not one to delegate tasks, the organizational capacity of the Association was not developed fully, and when he died much of its institutional history was lost.

The deputy of the Association, himself an HIV/AIDS counselor but not HIV positive, subsequently took over as president. This was an indication of the facilitating role of HIV/AIDS counselors, particularly those associated with NGOs, that was critical to the Association's formation. Faith-based organizations, such as the Sudan Council of Churches, also supported the establishment of the Association. At the time of interview, the Association had—at least on paper—roughly 250 members and, in addition to the base in Khartoum, 13 branches in the following areas: Bahr el Jabal, Juba, North Kordofan, Gadaref, Red Sea, White Nile, Unity, Kassala, Upper Nile, Elgezira, Sinar, River Nile, and West Bahr Alzar. The Association in Khartoum was the national headquarters, but the Juba-based organization in South Sudan gained an identity of its own and ultimately became independent, a reflection of Sudanese politics. Several other autonomous organizations of people living with HIV subsequently emerged in what is now South Sudan.

With assistance from the Agency for Cooperation and Research in Development (ACORD), a British NGO that has an office in Sudan, in 2005 the Association drafted a 2-year strategic plan (Sudanese People Living with HIV

Care Association, and ACORD, 2005). It stated that the Association's strategic mission was to provide "comprehensive care to its members and to improve the general awareness among people in Sudan about HIV/AIDS" (p. 6). Its strategic objective included working to ensure the economic, social, and political rights of people living with HIV/AIDS.

The Journey to Asserting Recognition

Moving From Support to Public Advocacy

At the time of interview the Association had many roles, including supporting its members and engaging in public education and advocacy. Its members provided individual support such as conducting home visits and providing names of sympathetic medical providers to the newly infected. They also traveled to meetings around the country to talk about their experience of being infected with HIV and to advise the public about HIV. One participant described the impact of such testimonies at these public gatherings:

> We always ask doctors to give a summary about HIV and then we ask what if we had a person living with HIV with us here, what would you do to them? Some people respond, "Put them in prison, segregate them, and burn them. Why bring them here?" After that, when a person living with HIV tells his experience the audience changes, and they apologize. They find out that the person is a father responsible for a family or a mother taking care of her children.

The type of impact the Association had in reducing stigma is illustrated by the following story. A participant described being subject to severe discrimination by a dentist who refused to treat her when she learned she was HIV positive. Shortly after that, her HIV-positive husband was refused treatment by his medical doctor. She explained how she indirectly confronted this doctor through the Association's public education efforts:

> It also happened one time that my husband [needed medical attention], so I said, "Let's go to the hospital." We went there and spoke to a counselor and asked her to refer us to someone who would help. She referred us to the professor. When we arrived at his hospital, he was very welcoming. He was having breakfast and wanted us to eat with him. I told him I was with someone who was HIV positive and needed his attention. As soon as he heard that he shouted and threw us out; he almost threw the food in our faces and said that we should never return to him. But later, I was at the university doing a lecture [on behalf of the Association] and he was in the audience. I stood up and gave my personal experience, looking him in the eye. I said that unfortunately there are doctors that discriminate and do this and this. He stood up

and apologized publicly on behalf of all doctors. I knew why he was doing so, but I didn't want to comment. He had tears running down his cheeks; he was embarrassed by what he did to me.

Another HIV-positive woman reported how being a member of the Association gave her the strength she would not have previously had to face the public and inform them about HIV/AIDS:

> I will tell you a story. I carry an identification card that shows I am a member in this Association. I took my girls to be photographed at a studio, and I dropped that card. When I went back, I found the man very changed and afraid of me. So what I did was to tell him about HIV/AIDS and encourage him to join the Association.

The Association's membership provided mutual psychological and emotional support, and a forum for sharing experiences of being HIV positive. One HIV-positive woman described how the Association offered a sense of belonging and solidarity: "People support each other. You can then remove all bad thoughts from your head and live a normal life." For some, the Association presented opportunities to socialize and even find potential marriage partners in an otherwise isolated life. One HIV-positive man spoke about the fact that the Association provided a sense of purpose and meaning in the lives of its members: "I am doing good deeds through this work, so that newly infected people will find the situation different from how we found it. They will find rights and medication."

Recruiting Members and Establishing a Venue

Key steps in asserting recognition included having a public face for the organization, establishing premises, and recruiting members among those living with HIV. The enormity of this challenge was daunting to participants, because the prevailing stigma effectively made the epidemic hidden. One participant expressed it as follows:

> One thing affects me a lot, and that is that we cannot put our hands on what exactly is happening in Sudan. Since last year we are talking about the three by five initiative.[3] We are saying that Sudan has many thousands of people living with HIV and many have died, but you cannot know exactly how many die and you cannot find out where the people living with HIV live. In the Association we only have 250 members, so where are the other thousands? Where?

At the time of interview, the Association's leadership had managed to secure, with funding from an international NGO, one year's rent for a building in Khartoum. This was seen as a critical step by members. For

example, one member explained that having a place to meet would raise the visibility of the Association and in turn the self-esteem of its members. At the same time, however, members were also concerned about the stigma they would face from neighbors in the area. One participant put it this way:

> I told them [his fellow members] that as soon as they start renting, they should go to the officials in the neighborhood, talk to them, and socialize with them in a friendly way. I think when the people see the sign put up saying "AIDS," they might create a problem for us—maybe take us to court or throw stones at us.

An initiative to establish an association for people living with HIV in Djibouti reportedly failed because of resistance and even hostility from neighbors, according to a UNAIDS consultant (K. Cherabi, personal communication, November 11, 2007).

Establishing a Name and Identity for the Association

A related challenge in creating a public face for the Association was agreeing on its name. Members perceived that changing the name from "Patients' Friends" to "People Living with HIV Care Association" was an important step because it made clear that it was for people living with HIV. One HIV-positive participant compared the new name to what he felt were more positive names of other similar associations in the region, such as *Al Hayat* ("life") in Algeria, which does not mention HIV/AIDS in the title.

Renaming the Association raised a question concerning whether the membership should be restricted to those with HIV or also include individuals affected by the disease, such as the counselors who helped establish the Association. The fact that the Association included both had been important for the many members who preferred to keep their positive HIV status from their family and social networks. As one HIV-positive member described it, this was particularly important to her as a woman:

> I travel to awareness sessions for other branches. But in Khartoum I do not like to present myself as HIV positive because they will recognize me immediately. Once I had to give a lecture, but when I finished someone said we were all HIV positive at the Association. So immediately a high-ranking woman stood up and said that the Association is made up of positive but also nonpositive people, and everyone is encouraged to join. She saved me because in the audience were former colleagues of mine at the university who live in the same neighborhood as I do. It would have been a disaster for me.

Some members said that the involvement of counselors and others sympathetic to the plight of those with HIV helped defuse stigma in wider Sudanese society. One HIV-positive woman explained, "The larger the number of infected and noninfected people who join the Association, the more understanding there would be about HIV/AIDS in society at large."

Organizational Challenges to Achieving Recognition

Institutional Development Challenges

Despite the growth of the Association, not all of the members' views were positive about its achievements. Many had very high and arguably unrealistic expectations of the Association's capacity to respond to the epidemic in a context of persistent poverty and the members' minimal access to antiretroviral therapies at that time. Some hoped, for example, that the Association would help them find housing, secure jobs, and gain access to antiretroviral therapies, all expectations that were clearly beyond the Association's scope. One member, when interviewed for an unpublished study on HIV-related stigma in Khartoum, stated,

> The main problem is how to provide people living with HIV with a decent life. Our priority is how to find support for them in order [for them] not to be homeless [and] to come out from their appalling psychological, economic and social situation. (Christian Aid, 2008, p. 27)

The lack of social safety nets in Sudan puts NGOs such as this Association in the position of trying to meet a wide range of needs. In such a situation, managing members' expectations and making clear both the responsibilities and benefits of membership is a challenge.

The Association also faced multiple institutional development challenges that no doubt mirror those of similar institutions. In 2005 it relied on volunteerism, yet given the widespread poverty and loss of livelihood for many of the HIV-positive members, unpaid efforts for which there was no funding for transportation expenses were difficult to sustain and organize. As a participant at SNAP noted, "AIDS is not the only problem. The main problem is poverty." Not surprisingly, poverty among its members constrained their collective impact.

The above-mentioned report on HIV stigma in Khartoum noted that because of the institutional weakness of the Association, it was often bypassed by donors who cited weakness in their financial management, reporting, proposal writing, and organizational capacities (Christian Aid, 2008). In this sense, our

findings were consistent with Fraser's (1996) arguments that cultural recognition to redress the loss of status was not sufficient to redress the social exclusion brought by stigma; addressing the concomitant economic exclusion was also necessary. She argued that "[e]conomic harms that originate from the status order have an undeniable weight of their own. Left unattended, moreover, they might impede the capacity to mobilize against misrecognition" (p. 21). In other words, with HIV exacerbating poverty, the challenge of counteracting stigma and discrimination became all the more difficult.

The first step to founding an organization was the need to create solidarity among group members, which in itself was a challenge. One participant from an AIDS-related organization explained why this was the case:

> The main challenge I see is even though they are a group of people united, they are still taking it as an individual problem. Each one wants to solve immediate problems, not a holistic thing. They are fighting for HIV, but they are not fighting for every person living with HIV; they are fighting for themselves. It is still a fragmentation; they lack a perspective far ahead. So if one is fighting for something, I do not get the feeling that he or she is fighting for the group.

At the time of the fieldwork, the Association was just beginning to become more professional and its members were facing the challenge of transforming a group of individuals into an institution. In the end, institutions such as this one cannot depend on volunteerism and individual effort indefinitely if they are to increase in scale and have a consistently strong impact. Making the transition to a professional institution requires outside monetary support and financial accountability. It also involves structural changes.

There was also a striking acknowledgment among some of the participants of the personal costs entailed in mobilizing those infected with HIV to combat stigma in society. Such sacrifices capture a process of claiming a legitimate public face through collective action of those afflicted. One member poignantly expressed how much is required:

> The effort has to come from the people living with HIV/AIDS themselves. Nobody gives others their rights, whether social or material rights. They themselves have to ask for their rights so that they can obtain them; this is the only way. Changing the society needs a big effort from the infected people. Many of them will need to sacrifice their reputation and so forth. They need to meet with officials, talk in the media; it needs an effort from us first to ask for our rights.

Some Signs of Progress in Asserting Recognition

When we asked participants from the AIDS-related organizations about the contribution of the Association to the reduction of AIDS-related stigma, the prevailing view was that it had played a critical role. Some noted, however, that it was difficult to separate the effects of the different components of the response to HIV/AIDS, including the simultaneous expansion of voluntary counseling and testing centers. Several cited the existence of a draft law by the Ministry of Justice in partnership with other stakeholders for the protection of the rights of people living with HIV/AIDS, as well as a paragraph in the National AIDS Policy on the need to deal humanely with people living with HIV/AIDS, as critical aspects of the Association's success.

The HIV-positive members of the Association pointed to some clear signs of progress despite the intense stigma they still faced. Comparing the experience of those who had been infected for longer with more recent experience is instructive. The following two quotations highlight very different experiences with the health system that happened with almost a decade between them. One woman, infected through a blood transmission 8 years before the interview, described her experience with the health system at the time:

> I suggested going to a specialist, but my husband was hesitant because of how the doctor would talk to me. He finally took me to the doctor and I will never forget the doctor's words. He started writing the price of a million and three hundred thousand and he said, "You will not be able to buy it and you have to take it in order not to die." I [said] it was true that I didn't have any money so that means I will die. He said, "Okay, die; it is better for those like you to die." I was paralyzed for six months because of what the doctor told me. I could not move. They had to take me to the toilet and feed me. I isolated myself and told them I wanted to die alone.

In a similar but more recent situation, another participant, an HIV-positive man, fought back:

> If it is a private clinic I do accept his refusal to treat me when I tell him I am HIV positive, but if is a public hospital, then I do not accept it and I go to the highest authority to complain.

Capturing the Attention of Policymakers

By 2005, the Association had already transcended its role of members offering mutual support to become more of a public forum for debate within the community

of people infected with HIV. It had also become an interlocutor with both governmental and funding institutions about the appropriateness of HIV/AIDS interventions. Hearing the perspectives of the HIV-positive members of the Association provided an opportunity for policymakers to learn their criticisms of past and current interventions in HIV policy. For example, several participants were critical of a workshop on home care for Association members that reportedly failed to include their families. One member said,

> I was hoping the training would be for families, because the infected person knows he or she is positive, but maybe something will happen to him; therefore, the family members need to know what to do when the person gets really sick.

In fact, we learned through interviews with AIDS-related organizations that family members would have been welcome at the workshop, but these individuals were concerned about disclosing their HIV status to their families.

In Sudan, as in most developing countries, AIDS-related interventions currently focus on those with HIV as individuals. Yet in Sudan as well as surrounding regions, addressing the wider family would arguably be beneficial. Rotheram-Borus, Flannery, Rice, and Lester (2005) argued that because the history of the epidemic in the West is associated with men who have sex with men, who at the time were perceived to be living on their own, there has been resistance to family interventions. In developing countries, the family is often the only reliable social safety net. Family members, in addition to individuals with HIV, need help coping with the disease.

The Association members were playing a vital role, not only in terms of helping individuals negotiate health care, but also beginning to engage in wider advocacy about the health services response to HIV in general. Interviews were replete with examples of health care personnel discriminating against people living with HIV, and the role of the Association's members in intervening. This interaction between civil society and the health system is particularly important, as Sudan faces the challenge of treatment rollout and adherence. In 2007, the president of the Association stated that discrimination toward those with HIV by health care providers had substantially reduced over time, but that women members still reported significant obstacles to seeking gynecological care (J. Oshala, personal communication, February 7, 2007).

By 2008, according to a report by SNAP, the Association had achieved representation on the National AIDS Council, the highest HIV/AIDS policy body in the country; the Country Coordination Mechanism; the steering committee for coordination of the Global Fund for AIDS, Tuberculosis and Malaria; as well as the executive board of the Sudanese AIDS Network, an umbrella organization for NGOs working in the field of HIV and AIDS (SNAP, 2008). By 2010, the Sudanese report to UNGASS (SNAP, 2008) noted that the Association was represented in all decision-making fora at federal and state levels and coordinating bodies. In 2009, it supported 12 service delivery centers not only for the chronically ill but also for families affected by HIV/AIDS.[4] Moreover, on World AIDS Day in 2009, the Association presented the Sudanese president with a certificate of appreciation, at which point he stated that his government would continue to support HIV activities and that the rights of the people living with HIV and other affected groups would be protected (SNAP, 2010).

Changing Religious Discourse

In the Middle East and North Africa region, where religious identity and values are central to public debate, the Sudanese experience also illustrates an emergent discourse on HIV regarding religion. The role of faith-based organizations supporting the Association set a positive example for other faith-based organizations in the region. Although participants described an initially difficult interaction with staff at the governmental Muslim charity department, Diwan al Zakat, they reported a remarkable improvement as they witnessed that the stigma associated with HIV/AIDS had declined. UNAIDS–Khartoum noted that the Diwan al Zakat played a critical role in receiving private-sector donations for people living with HIV/AIDS, money it was able to pass on to members of the Association (H. Hassan, personal communication, June 29, 2006).

UNDP hosted a meeting in 2008 that brought together 100 Muslim and Christian religious leaders to discuss their role in responding to HIV/AIDS in Sudan. They produced a declaration of commitment on HIV/AIDS, which calls for awareness campaigns, outreach to vulnerable groups, and treatment and care for those infected and affected by HIV (SNAP, 2010). At that meeting, a representative of the Ministry of Guidance and Endowment said that "an individual living with HIV/AIDS is someone passing through an ordeal and who God wished to test. He is our brother and we should not discriminate against him" (Sudan religious leaders campaign, 2008). This positive discourse on HIV among religious leaders in a country with an Islamist government set an important precedent for other countries in the region. The mere presence of an Association for people living with HIV has contributed to the changing national discourse.

Discussion

In this article we present a study documenting the formation of an association for people living with HIV/AIDS.

The story begins with the brave efforts of a charismatic individual to establish an official organization. We argue that for the individuals involved in the Association, joining and becoming active within it was an effective strategy for addressing HIV-related stigma, which is known to be a main barrier to accessing HIV testing and treatment services in Sudan. We conclude that in a society where HIV/AIDS is of low prevalence, highly stigmatized, and hidden from public debate, the formation of such associations can set in motion the processes associated with what Taylor (1994) termed a "politics of recognition" (p. 25). That is, people living with HIV have created a collective identity that draws on the social marginalization as well as moral and religious disapproval they face. By fostering this group identity they have asserted their claims to adequate health services and social respect, and in so doing have promoted the rights of people living with HIV. Such recognition is a prerequisite to scaling up prevention and treatment programs.

The struggle to have the Association recognized also entailed addressing the poverty most of its members experienced. In fact, their poverty was the main constraint to expanding the Association's volunteerism. Given that their HIV status exacerbated their poverty, the HIV-positive members of the Association were not in a position to engage fully in activities of the Association that would entail personal costs for them, such as for transportation. Their economic uncertainty therefore posed constraints in their efforts to mobilize against stigma and discrimination. The process of having the needs of those with HIV in Sudan met therefore required both political and economic changes. The public had to recognize that those infected had the right to participate in society. The public also had to understand that they needed to have their economic disadvantage redressed.

Our findings illustrate the importance of viewing stigma as a dynamic process both at the individual and social levels. Scholars such as Castro and Farmer (2005), as well as Link and Phelan (2001), have shown how stigma relates to the life trajectory of illness. Sayles, Ryan, Silver, Sarkisian, and Cunningham (2007) focused on how social processes influence individuals' trajectories as they attempt to reintegrate into their societies. They related this process to the stages of individuals' disclosure regarding their serostatus. The first stage, withdrawal and nondisclosure, is often followed by individuals' acceptance of their condition, and in turn they exert efforts to regain social acceptance. The authors identified a subsequent stage they called "resiliency," which can be linked directly to the process of joining support groups.

Lyttleton's research in Thailand (2004) documented how joining a support group "entails a form of self-transformation concomitant with the act of publicly acknowledging one's HIV status" (p. 3). Similarly, Liamputtong et al. (2009) showed that for Thai HIV-positive women, who were heavily stigmatized, joining support groups was their way of forging a collective identity and challenging stigma and discrimination. Lyttleton noted, however, that given the need for public disclosure of one's HIV status, not everyone who is HIV positive would be willing to join such support groups. He posed the question as to what lines of differentiation, such as gender, work against joining such support groups (Lyttleton, 2004; Walch, Roetzer, & Minnett, 2006). As Robins (2006) found in the case of South Africa, many HIV-positive individuals preferred not to affiliate themselves with the prominent Treatment Action Campaign because of the associated pressure to disclose their HIV status.

The Need for Future Research

One of the limitations of this study is the absence of voices representing HIV-positive individuals who are not members of the Association; future studies could compare the experience of stigma across these groups. Longitudinal studies, which follow individuals over time and can analyze the dynamic nature of stigma in closer detail, are also needed. Moreover, studies that compare the processes of recognition of similar associations across the region in countries with different political contexts would provide additional insights on the dynamic nature of stigma.

Implications for Programs and Other Settings

In a critique of the themes addressed at the *2006 International AIDS Conference*, Horton (2006) bemoaned the lack of attention to civil society. The discourse on HIV/AIDS, he argued, is polarized between the focus on the biomedical needs of the individual and the more broadly focused public health approaches. There has been little focus on the intermediate, community-based level of action. NGOs have been a critical part of the response to HIV/AIDS, but their activities are often on a small scale and their impact is undocumented. However, there is a limited literature on the organizational challenges faced by such associations in scaling up their activities (DeJong, 2003). One of the impediments to the Association in Sudan realizing its potential was its organizational weaknesses, such as the lack of clear governance arrangements or systems for monitoring and evaluation. One of the lessons of this experience for other contexts is the need for careful attention to governance and strategic planning systems within such organizations.

Recent analyses of HIV-related stigma have pointed to an omission of analysis of intermediate, community-based initiatives to reduce stigma (Mahajan et al., 2008). Much of the published stigma literature focuses on stigma as experienced by individuals rather than analyzing the community and social processes that can either generate or reduce stigma. The formation of the Association in Khartoum illustrates the community discussion that writers on AIDS-related stigma argue is needed to counteract stigma at the societal level (Campbell et al., 2005; Mahajan et al.; Parker & Aggleton, 2003). Stigma surrounding HIV/AIDS is often acknowledged as the main impediment to programs in the Middle East and North Africa region (Akala & Jenkins, 2005). Such associations, as the Sudan case illustrates, have the potential to mobilize stigmatized communities and stimulate public debate. In reference to South Africa, Jewkes (2006) argued that writers on stigma have highlighted its negative aspects, but have emphasized fewer positive social responses to the epidemic.

The people we interviewed reported that belonging to the Association had reduced their perceived social exclusion and had given them an important avenue for meaningful involvement in addressing HIV/AIDS. As Lyttleton (2004) has argued about such groups in Thailand,

> Groups of people living with HIV in part perform the social function of allowing those with HIV/AIDS a public and symbolic space, and, in this respect, a sense of belonging doubles both as a crucial buffer against stigma and as a corrective to induced shame. (p. 12)

Conclusion

This article provides an example of how collective action and social mobilization of people infected and affected by HIV have helped counter stigma even in a context where HIV is highly stigmatized and at low prevalence. The Association's members in Sudan played a critical role not only in helping individuals negotiate health care options but also in rendering more visible those with HIV and their needs. Becoming more visible is particularly important as the country strives to scale up access to treatment. By providing a platform to voice the collective needs of people living with HIV, such associations also have the potential to influence policy. In low-prevalence and highly stigmatized settings such as the Middle East and North Africa, the emergence of such groups, which is rarely documented, might positively shape responses to HIV for two reasons. First, in HIV/AIDS policy discussions in the Middle East there has not been enough emphasis on how to support people with HIV/AIDS without simultaneously stigmatizing them. Second, not understanding the needs and experiences of people with HIV

represents a lost opportunity to learn valuable lessons for HIV/AIDS policy.

The mere existence of associations of people living with HIV/AIDS, however, does not guarantee these developments because an association's degree of recognition influences its ability to assert political demands. Moreover, Lyttleton (2004) reminded us that such support groups are not carbon copies of those in the West. The struggle for recognition exemplified by the Association in Sudan illustrates that there is a need to acknowledge the material basis of exclusion experienced by those with HIV in Sudan. It also points out that given the absence of formal social safety nets, families play a key role. Meeting the Association's demands requires both social change and economic redistribution. Asserting public recognition might require engaging not only with policymakers and health care providers but also with religious leaders to influence the discourse around HIV. For other associations worldwide, the challenge is to complement and then move beyond the mutual support and public education role to advocate for legal and social change and improved policy.

Notes

1. United Nations agencies differ in their geographic definition of the Middle East and North Africa region, but in this article we use that of the Joint United Nations Program on AIDS, in which Sudan is included.
2. Weishut (1997) documented the role of a support group for people living with HIV in Israel in offering psychosocial assistance to its members and helping them negotiate with Israeli health services.
3. An initiative of the World Health Organization and

UNAIDS (2004) to reach 3 million HIV-infected people in need of antiretroviral therapy by the end of 2005.

4. By 2009, care and treatment centers were available in all 15 states, totaling 32. That same year there were 1,996 individuals on antiretroviral therapy in Sudan (SNAP, 2010).

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Author Biographies

Jocelyn DeJong, BA, MPhil, PhD, is a professor at the Faculty of Health Sciences, American University of Beirut, in Beirut, Lebanon.

Iman Mortagy, BA, MSc, is an independent researcher based in Colchester, United Kingdom, and Cairo, Egypt.