

Commentary

Thirty Years into the HIV Epidemic: Social Work Perspectives and Prospects

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June 5, 2011, marked the thirtieth anniversary of the publication of the first case reports of HIV among gay men in San Francisco and Los Angeles, generally the point in time agreed upon as the start of the epidemic. From the start, social workers made key contributions along with other health providers in developing knowledge and services to help those affected and infected and avoid future infections. HIV social work contains all of the challenges and satisfactions entailed throughout the social work profession due to the wide array of activities we perform as social workers—case management, other forms of direct clinical practice, supervision of social workers, professionals, and para-professionals, empowerment practice, program development, engaging stakeholders, participation in policy setting, and advocacy of every type, stripe, and category. Our work with individuals, families, groups, and communities uses the entire array of social work competencies, in terms of our abilities to assess needs on a variety of systems levels and identify resources to formulate and implement interventions. While the evidence base for these interventions might not have been fully developed, social workers working with HIV-affected clients had to be adept at formulating best practices from what was available in their settings and in their communities.

From the beginning of the epidemic, social workers have had the opportunity to engage the human experience in depth, responding with a variety of ways to help, ranging from crisis and trauma work to supportive interventions, as well as therapeutic interventions with those living with progressive physical and social losses. Our efforts have consistently stressed the need to support strengths and address both environmental supports and underlying mental health issues, not only for the persons with HIV but also for their family members and social networks. In addition, social workers

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with our ethic of acceptance and diversity were willing and able to address HIV's conundrums: fear of the unknown, pervasive stigma, and a rapidly evolving epidemic with novel treatment responses emerging almost every year, set within the coexisting conditions of poverty, isolation, mental illness, and addictions. HIV often entails "off time" life events (Hagestad & Neugarten, 1976), whereby individuals may experience illness and take care of others who are sick and dying at ages far below what is developmentally normative. These circumstances all entail complex social and emotional issues that need intensive psychosocial interventions.

Like our clients—whether they are people, systems, or communities, we have had to learn to thrive on challenge, to become resilient, and to grow from the experience. This is particularly critical when applying the central social work paradigm of the connection between the person and the social environment (Karls, O'Keefe, & National Association of Social Workers [NASW], 2008) to a new disease. Social workers have learned that we need to care for ourselves in order to care for others on a consistent basis. The alternative is burnout, compassion fatigue, and disengagement from the workforce (Demmer, 2004). While some have moved on to other challenges, social workers have often been the catalysts and leaders who have created and sustained solutions to the dilemma of HIV (Willinger & Rice, 2003).

LOOKING BACK: A SHORT HISTORY OF HIV/AIDS SOCIAL WORK

In the early 1980s, HIV/AIDS became visible within health care systems, first on the east and west coasts and later throughout the United States. As social workers, like everyone else, we were unprepared, knew little, and had to approach these events through the lenses of our own experience working with clients, be they in health care or in other fields of practice. The social work response initially emerged as workers attempted to assist those with this new, often mysterious deadly syndrome. Our professional colleagues, at the beginning of the epidemic, had to be dedicated and innovative. In our initial efforts, we found ways to work with other disciplines that often had more power than we did. As social workers, we had to be flexible and responsible, often making things up to create new strategies as we went along. Much of our knowledge and techniques in the developing field of HIV practice came from other fields of social work practice including oncology practice, medical social work, and service to the frail and aged. Our historical work with the disadvantaged—be they adults, children, or their families—provided a good foundation for this rapidly declining and vulnerable community. The review that follows is only a sample of the achievements made by social work in response to HIV, and I regret leaving out any significant organizations or people who made great contributions to our field.

Largely our history is recorded only in the limited articles written for practice audiences, less so for research and evaluation audiences. Barbara Willinger and Alan Rice (2003), however, have done us a favor in pulling together recollections of various social workers throughout the epidemic and cite works by prolific authors such as Michael Shernoff, including his efforts to start a Social Work HIV Journal, *Readings and Writings*, which attempted to track a bit of what went before.

PRACTICE INNOVATIONS

Three decades ago, HIV first appeared in health settings and the emergence of key services owes much to the established social work methods that were quickly adapted. Early on, care consisted of treatments for opportunistic infections and some prophylaxis, although the shifting array of proposed treatments reflected an ongoing search for solutions. At the time, although little could be done on a medical level, the need for social care was overwhelming. Skills such as crisis management, assisting with “adjustment to illness” (a term used pervasively in health social work), medical compliance, decision making about disclosure, addressing family conflict, legal-ethical issues, and linkage to the limited other available services were paramount. Whether the persons carrying out these tasks were called social workers or not, a majority of the activities of those providing service fit squarely in the social work domain.

First and foremost, social work intervention, in all its parts, had enormous applicability to HIV. Counseling skills such as assessing needs, treatment planning, identifying priorities, supportive listening, problem solving, and crisis management were critically useful. However, the social work strength-based approach (Graybeal, 2001) of working with the person within their social environment was especially useful to help both infected and affected people to work with others using a psycho-social-spiritual approach (Tomaszewski, 2010). In particular, we as social workers learned to be sensitive to the cultural meanings of loss, seeking help with illness, caring, and taking care of oneself as these meanings vary across the diverse contexts of our clients' lives (Kaopua, 1998).

The crucial role of support groups provided bridges for isolated people with HIV, their caregivers, and their families (Weiner, 2003; Willinger, 2003). Often in need of emotional contact and direct support, these groups created normality in a highly unpredictable situation. In fact, social work's role in involving families, be they families of origin or choice, and mediating in times of family challenges are directly traceable to our initial efforts in HIV care provision. From our tradition, involving multiple systems social work has created new fields of practice including family mediation, family therapy for the persistently ill, and family-based care.

Soon we adapted case management and its medical cousin, discharge planning, to the needs of people with HIV and their families. Case management is a concept borrowed from our earlier work in gerontology and mental health. Based on ongoing assessment and coordination of services, case management operationalizes the referral process, including an ongoing assessment, development, implementation, and coordination of plans of services in order to provide ongoing support for the person and their family (Chernesky & Grube, 2000). Often social workers became a critical part of people's lives by convening the care team and holding patient and family conferences.

On an organizational level, some social workers led development of regional case management programs, using their clinical and administrative expertise to shape a panoply of client-centered services for those who were refused services by existing facilities. For example, Susan Gallego was instrumental in developing culturally competent services at AIDS Services of Austin, Texas. Helen Land developed caregiver support groups in Los Angeles and designed different types of support groups for different populations (e.g., multicouple groups, gay men, etc.). In Chicago, we convened a coalition of social workers, nurses, and others and formed a "case management cooperative" created to share ownership of a citywide system of care coordinated by the AIDS Foundation of Chicago. Of course many of the innovations occurred in New York under the auspices of the Gay Men's Health Crisis, which formed of necessity to address the emergency of caring for so many needy people with HIV. In a few places, case management was integrated into other service systems. For example, Charles Emlet led a large case management program integrated with aging services in Alameda, California. The Area Agency on Aging in Phoenix, AZ, has been integrating aging services with HIV services for many years.

Finally, client and systems advocacy, an essential part of social work, are indispensably a part of HIV social work. Empowering clients to advocate for themselves, supporting mutual help, individual problem solving to make systems more responsive, and legislative and policy work all resonate with standard social work practices. Among all these efforts, social workers took the lead in creating advocacy responses.

LEADERSHIP

Has social work established a domain for the profession in the HIV/AIDS field? Social workers have been at the forefront of HIV/AIDS services but all too often in secondary roles or, worse yet, without revealing they are social workers. There are two levels of leadership for social work HIV work: first, internal to the social work profession, and, second, to leadership of HIV programs or systems by social workers. On the larger level, many social

workers have had key positions in developing programs and policies, serving as program directors, and chairing task forces and planning councils. Highlighted here are a few noteworthy leaders in our field. David Harvey established and was executive director of the AIDS Alliance for Children, Youth and Families for many years. Tom Sheridan was the policy director at AIDS Action when the Ryan White program was launched, and Nathan Linsk, Cynthia Poindexter, and Vincent Delgado were instrumental in the initiation and development of the National Association on HIV Over Fifty.

Social workers have also provided leadership in a number of population specific and research areas. Helen Land was among the first to call attention to undocumented Latinas infected and caring for family members with HIV—and they did so often anonymously due to stigma in their families and communities. She was awarded one of the first R01 National Institutes of Health grants given to study the stress process and its affect on physical and mental health over time, including the effects of multiple bereavement and bereavement recovery. Larry Gant has conducted a wide array of research and program evaluation dealing particularly with issues for African American men in urban areas. Lori Weiner has taken leadership in a variety of areas related to HIV and children at the National Institutes of Health. Jack Stein, after having chaired the National Association of Social Workers initial HIV Task Force (see later), has moved ahead in a number of key leadership roles for the Substance Abuse Mental Health Services Administration as well as the National Institute for Drug Abuse.

We should recall and celebrate how social work has incorporated HIV into our infrastructure and support programs. A number of efforts have organized leadership of the social work role in the HIV epidemic, and some institutional response has been successful. As early as 1985, a number of cities created SWANs, Social Work AIDS Networks, which provided support, consultation, networking, and education to social workers addressing HIV in their areas (Ostrow, 2003). A National Social Work AIDS Network was established under leadership of Willis Green and subsequently Darrell Wheeler and Ednita Wright. While local SWAN groups may still exist, we have only this year established an ongoing professional organization addressing HIV and social work, the newly established Professional Association of Social Workers in HIV and AIDS (PASWHA, <http://www.paswha.org>), led currently by president Alan Rice, LCSW, which is a membership organization providing support, resources, and advocacy.

Three of our pioneering leaders, Vincent Lynch, Gary Lloyd, and Manual Fimbres, came together in Boston in 1989 with support of the New England AIDS Education and Training Center to launch the first national conference on HIV and social work. The HIV Social Work Response conference is a signal achievement as the only consistent entity that has regularly addressed social work HIV roles and has had significant collaborations with the Ryan White CARE program and a set of schools of social work and HIV

organizations. This year, over 500 participants came to the conference in Atlanta, GA. Each year the conference is rotated in various parts of the country, with next year's conference scheduled for Miami, FL, and the following in Chicago, IL. Lynch, along with Larry Gant, Darrell Wheeler, Patricia Stewart, and Willis Green, also hosted a Summit on Social Work in the African American community in Atlanta in 1998, which resulted in a book based on conference presentations (Gant, Stewart, & Lynch, 1998). Lynch also established the National Center on Research and Training on Social Work and HIV in 1997. The Center oversaw the annual conference and developed a number of research and policy initiatives.

We have been fortunate that the National Association of Social Workers has taken on several initiatives. NASW appointed an HIV Task Force that functioned from 1992 to 1995, providing educational programs, stimulating at least one book on HIV social work and a network of resource people to NASW chapters, and formulating a set of recommendations for the profession, which were not adapted. NASW has supported special journal issues addressing HIV, and its journals have served as an ongoing venue for HIV content, as well as supporting important legislative initiatives related to people with HIV/AIDS.

Social workers, when they could find a way, have also addressed the global HIV pandemic, as volunteers, consultants, and educators. Gary Lloyd worked in the World Health Organization Global Program on AIDS in the very early years of the epidemic, along with Jonathan Mann, MD, whose vision for human rights and HIV is legendary. A legend. Lloyd then went on to work in Africa on the HIV issues, setting the role and tone for many others.

EDUCATING THE WORKFORCE

The NASW Task Force (see earlier) also led to NASW successfully obtaining funding from the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration to set up an ongoing educational project to address training needs of social workers and related professionals regarding mental health issues related to HIV. This HIV/AIDS SPECTRUM: Mental Health Training and Education of Social Workers Project has been sustained now for 12 years under the watch of Evelyn Tomaszewski and has now trained more than 10,000 providers.

SPECTRUM may represent the most focused approach on social work education; however, social workers have also contributed to education in a number of ways. While the Health Resources and Services Administration's AIDS Education and Training Centers (AETCs), recognize social work education as secondary to medical, nursing, and dentistry education, social workers have always been included in the Training Pool. In at least one

center (Midwest) the leadership has consistently derived from social work under the oversight of Nathan Linsk and the Jane Addams College of Social Work.

Social workers have also been active in public education, social media, and prevention education programs. Michael Shernoff began with public information programs for gay men and addressed all gay men, both HIV positive and negative, through his workshops, *Hot, Horny and Healthy: Eroticizing Gay Sex*, that set the standard for explicit information in prevention programming. He also contributed a pivotal article about HIV information for health providers, "Why every social worker should be challenged by AIDS" (Shernoff, 1990).

Finally, social work has begun to develop a published knowledge base. In addition to the above, Micheal Shernoff developed *Readings and Writings for HIV Social Work*, a home-grown publication. From this beginning, the NSWAN group laid the groundwork and established this journal, *Journal of HIV/AIDS and Social Services*, now in its tenth year.

DEVELOPING SYSTEMS RESPONSES

Social work has taken the lead in providing policy and legislative responses, whether they be the National Ryan White CARE Act or participating in local efforts to initiate, discourage, or enhance given legislation. Some of the leaders in this area include Tom Sheridan, AIDS Action; David Harvey, AIDS Alliance; Mildred Williamson (Illinois programs and AIDS Alliance); and the AIDS Institute (for many years headed by a prominent social worker, the late Gene Copello).

A LOOK TOWARD THE FUTURE

It is probably as difficult to recall the world before HIV/AIDS as it is at present to imagine a future world without AIDS. Both scientists and politicians have given up setting deadlines about when the HIV epidemic will be over, and while we need to maintain hope and optimism, the best course is to plan for future generations of HIV. However, the future may look different from the past, especially if vaccine efforts ever become viable; nevertheless, the widespread existence and increased accessibility to HIV antiretroviral drugs are exciting prospects.

POLICY

The policy model needs to be changed. HIV needs to be normalized, to the extent that it is a long-term chronic condition that can be managed with

support and drugs. Troubled though some may be about a decreased focus on confidentiality within the more recent Centers for Disease Control and Prevention (CDC, 2006) routine testing recommendations, the call for near universal testing is overdue (see later). Moreover, the focus on identifying those most difficult to reach should engage social workers, especially those with community training. The initial principles of prevention still prevail: encourage people to know their status and be tested accordingly; maintain confidentiality and client participation in treatment; and refer those who need it to care that is more specialized. The National HIV/AIDS Strategy, released in July 2010 by the Obama administration, is a critical step forward in having a policy that focuses on care, prevention, and health disparities (Office of National AIDS Policy, 2010).

PROGRAMS

The several extensions and revisions of the Ryan White CARE program have meant that the array of city, state, and community services will have some degree of protection; however, the future viability of any specific HIV program is uncertain. Increasingly, as people with HIV live into their older years, the interface with other federal entitlement and insurance programs, including Medicare and Medicaid, will have ongoing importance. While service packages may appear similar, the duration of HIV related services is indefinite; therefore, the need for ongoing advocacy and flexibility during changing times will continue.

Housing may be a pervasive issue, but to date effective models of group living, shared housing, and specialized housing such as housing for families with multiple members with HIV are in existence. The continuous issue is to advocate for equal housing for those with HIV and the continuation of such programs as Housing Opportunities for Persons with AIDS (HOPWA) and a variety of supportive living options when needed. The issue of housing and its long-term care access and possible discrimination to people with HIV require ongoing attention and action.

The HIV workforce is also changing. In fact, the pandemic has changed the face of social work forever, as social workers have adapted skills, roles, and knowledge tailored to address the HIV context. Social workers have become adept at understanding anti-retroviral medications and helping clients achieve treatment adherence using a number of tools and techniques (Kaopua & Linsk, 2007). Social workers have also embraced case management as never before and provided leadership in developing and maintaining service networks. As the veteran HIV workers drop out or retire, those coming to the workforce may not have the lived experience dealing with too little information, fear, stigma, and changing priorities. In fact, HIV has grown a whole array of HIV specialists. Specific HIV training programs are

also needed to prepare future social workers to address the HIV-related needs of clients in almost all fields of practice. What is more, like the larger HIV workforce, incentives are needed to replace exiting workers so HIV concerns continue to be addressed. While some schools of social work teach HIV-related courses, all schools will need to encompass HIV information, as the HIV systems continue to be overwhelmed by resource needs. The HIV workforce needs to include social workers at adequate salaries, with sufficient support to entice workers to continue in the field.

Globalization is a reality in HIV care. As the epidemic epicenter has moved to Sub-Saharan Africa and South Asia, funding has shifted to these areas. U.S.-based social workers are invited increasingly to assist with education, service design, and implementation in the international arena. At this writing, USAID has included social workers in the PEPFAR initiative to train para-professionals as well as help to strengthen social welfare systems. UNICEF has launched an initiative to assess social work needs and develop new models of child protection social services based on local needs. However, the global response also relates to the experience of many immigrants coming to the United States. Working with African-born HIV-positive individuals or their families requires consideration of how to adapt standardized client tools and services to those who have come from another culture. Finally, some organizations including social service agencies are raising funds or in kind materials to provide needy people with a supplement for existing resources. Unfortunately of concern is the experience that some immigrants and refugees have refused information and counseling from those from their own culture, due to fear that such services will lead to unintended disclosure and stigma.

Those involved in prevention and testing are attempting a sea change in the CDC's changing the policy from opt-in testing to routine opt-out testing. The traditional model includes a strong focus on pre-test counseling and informed consent prior to the test. The shift to a routine opt-out testing approach is one where all patients (except for those in very low incidence geographic areas or age groups) are routinely informed about and given an HIV test unless they decline. This shift is good news and bad news for us as social workers. The bad news is that cherished values are at risk with possible harm to our clients. We may interpret this change as beginning the demise of ensuring informed consent and pre-test counseling. However, the other side of this trend is the movement toward being sure that everyone knows their HIV status, engages in risk reduction/prevention, and obtains the care needed when they are seropositive.

Clearly, the role for social workers is to support constructive changes be they at policy, program, or client levels. In fact, the CDC test recommendations include client consent, but the form of consent is different. Social workers can help shape institutional and community responses in an effort to move the increasing rise of the epidemic to decrease HIV. Addressing this

policy shift requires a combination of macro, micro, and mezzo practice and may result in turning the tide to a more responsive testing and care system. For more information, see *Morbidity and Mortality Report* (CDC, 2006).

FOCUS ON THE FUTURE

Let us conclude by considering what was once inconceivable: Where will we be 30 years further into the epidemic? It is not surprising news to many that HIV is likely to be still with us three decades from now. Even if progress continues on vaccine and cure, those already infected and living with HIV will remain. All too likely, we will continue to see new cases, hopefully at a less alarming rate than we now have come to expect. We offer a number of optimistic predictions to this pessimistic scenario of how social work and related fields may successfully impact the future of HIV.

1. Given ongoing attention to addressing diverse populations, health disparities, and social justice, social workers and others will be successful at reducing stigma at the individual, family, and community levels. HIV will be seen within the context and continuum of risk, health, and chronicity. There will be common understanding that the virus can affect anyone, and everyone with HIV is deserving of services, compassion, and quality of life. To do so we will need to sustain our system responses and advocate for humane treatment and a reconceptualization of people with HIV as valued contributing members of society.
2. We will move from AIDS awareness about basic facts to changing social norms in order to publicize and ensure that prevention and care are seen to be effective and worth the investment. Social workers, our clients, our neighbors, and families will understand that the best way to confront HIV is to be knowledgeable, know our HIV status through a considerate testing system, reduce risk-taking behaviors effectively, and provide humane treatment at reasonable cost. Within these efforts, the social work role is greater than education, because it also includes support and advocacy for testing and treatment, again reducing the stigma of HIV/AIDS for all.
3. Social workers in all fields of practice will be informed about HIV, inform their clients about HIV, and help clients make decisions about their own risk of seroconversion, testing, and support needs.
4. HIV care and services will be integrated with other health services into a sufficient ongoing health care package so all obtain the health care they need. Social work will be an integral part of those services providing support, coordination, counseling, and individual and systems advocacy.
5. The lessons learned from the HIV epidemic in all ways—biomedical, advocacy, social intervention—will inform other health and social problems, and HIV will be seen as a portal to learning best practice models

for an array of issues. Already we know more about the HIV virus, and have a wider range of treatments, than we do about many other illnesses. One of our successes has been the fast track of incorporating HIV research findings into clinical care. In the psychosocial area, we have improved upon case management, support group provision, and therapeutic models and we have addressed issues of disclosure and stigma in ways that represent significant advances over past practices. Future developments will include technology transfer from the HIV field into other areas and vice versa. Examples include borrowed knowledge about treatment adherence from the fields of diabetes and hypertension care, which is now expanded and enhanced through our HIV care efforts to benefit other health and social problems. Even the term “adherence” now in common usage came from the HIV experience. To this extent knowledge from HIV prevention, care, and support will be seen as a catalyst to improve practice and policies. Social workers will help inform and lead this process.

6. Medical treatment and psychosocial services will be evidence based, encompassing a mature set of proven techniques so that such interventions will ensure quality of care and quality of life. Social workers will contribute to this evidence base through applied research projects so that we may demonstrate which psychosocial interventions are valuable and effective and can be targeted successfully at specific populations.
7. The eradication of the HIV epidemic will be in sight along with other life-threatening and stigmatizing diseases, and social workers will be recognized for their roles in working toward a world without HIV/AIDs.

CONCLUSION

HIV brings us many lessons, not the least of which is the humility of knowing that medical science cannot be relied upon for a reasonably timely solution to all emerging diseases. It has taken 30 years to develop the dozens of effective medications to date to address HIV, and recent developments shed hope on the use of medications to counter the effects of HIV, prevent transmission, and build stronger immune systems or even eradicate the virus. However, most of our interventions continue to provide supportive contexts for clients to live, address problems, and develop hope for the future. Social work, by our mission and our domain to address the psychosocial environment, will remain a critical player in addressing existing and emerging issues related to HIV. This journal provides a forum to document our successes and achievements as well as discuss the challenges we face as social workers concerned about HIV/AIDS care and support. Toward this end we hope to also use the journal to record our history as we move hopefully toward the next decades toward a world free of HIV.

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