

Analyzing the Role of Social Workers in Supporting People Living With HIV in New York City During the 1990s

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Abstract

Social workers play a crucial role in empowering people living with HIV (PLHIV) and their family members. This qualitative study aimed to reflect social workers' experiences working with PLHIV in New York City in the 1990s. Using a qualitative narrative inquiry method and convenience sampling technique, two social workers who experienced working with PLHIV in New York City in the 1990s were interviewed for this study. Findings revealed that since the beginning of the epidemic, social workers have played crucial roles in providing a range of psychosocial services for PLHIV, including individual therapy and support groups. Furthermore, social workers acted as advocates who demanded social rights and social justice for the HIV population. Finally, social workers, in the early discovery of HIV, collaborated with the community of PLHIV to establish some of the early nonprofit organizations to overcome the structural barriers, including gender inequity and stigma, for PLHIV to live well.

Keywords

AIDS; history; HIV; inequality; social work

Introduction

During the late 1970s, a new disease known as gay-related immunodeficiency (GRID) took many lives in the gay populations in New York, Los Angeles, and San Francisco, U.S. (Nelson et al., 2016). Medical researchers later discovered in the 1980s that the human immunodeficiency virus (HIV) was the virus that caused the disease and decided to rename it GRID (Booth, 2017). The United States society at the time considered HIV gay cancer and God's judgment towards the gay population (Miller, 1989). Furthermore, HIV became synonymous with a moralistic condemnation of homosexuality (Poirier, 2020). This, in turn, led to a delay in recognizing the existence of HIV and associated treatments and a high level of stigma and discrimination among PLHIV—including women and children (Greene, 2007). During the early discovery of HIV in the late 1980s, New York City had the largest concentration of cases of HIV and acquired immune deficiency syndrome (AIDS) in the country (Thomas et al., 1993). The community at the time grappled with the fear of this virtually unknown virus, and PLHIV experienced pervasive and other coexisting conditions of poverty, isolation, mental illness, and addictions (Linsk, 2011).

By the 1990s, it was estimated that about 200,000 cases of HIV had been detected among New York City residents (Kaiser Family Foundation, 2021). Thomas et al. (1993) added that ten years after the first HIV case, New York City had reported nearly 20% of all U.S. cases. In 2020, it was estimated that 37.6 million people were living with HIV across the world, of whom 35.9 million were adults and 1.7 million were children 15 years of age and below (U.S. Department of Health & Human Services, 2023). Globally, AIDS-related deaths have significantly decreased (by 61%) since the peak of HIV transmission in the 2000s. In 2020, it was estimated that 690,000 people died due to AIDS-related illnesses, compared to 1.2 million in 2010 (U.S. Department of Health & Human Services, 2023). Further, there were approximately 57,689 PLHIV in New York City in 2017, compared to 200,000 in the 1980s (NYC Department of Health and Mental Hygiene, 2020). However, this does not mean that the HIV/AIDS epidemic is over (Bell, 2020).

Despite the significant global reduction in AIDS-related deaths and the progress made in managing HIV transmission, social workers continue to play a crucial role in providing psychosocial services to PLHIV (Owens et al., 2023). Social workers have been at the forefront of efforts to provide comprehensive social assistance to PLHIV (Shernoff, 1990; Wheeler, 2011). Ruth and Marshall (2017) described "social workers responding early and forcefully to the HIV epidemic, engaging broadly in outreach, advocating for destigmatization, and crafting culturally responsive preventive interventions" (p. 241). However, there has been a shortage of knowledge related to the reflection of the social work profession during the early discovery of HIV in the 1990s. Humble et al. (2012) stated that from 1987 through 2006, only 5.5% of the articles published in the four leading social work journals—*Social Work*, *Families in Society*, *Health & Social Work*, and *Social Work in Health Care*—were related to HIV/AIDS.

Through this qualitative study, the researcher interviewed two social workers who had experiences working with PLHIV in the early 1990s, a period when HIV became noticeable in the U.S. healthcare system (Booth, 2017). This study analyzes social workers' role in supporting PLHIV in New York City, United States, in the 1990s. Knowledge regarding social workers' role in the early discovery of HIV is crucial to highlighting the development of the social work profession in the area of HIV/AIDS, from addressing the trauma experienced by clients to developing policies and programs to advocate for PLHIV.

Literature review

The emergence of the HIV epidemic in the 1980s brought unprecedented challenges, initially focusing on the white gay male population. This literature review will examine past research on the emergence of the HIV epidemic in the 1980s. This section will also highlight research findings on the government's response to the epidemic, including insufficient funding and discriminatory policies related to the homosexual community in the 1990s. Finally, topics related to developing social work practices in providing services to PLHIV will be explored from the 1990s.

HIV research and marginalized communities in the 1990s

In the early development of the HIV epidemic, studies focused more on examining HIV transmission in the white gay male population. Longini et al. (1989) documented a high percentage of HIV cases among gays. Valdiserri et al. (1988) reported that 69% of their subjects who were gay ($n = 1,384$) tested positive for HIV. Furthermore, gay individuals living with HIV also reported experiencing high levels of psychosocial distress due to the inequality that gay individuals living with HIV experienced in society and medical communities, including rejection by families, homelessness, loss of jobs, denial of employment, and unfair treatment by employers and colleagues. Blendon and Donelan (1988) conducted a study to examine stigmas towards PLHIV. They reported that one in four people were reluctant to work with, allow their children to go to the same school with, or live in the same neighborhood with people diagnosed with HIV. To overcome issues of stigma and discrimination among PLHIV, many self-help and volunteer programs organized by gay communities emerged in large cities such as New York and Los Angeles (Bohm, 1987).

In the late 1990s, HIV transmission was also commonly detected among other marginalized communities, including intravenous drug users (IDUs), women, and children (Des Jarlais & Friedman, 1988; Orkin, 1989). Shernoff (1990) reported that in the 1990s, more than 80% of women with AIDS were black or Hispanic, and more than 90% of all children with AIDS were black or Hispanic from inner-city areas where the source of HIV infection is intravenous drug use (IDUs). Furthermore, an increase in HIV cases among infants and the complexities of HIV, including late HIV detection, contributed to many deaths among children with HIV in the United States in the 1980s (Grossman, 1988). The misconception that HIV can only be transmitted to the MSM population delayed the response from the United States government to address the psychosocial and medical needs of PLHIV in the 1990s (Cole & Denny, 1994; Hays et al., 1990). Studies conducted during Ronald Reagan's administration, the 40th United States President who oversaw the increase in HIV-related deaths, reported mixed findings. For example, a survey by Hays et al. (1990) noted that Reagan's administration was stigmatizing the MSM community, provided insufficient funding for HIV research and treatment, and initially supported mandatory HIV testing. In addition, Francis (2012) described that the Reagan administration, known for its emphasis on family values, viewed homosexuality as a form of deviance. As a result, the government and community ignored the social and cultural factors that contributed to the spread of HIV, including discrimination against the men having sex with men (MSM) community.

In contrast, a study by Jacobson (2020) indicated that the Reagan administration and its policies sought to strike a balance between community apprehension and the perception of HIV associations with specific groups, such as MSM and intravenous drug users (IDUs). The 1990s

also witnessed an important milestone in establishing the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act (Bowen et al., 1992; Ginossar et al., 2019). The Ryan White CARE Act was passed in 1990 to help low-income and uninsured people with HIV get care and support. In 2011, the CARE Act received reauthorization from the federal government, which opened opportunities for an increase in funding from US\$220 million in 2010 to US\$2.3 billion in 2011 (Cahill et al., 2015). Until today, the Ryan CARE Act has become a safety net for PLHIV to continue engaging with appropriate medical and psychosocial treatment services (Bowen et al., 1992).

The development of research on the role of social workers providing services to PLHIV in the 1990s to current

Social workers were at the forefront of the AIDS epidemic in the early 1980s, providing support and social services for PLHIV (Shernoff, 1990; Willinger & Rice, 2003). As early as 1981, social workers in hospitals and medical settings began offering specialized group and individual therapy to help AIDS patients deal with their illness and grief (Willinger, 2003). In New York City, social workers advocated for housing and support for homeless people with AIDS (Willinger & Rice, 2003). Pioneering social workers from New York, such as Shernoff and Palacios-Iimenez, were among the pioneer social workers who developed safe sex educational materials for gay and bisexual groups to prevent HIV transmission among marginalized groups (Shernoff, 1990). However, in the first decade of the epidemic, the profession fell short in preparing most social workers to address the crisis (Peterson, 1991). In an early survey by Dhooper et al. (1987), 80% of 128 responding social workers said they would refuse to provide services to a person with AIDS if they were working in a hospital. This was echoed by a 1988 survey that was conducted by Peterson (1991) among social workers, which revealed that nearly three-quarters of the respondents felt they had no professional reasons or motivations for being knowledgeable about HIV/AIDS and called for schools of social work in the United States to provide all students with information about AIDS and how it may affect different client populations.

Furthermore, a study by Ryan (1988), who was awarded Social Worker of the Year in 1988, reported that the early experiences of PLHIV in the 1980s were painful because there were limited programs and resources for PLHIV. This was echoed by Haney (1988), who shared the experiences that they encountered as PLHIV, such as stigma and discrimination, and called for action to empower PLHIV. Additionally, Mantell et al. (1989) shared that during the early discovery of HIV in the late 1980s, social workers at the St. Luke's-Roosevelt Hospital Center in New York City were able to provide services to only 40% of PLHIV due to a lack of dedicated services to PLHIV and limited training opportunities to train social workers working with PLHIV. In the 1980s, there was an effort to discuss the role of social workers in advocating for equal rights for PLHIV. Reamer (1988) described among the early responses by the Delegate Assembly of the National Association of Social Workers (NASW) in 1984 was to publish a policy statement to recognize that AIDS was a public health crisis and called for an agenda to develop social work ethics when working with PLHIV.

Schinke et al. (1988) also advocated for introducing a sociopsychological training curriculum for human sexuality for social work students to ensure they are fully equipped to work with PLHIV. Shernoff (1988) also called for the integration of safe sex counseling into social work practice, and Goldberg (1989) discussed the dilemmas faced by social workers in maintaining or breaching the principle of confidentiality when working with clients with HIV. Moreover, Lomax and Sandler (1988) reported the importance of social workers understanding the

psychosocial aspects of AIDS, including stress, denial, and suicide ideation. They later added that counseling sessions with social workers might reduce anxiety, alleviate depression, mobilize healthy defenses and coping skills, and promote acceptance among PLHIV. At the same time, a study by Gambe and Getzel (1989) and Willinger (2003) highlighted the importance of social work group practices for HIV gay men to cope with psychosocial crises caused by AIDS. Another study by Carter (1989) also reported that social workers played essential roles in addressing the societal implications of HIV and AIDS, including the financial burdens and losses of family members due to AIDS.

In the 1990s, there was an expansion of studies that examined the role of social workers in providing services to PLHIV. Quantitative studies from Taylor-Brown and Garcia (1995), Reamer (1993), and Marder and Linsk (1995) reported that social workers played significant roles in empowering their HIV clients, ranging from assisting in finding HIV screening and testing, accessing proper health treatment, and advising clients' rights on the privacy and confidentiality of HIV and their status. Studies by Metcalfe et al. (1998) and Shernoff (1990) also described the roles of social workers as advocates who can improve the quality of life for PLHIV. These studies acknowledge the growth of the social work profession, from providing casework or individual and family counseling to their involvement with social-policy debate. As mentioned by Reamer (1993), six significant ethical and civil liberties guide social workers as health communicators for PLHIV: mandatory screening and testing of clients for HIV, client access to health insurance, professionals' duty to treat HIV-infected clients, privacy and confidentiality, client involvement in AIDS research, and relevant legal issues.

In the 2000s, more studies highlighted the roles of social workers in providing services to PLHIV. In the early 2000s, a survey from Reese and Sontag (2001) suggested that social workers advocate for clients living with HIV by linking them with health insurance, resolving psychosocial issues, and collaborating with other professionals, including nurses and doctors, to serve their clients best. Similarly, Willinger and Rice (2003) reported that social workers working alongside nurses at hospitals were involved with patients' intake and developed discharge plans for HIV-positive patients. Furthermore, Reese and Raymer (2001) described social workers' advocacy for patients' active participation and reported that increased involvement of social workers in hospitals significantly lowers the total operation costs. There was an emergence of empirical studies in the mid-2000s that documented the role of social workers in providing pre- and post-HIV test counseling and intensive case management at hospitals (Eaton et al., 2017; Edmonds et al., 2015; Povian & Runcan, 2017). In addition, Murphree et al. (2018) described that social workers provided comprehensive case management among recently released prisoners living with HIV coping with depression and substance abuse, which likely will increase their HIV treatment retention. Tan (2013) described social workers assisting PLHIV with various services, including spiritual and grief counseling for clients and their family members.

Similarly, Povian and Runcan (2017) also reported that social workers are trained in assessment, advocacy, case management, and crisis intervention, which qualified them to assist PLHIV. Wheeler (2007) and Wiener (2003) wrote a personal reflection of one social worker working in the early days of the GRID epidemic, later known as HIV. In this critical – yet rare – work, the author described common emotional reactions of HIV patients, including the disclosure of their HIV-positive status, anxiety in dealing with HIV symptoms and effects, loss of self-esteem, and fear of death. This qualitative study aims to speak to their courage and strength in working with people with HIV. It is essential to reflect on the social work profession, which advocates for social justice and human rights for all, including people with HIV.

Finally, Linsk (2011) provided both insightful commentaries and conceptual articles concerning the roles of social workers within 25 to 30 years of the HIV epidemic, where they found that 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.

The purpose of this qualitative study is to reflect on social workers' experiences working with PLHIV in New York City in the 1990s. During this time, the New York community grappled with the fear of the unknown virus, and PLHIV experienced pervasive and other coexisting conditions of poverty, isolation, mental illness, and addictions (Linsk, 2011).

Theoretical framework

This study applies systems theory and political culture theory to shed light on the experiences of social workers who provided services to PLHIV in the 1990s. The first theory is a systems theory. According to Gitterman et al. (2021), systems theory posits that:

- People are not independent; numerous systems and environments shape them.
- These systems include families, friends, cultures, workplaces, and society.
- Understanding how these systems interact is critical to grasping human behavior and growth.

Using systems theory, social workers can view individuals and their problems within the context of their environment, recognizing that individuals are influenced by and also influence the systems around them (Teater, 2019). Eventually, this theory allows social workers to identify and address the individual's needs and the systemic factors that contribute to those needs. Systems theory also encourages advocacy for systemic changes, challenging discriminatory policies, and promoting healthcare access. For instance, policies advocating for comprehensive sex education in schools can contribute to a more informed and inclusive society. In this study, systems theory can be used to understand the systemic factors that can affect the overall quality of health and well-being of PLHIV, including the relationships, support networks, community resources, and societal attitudes towards PLHIV. According to Gitterman et al. (2021), systems theory enables social workers to identify and address underlying systemic barriers impacting the lives of PLHIV. These barriers include stigma, discrimination, lack of access to healthcare and support services, poverty, and inadequate policy and legal protections.

The second theory is the political culture theory. According to Heywood and Chin (2023), there are three tenets of political culture theory:

- Examine society's prevailing attitudes and values, significantly impacting how people see and deal with different social issues.
- Determine how social problems are defined and framed in terms of government involvement.
- Explain how political processes and ways of making decisions affect policy outcomes and strategies for putting them into action.

According to Eboko and Mbengue (2018), political culture theory holds that individual behavior emerges from cultural options and dispositions. This theory can explain social workers' role in providing equal access to health care, the right to treatment and care, and reproductive health for PLHIV. During the 1990s, PLHIV faced limitations in fully exercising their rights due to the stigma and discrimination associated with HIV diagnosis, which portrayed HIV as a moral disease. Political and cultural inequalities during this period restricted the ability of PLHIV/AIDS to assert their rights. The political culture theory helps in understanding how the broader political and cultural milieu influenced the work of social workers, shaping their strategies, advocacy efforts, and the challenges they faced in supporting individuals experiencing stigma and discrimination (Altman & Buse, 2012).

Method

Study design

To understand more about the social workers' roles and practices with PLHIV in New York City in the 1980s, we used a qualitative-cross-sectional research design – specifically, narrative inquiry. The exploratory nature of qualitative methods also allows the researcher to capture participants' thoughts to gain a deeper perspective on their reflections, shed light on social work development, understand social workers' early and vital roles in advocating for PLHIV, and contribute to the limited literature on this topic.

Sample and sampling

This study followed a convenience sampling technique to recruit participants based on accessibility, willingness to participate, and meeting the participants' selection criteria. Our social work professor, who lives in New York City, helped recruit participants for this study, and the professor suggested that we contact two social workers in New York City who have been known for their advocacy and empowerment work, specifically among PLHIV. We then contacted the participants via email, and they agreed to participate in this project precisely because this was also the first request they received concerning reflecting on their practices with PLHIV in the early 1990s in New York City. Participants were selected for this study because of their rich and valuable stories and experiences working with people with HIV during the early discovery of HIV, specifically in New York City.

Our study's population consists of social workers in New York who provided services between the late 1980s and the early 1990s when HIV was first discovered. Three significant factors formed the basis for relying only on two participants. To begin, the participants in this study are a difficult-to-reach group: New York social workers with HIV/AIDS experience from the 1990s. Given the significant time lapse (more than 30 years), locating individuals from this demographic presented inherent challenges. Second, both selected participants were active social workers in the early 1990s, providing critical services to PLHIV. Their responsibilities included facilitating group work, providing individual counseling, and speaking at community educational events.

Furthermore, both participants were currently employed as social work professors and remain actively involved in working with people living with HIV. Their long-term commitment and involvement in the field add to the breadth of their experiences and insights. Finally, our

participants' extensive professional backgrounds contributed significantly to the study. Participant 1 had an impressive publication record of over 100 journals and books on PLHIV and is well-known around the world for advocating for HIV/AIDS rights and justice. Participant 2 was among the founders of the NGO in New York to provide psychosocial services to PLHIV.

In terms of participant recruitment, the study's goal of reflecting the role of New York social workers during the early discovery of HIV resulted in an estimated age range of 50 to 60 years. We used convenience sampling to recruit participants, a non-probability method that allows us to collect data from an easily accessible group. We decided whether to contact participants who met the inclusion criteria after receiving a recommendation from a social work lecturer who was aware of the study's goals and the difficulties of the target population. This method effectively ensured that participants had the specific experiences and qualifications required for our research.

The goal of this study was to analyze the role of social workers in supporting PLHIV in New York City, United States, in the 1990s because the 1990s was a significant period when HIV was first discovered and became visible in the health care system of the United States (Greene, 2007). By its nature, qualitative research does not involve generalization, hence the use of a small sample. Further, Creswell and Poth (2016) suggested at least two participants for a narrative inquiry. All two participants invited the first author to meet at their Manhattan, New York offices. New York City was selected because it was one of the earliest cities in the world where HIV was first detected, and it was reported that during the 1990s, 20% of all HIV cases in the United States were from New York City (Thomas et al., 1993). Second, this city experienced rapid development in terms of medical research and psychosocial interventions to support and assist PLHIV (Rowan & Honeycutt, 2010).

Participant selection criteria

This qualitative study interviewed two social workers with practical experience working with PLHIV during the 1990s. All participants had extensive working experience with PLHIV. The 1990s marked a crucial period when HIV was first discovered and became prominently visible in the healthcare system of the United States (Greene, 2007) approximately 33 years ago. Our chosen sampling method, which used convenience sampling, guided the decision to concentrate on only two participants. In this method, participants are selected based on their accessibility and availability for the research. Our social work professor recommended contacting these two participants, who met the eligibility criteria and graciously agreed to participate in our study. Additionally, the selection of these two participants was deliberate, considering their alignment with specific criteria:

1. Both participants were currently working as social workers.
2. They resided in New York City.
3. They possessed social work practice experiences as health advocates for clients living with HIV in New York City during the early discovery of HIV in the 1980s.

Data collection

Data from this study were collected using one in-depth, face-to-face interview with each participant to share their narratives. Before the interview, participants were asked to complete

a short sociodemographic and background questionnaire. On average, each interview lasted about 40 minutes. The researcher used a semi-structured interview protocol and a pre-designed form to ask the questions briefly and recall the research questions during the interview. All interviews were audio recorded with the participants' permission. Participants shared reflective insights into their social work experiences with PLHIV in the 1990s. They elaborated on their roles in providing social work services to advocate for people with HIV during the early years of HIV discovery in New York City, shedding light on the challenges they faced during that time.

Data-analysis procedure

All recorded interviews were carefully transcribed verbatim and analyzed by the first and second authors. The first, second, third, and fourth authors analyzed the interview transcripts based on Fraser's (2004) guidelines for personal story analysis in narrative research, starting with listening and relistening to the recorded interviews, followed by transcribing the audio-recorded interview. All the themes that emerged from the data combined to create in-depth stories about the roles and shared experiences of social workers when working with clients living with HIV during its early discovery in the 1990s.

Rigor and trustworthiness

This research aims to analyze the role of social workers in supporting PLHIV in New York City, United States, in the 1990s. We implemented three steps to ensure the reliability of the findings from this study. First, we conducted member checking with all participants by ending all the themes that emerged from the data analysis through email. They all agreed with the final themes, with no further revisions suggested. Secondly, we conducted peer debriefing by presenting the themes to our peers, who are researchers conducting studies examining the experiences of PLHIV in the United States, particularly in New York City, for more than 20 years. They also agreed with two themes that emerged from this study. Finally, we practiced reflexivity throughout the study, actively listening during the interviews, seeking feedback from peers to avoid bias, and maintaining transparency.

Ethical considerations

The study was approved by the Ethical Committee of Adelphi University, United States (Ref. No. 020316). The following specific ethical considerations were taken into account before, during, and after undertaking the study, including participants reading and signing a written consent form before the interview, which they then talked about with the researcher. The researcher clarified that participating in the study was optional and that people could quit anytime. Before the first interview, the researcher told the participants about the study's goals, benefits, and possible risks. With the participants' permission, all interviews were recorded on audio. The focus of this study was to analyze the role of social workers working with PLHIV in the 1990s in New York City. While the researcher anticipated that the discussion of their previous experiences might trigger traumatic memories, none of the participants exhibited any emotional distress. None of the interviews were terminated as a result. The researcher nonetheless provided every participant with a list of nearby professional services, such as social workers, counselors, therapists, and psychologists, at the end of the interview in case of a delayed stress-related response.

Results

Participants' backgrounds

Both participants were social workers and lecturers who began social work activities in the early 1990s. They are both in their late 60s and have been actively involved with advocating for PLHIV and writing many research papers and books to highlight the importance of social work practices, including with HIV/AIDS clients and group work practices. Participant 1 has been involved with local and international social work practices to create awareness about HIV and AIDS. Participant 2 is a senior social worker working at a nonprofit organization (NPO) that provides services to PLHIV. During the interview, both shared that they still offer social services to PLHIV.

Addressing stigma and discrimination

Participants reflected that during the 1990s, community members in New York City were still grappling with understanding the new virus that affected and contributed to many deaths, specifically among the gay population. Participants added that people with HIV were heavily stigmatized and discriminated against due to a lack of understanding and incorrect knowledge about its transmission. As a result, many HIV patients were left untreated. Participant 1 reported:

At that time, I remember that the hospital would not treat people with HIV. At the Veteran's Hospitals (VA), they would not pay attention to this patient because they were afraid they would contract the virus. They do not feed him or really take care of him, and it is very stigmatizing. So, it became a real issue for humanity, and people with HIV were not getting any care.

Participants elaborated on how the introduction of highly active antiretroviral therapy (HAART) medications in the late 1980s changed the epidemiology of HIV from a fatal to a chronic illness by suppressing the virus and restoring immune function. These medications have resulted in their clients living longer. However, participants also described their role in enhancing the quality of life among clients with HIV, including addressing the psychological effects of HAART. With clients now living longer, Participant 1 recognized the need to address not only the physical aspects of the illness but also its profound psychological effects, leading him to engage in support groups and counseling.

In addition, Participant 2 described how, as HAART medications emerged to challenge the lethality of the virus, he found himself at the intersection of medical breakthroughs and the psychological complexities faced by his clients. Participant 2 also shared that rapid HIV transmission in New York City created an urgent need for social workers to provide services, including different types of support groups for clients with HIV and their family members. Participant 2 shared:

It was such an emergency. That is why we [social workers] need to do different support groups: one for the carers and partners because of what they were going through, you know, with all that stress from caring for HIV-positive family members. Plus, we have a bereavement group, too.

So, it was just a very intense kind of situation, from the way that I understood it.

Both participants also reported that the urgent need to address various HIV issues in New York City during the 1980s resulted in social workers and community members collaborating and establishing nonprofit organizations focusing on improving the rights of PLHIV. Participants 1 and 2 shared that they decided to be involved in the establishment of an early nonprofit organization (NPO) to address the severity of the impacts of HIV on the gay population at that time. This organization eventually served as a model for other NPOs to assist different populations, including women and people of color living with HIV. According to Participant 1:

So, I helped establish the Gay Men's Health Crisis (GMHC) to address the HIV and AIDS situation at that time because there were more and more HIV-positive people dying. We had thousands of volunteers, and they will visit people and their homes, and they will help people shop and go to the doctor. They also have programs and organize AIDS prevention education, safer sex, and prevention for gay and bisexual men and women.

Reflecting on his involvement in the establishment of the same NPO, Participant 2 shared:

The situation demanded immediate action, and we recognized the need for a comprehensive response. Establishing GMHC was crucial because, during that period, we witnessed an alarming increase in the number of PLHIV. Our organization became a beacon of support, with a vast network of social workers and volunteers engaging in various forms of assistance. From home visits to aiding with everyday tasks like shopping and doctor visits, we played a vital role in providing emotional and psychosocial assistance to those affected.

Advocating for better rights for PLHIV

Both participants considered their roles in educating members of society, such as medical professionals, religious institutions, and community leaders, to address stigmas and discrimination experienced by PLHIV and support community members in establishing nonprofit organizations that advocate for the better rights of PLHIV. Participant 1 described:

I wrote to them about the thing that I felt was wrong: they were not seeing people with HIV and demanding that is not appropriate. I also suggested that they provide support for people with HIV. Finally, they invited me to be on a committee to share how religious leaders and community members should support people with HIV.

Both participants also shared that in the 1980s, the field of social work faced significant challenges as it grappled with emerging health crises, including the HIV/AIDS epidemic. They shared that during this time, many social workers were actively involved in providing support and care for individuals with chronic illnesses such as tuberculosis (TB) and cancer. As a result, these experiences gave them valuable skills and protocols for addressing the psychosocial needs of patients facing long-term health conditions.

Participant 2 mentioned that hospitals approached him to share knowledge and create guidelines for working with HIV patients based on his prior experiences with TB patients. Based on some similarities between the psychosocial aspects of TB and HIV, he then developed guidelines for social workers to work with PLHIV, emphasizing a holistic approach to patient care that encompassed not only the medical aspects but also the emotional, social, and practical dimensions of living with a chronic illness. Participant 2 shared:

During the 1980s, social workers were known to work with other chronic illnesses such as TB and cancer. So, they [hospitals] invited me to talk about HIV, and I established guidelines for working with HIV patients, which are almost identical to those that I developed earlier for working with TB patients.

In response to this invitation, Participant 2 leveraged his knowledge and expertise from working with TB and cancer patients. Drawing parallels between the psychosocial aspects of TB and HIV, he developed remarkably similar guidelines, emphasizing a holistic approach to patient care that encompassed not only the medical aspects but also the emotional, social, and practical dimensions of living with a chronic illness.

In the mid-1990s, amidst rising HIV/AIDS cases and misinformation in their community, Participant 1 and his student embarked on a mission to combat the HIV epidemic's spread. Later, he added that they devised creative ideas to reach a wider audience and dispel common misconceptions about HIV transmission because of their passion for public health advocacy. Recognizing the power of mass media, they decided to launch their own radio and television channels, envisioning them as platforms to educate the community with accurate information about HIV/AIDS. Furthermore, to inform the community about HIV and to improve the lives of PLHIV, both participants described feeling motivated to collaborate with PLHIV to publish journals, books, and articles related to the psychosocial aspects of living with HIV and AIDS.

Similarly, Participant 2 found motivation in collaboration as a means to effect positive change in the realm of HIV education and support. Recognizing the need for accurate information and a nuanced understanding of the psychosocial dimensions of HIV and AIDS, Participant 2 partnered with individuals living with HIV to author impactful journals, books, and articles. This collaborative effort aimed to educate the community and illuminate the human aspects of the HIV experience. According to Participant 2:

The key thing, I think, is to organize a community of gays, lesbians, bisexuals, partners, and their friends to support HIV advocacy in the United States. And one of my students who died was very young, and he is one of the people who established what we called the AIDS Alliance, where they talked about the rights and dignity of people with HIV and AIDS early on. For example, society called them either "sufferers" or "victims." And we do not use that because it is so offensive. We advocated for the use of, first, "people with AIDS," and then it changed somewhat to "people living with AIDS."

Findings from this study highlight the proactive role of social workers in responding to evolving healthcare challenges, contributing valuable insights to developing guidelines that address the unique needs of PLHIV. Ultimately, this narrative underscores the pivotal role of social workers in shaping comprehensive and compassionate care for PLHIV.

The resonance of study findings with systems theory and political culture theory

Applying systems and political culture theory can shed light on the experiences of social workers working with PLHIV who faced stigma and discrimination in the 1990s and rights advocates (Gitterman et al., 2021). According to study participants, social workers deal with the challenges posed by these systemic issues while also supporting stigmatized individuals. Social workers interact with the complex system to shape policies, challenge discrimination, and advocate for improved rights. In this study, systems theory aids in unraveling the complexities of social work within the larger systems affecting PLHIV. It emphasizes the interconnectedness of elements and the systemic nature of problems and offers insights into how interventions and advocacy efforts can catalyze systemic change.

Political culture theory emphasizes the influence of societal attitudes and values on individual behavior. Political culture, societal attitudes, and discriminatory policies all pose significant challenges for PLHIV. According to the study's findings, in the 1990s, PLHIV in New York City faced widespread stigma and discrimination, exacerbated by misinformation about transmission, emphasizing the impact of societal attitudes and cultural factors on those affected, as explained by political culture theory. Participants in this study also stated that in the 1990s, social workers had to work within this political culture, respond to their client's immediate needs, and navigate a larger societal context that perpetuated stigma and discrimination against HIV patients. Finally, participants in this study also shared their experiences as advocates who challenged discriminatory policies, demanded equal access to healthcare, and championed the rights of PLHIV.

Discussion

These two themes—(a) addressing stigma and discrimination among PLHIV and (b) advocating for better rights for PLHIV—highlighted the critical role of social workers in empowering PLHIV during the early discovery of HIV in the 1990s.

The findings reaffirmed the stigma and discrimination experienced by PLHIV, including those living in New York City during the period under discussion. According to social workers in this study, society has often unfairly silenced the voices of HIV-positive people, including those who receive no medical care at hospitals. Furthermore, politicians decided not to allocate appropriate funding to improve the lives and treatment of those living with HIV, and some community members suggested inhumane therapies, such as tattoos and isolation, for patients with HIV. This is similar to what was reported in the literature during the 1980s (Blendon & Donelan, 1988), describing that PLHIV were subjected to unfair treatment by their employers, lost their jobs, and experienced homelessness.

At the same time, the introduction of highly active antiretroviral therapy (HAART) in the late 1980s changed the epidemiology of HIV from a fatal to a chronic-managed illness due to its capability to restore the immune systems of people with HIV in the stages of AIDS (Blendon & Donelan, 1988). According to social workers in this study, the medications caused social work practice to change from viewing HIV as a fatal illness to viewing it as a manageable chronic illness. As a result, social workers played crucial roles in addressing the urgency to provide various psychosocial interventions for PLHIV, including grief counseling and support groups

(Eaton et al., 2017; Edmonds et al., 2015; Ruth & Marshall, 2017). Similarly, the introduction of PrEP (pre-exposure prophylaxis) in 2012 as a preventive medication for individuals at high risk of acquiring HIV marked a significant milestone in HIV prevention strategies (Rivet Amico & Bekker, 2019). PrEP revolutionized the approach to HIV prevention by providing a proactive method for those vulnerable to the virus, offering them a daily oral medication regimen to reduce their risk of HIV transmission significantly. Since then, social workers have been crucial in educating and counseling individuals about PrEP's effectiveness and potential side effects (Lacombe-Duncan et al., 2021). Furthermore, social workers assist clients interested in PrEP by providing support in accessing healthcare services and helping them navigate the process of getting and adhering to PrEP medication (Lacombe-Duncan et al., 2021).

Social workers' roles are not limited to counseling but also advocating for clients' social rights and justice by organizing various social campaigns and movements. This research study proved that social workers were involved in establishing one of the world's first HIV and AIDS service organizations, the Gay Men's Health Crisis (GMHC), in the 1990s.

Findings from this study also reaffirmed social workers' dedication to working with clients living with HIV/AIDS during the beginning of the HIV pandemic in the United States, similar to studies from Taylor-Brown and Garcia (1995), Reamer (1993), and Marder and Linsk (1995). The themes found in this current study also revealed the roles of social workers as advocates who wrote journals and articles related to social work practices with PLHIV based on their own working experiences within this population. As a result, the journals and articles written by social workers contributed significantly to understanding HIV comprehensively through the lenses of social workers and HIV-affected groups. As Auerbach and Beckerman (2010) described, social workers have become agents of change to create a better society.

Participants in this study shared their involvement with public campaigns to address issues of social inequality and injustice regarding access to medical and psychosocial treatments for HIV/AIDS in society. They continue to play active roles in creating compassionate policies both at the local and international levels to build coalitions and end the stigma and discrimination surrounding HIV.

Limitations

This study has some limitations. First, participants were self-selected into the study, so results could be biased based on the subset of social workers who felt motivated to participate. The main focus of this study was to explore and reflect on the experiences of social workers during the early discovery of HIV. According to Walze and Groze (1991), social work emerged in the 1990s. Approximately 9,000 Bachelor of Social Work (BSW) and 11,000 Master of Social Work (MSW) were awarded from 1990 to 1991 by 404 universities offering social work programs in the United States (Schilling et al., 2008). As a result, the findings may not apply to other professions involved in supporting PLHIV simultaneously.

Further, the sample size was relatively small. However, this standard aligned with this study's research goal and aim: to analyze social workers' role in supporting PLHIV in New York City, United States, which was 33 years ago. Moreover, recruiting this type of sample can be challenging. Generalization was not the primary goal of this study.

Implications for social work practice and research

The study's outcomes emphasize social workers' crucial role in combating stigma and discrimination against PLHIV during the epidemic's early stages. It suggests the continuation of stigma-reduction strategies through public HIV/AIDS awareness campaigns and providing support and education to individuals facing societal prejudices. Additionally, employing strengths-based approaches to empower PLHIV by emphasizing resilience and fostering a sense of agency is recommended. Integrating these themes into social work education is essential for preparing future practitioners to address the needs of individuals living with HIV effectively. Curricula should include modules on stigma reduction, discrimination, and advocacy to ensure students grasp the historical context of the HIV epidemic's onset. The findings underscore the necessity for ongoing research to comprehend how stigma and discrimination impact HIV-positive individuals. Researchers should explore innovative interventions and advocacy strategies and conduct longitudinal studies to understand PLHIV's evolving needs. Moreover, research should evaluate the effectiveness of social work interventions in advancing the rights of PLHIV, contributing to evidence-based practices that inform policy and program development.

Conclusion

Social workers have been at the forefront of HIV/AIDS care, serving as clinicians, educators, and advocates, thus playing critical roles in combating the epidemic in the 1990s. They are pivotal in raising awareness about HIV/AIDS, delivering interventions to prevent transmission, and offering essential care services to PLHIV and their communities. Social workers provide comprehensive healthcare support through their social work practice, including counseling, treatment adherence guidance, and addressing co-occurring health issues. As educators, they empower communities with accurate information about HIV/AIDS transmission, prevention methods, and destigmatization efforts. Additionally, social workers act as advocates, tirelessly addressing systemic barriers to care, advancing policy changes, and standing up for the rights and dignity of those living with HIV/AIDS. In today's landscape, social workers continue to navigate the complex intersections of HIV/AIDS with other social determinants of health, such as poverty, homelessness, and substance use. The legacy of social workers' efforts in the 1990s continues to be felt today, as HIV remains a public health concern, and social workers continue to play a critical role in addressing its impacts.

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