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Gay Men's Health Crisis: A Historical Ecological Systems Approach

Introduction

Bronfenbrenner's Ecological Systems Theory (1979) describes the direct and indirect influences of the microsystems (i.e., others who have a direct contact with an individual), mesosystems (i.e., relationships between others in the individual's microsystem), exosystems (i.e., links between others that only affect the individual indirectly), macrosystems (i.e., the culture and political environment in which the individual lives), and chronosystems (i.e., transitions and shifts in the individual's lifespan) (Rosa & Thudge, 2013) in an individual's life (Rosa & Thudge, 2013; Mustanski, Burkert, Greene, Hatzembuehler & Newcomb, 2014). The ecological systems model has been used in prevention and intervention research, as a way to address the complexity of minority stress felt among many LGBTQ youth (Rosa & Thudge, 2013); to explore laws associated with the LGBTQ community such as the Defense of Marriage Act, the effects of other ideologies such as compulsory heterosexuality and sexual discrimination (Rosa & Thudge, 2013); and the way mass media constructed AIDS as a gay male disease, further affecting lifespans by linking anti-gay and anti-AIDS prejudice. Context, personal traits, time period, and community interactions act interdependently to affect one's life (Afuranski et al., 2014), cautioning that interventions that target single microsystems may not improve the individual's situation.

When AIDS first emerged in the United States, early cases were reported in Los Angeles and New York City (NYC). As the epidemic grew, NYC became a center for reported cases. By 1987, it was reported that 30% of the AIDS cases in the United States were in New York City. As of 1997, NYC had more cases than Miami, Los Angeles, and San Francisco combined (Fordyce et al., 1999). The concentration of cases in NYC, combined with existing societal homophobia and increasing levels of AIDS phobia, members of the gay community living in the city experienced increased discrimination. This exacerbated the conditions of the illness and created new struggles related to housing, working, and healthcare (Pedoto, 2017). Economic and racial injustices also played a part. Reported cases of AIDS increased much more rapidly in low income and minority neighborhoods than in high income and white areas (Fordyce et al., 1999). From the beginning of the 1980's until the end of the twentieth century, New York City remained a major hub of the AIDS epidemic, demanding mobilization and consistent community action.

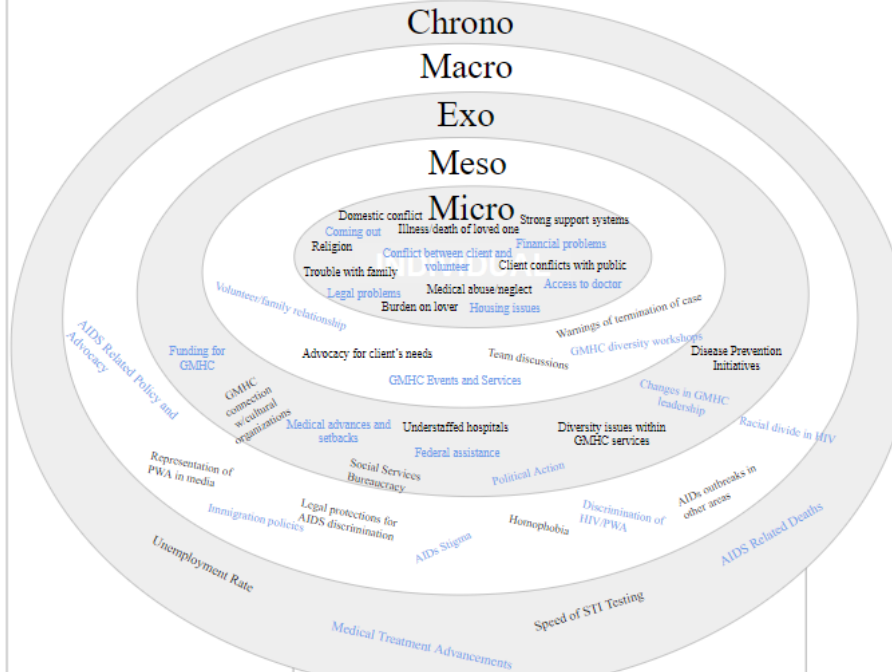
Gay Men's Health Crisis (GMHC) was organized in 1982 in response to the spread of a previously unknown "gay man's" disease and the lack of an adequate governmental response. GMHC provided a range of services that were provided by both professional staff as well as teams of client services volunteers responsible for helping people with AIDS cope with the emotional, social, and economic challenges resulting from the disease. This study uses Bronfenbrenner's micro-, meso-, exo-, and chronosystems (Rosa & Thudge, 2013) as a framework for understanding the relationships between GMHC and the government, relationships between members and clients, public perceptions of AIDS, and changes in the organizational structure of staff.

Methods

GMHC newsletters, client services team meeting minutes, and board meeting minutes from 1986 to 1988 included in the AIDS History Archive at Binghamton University were reviewed for this project. To increase the diversity of the sample, analyses focused on several client services teams located in Manhattan and Brooklyn.

A thematic analysis of the newsletters and minutes from the client services teams was better understood through Bronfenbrenner's Ecological Model was used as a framework to conduct. Understand how the experiences of people living with AIDS in the 1980s were affected by a variety of factors at the micro-, meso-, exo-, macro-, and chronosystem levels. Themes from the client services team minutes and agency newsletters were considered in relation to important historical events, and coded into different layers of the ecological model (Microsystem, Mesosystem, Exosystem, Macrosystem, and Chronosystem).

Results



Case 1: John

John is a 38 year old gay white man living with AIDS, PCP, and KS. He came to GMHC in November of 1987 looking for emotional support and financial guidance at the microlevel after he and his ex-lover were diagnosed with AIDS. From his ex-lover's past experiences, he learned to worry about the possible bureaucratic failures. GMHC was able to refer him to social services and find legal help for John (mesosystem). Because John did not have proper legal documents in order, he needed a social worker/advocate to ensure he received proper hospital care (mesosystem). With GMHC's support, he was able to get Medicaid, and AZI (meso-, exo-, and chronosystems). In addition, John participated in a new study at the Community Research Initiative which gave him access to new medications, which had a positive effect on his health (chronosystem).

Case 2: Billy

Billy is a gay man living with AIDS and PCP that had led to unemployment, isolation, and financial instability (microsystem). He came to GMHC in January of 1988 seeking help with the physical, emotional, and financial hardships he was facing. GMHC was able to alleviate some of this by providing meals along with emotional support by connecting him with volunteers (mesosystem) especially when his lover passes away due to AIDS (microsystem). AIDS stigma and homophobia (macrosystem) played a role in the loneliness he experienced during his hospitalizations. And the lack of AIDS doctors in NYC (exosystem) became a problem for him when his old physician disappeared without notice (chronosystem), and he had to search for alternate therapies. Some of the new treatments (i.e., herb and vitamin based therapies, and possible treatments for and management of PCP) may have led to Billy gaining weight and to his health stabilizing (chronosystem). Thus far, Billy's need for GMHC seemed to grow and decline as his life passed through periods of hardship and stability (chronosystem).

Case 3: George

George is a 28 year old white, gay, man, living with AIDS and ARC. He came to GMHC in June of 1987 due to physical and mental health challenges. George has trouble moving due to the virus attacking his nervous system and atrophying his brain. He is also depressed. George takes AZT to treat his physical symptoms and antidepressants for his depression. George's mother is consumed with caring for him, while his father is tolerating the situation (microsystem). George was also really fond of his home health care attendant. Unfortunately, she was switched with another attendant (microsystem). The new attendant is very good, but George misses his old attendant. George became paralyzed from the waist down and experienced a lot of mental confusion. He was hospitalized, and is experiencing acute bed sores because the hospital was not changing his dressing (exosystem). Robert, George's volunteer, called the ombudsman office at GMHC (mesosystem) and George's mother called the State of New York to report it (mesosystem). The hospital was cited for this mistreatment (exosystem). George seems to be doing better and was released from the hospital and allowed to return home (mesosystem) interacting with microsystems.

Case 4: Seth

Seth is a 45 year old IV drug-user, who is housing insecure and who struggles with drug addiction. The client-volunteer relationship is tense (microsystem). Seth is described by his volunteer Kevin as "difficult to work with" and as being a "whiny manipulator". Kevin recommended that Seth take the advice of his psychologist and join a therapy group, but Seth just wants to find some Valium to "reduce stress". Seth continues to abuse drugs, and Kevin gives him a warning that continued drugs abuse will result in GMHC terminating services (mesosystem). Whenever Kevin brings up AIDS, Seth changes the subject, suggesting he is in a state of denial about his situation. In a team discussion, another volunteer says that volunteers need to not let clients get to them, nor let clients make them feel guilty (exosystem). It's possible that clients sometimes engage in problematic behaviors with their volunteers because they see them as "angels of death".

Summary of various findings from the ecological system across levels

This project followed several GMHC clients over three years (1986-1989) to document and attempt to understand the experience of living with AIDS during the mid-to-late 1980s while receiving services from GMHC.

Despite a range of challenges in their individual lives due to AIDS, GMHC was able to facilitate support at the micro- and mesosystemic levels. Larger macrosystemic and exosystemic factors also had an influence on clients' lives. Homophobia, AIDS-related stigma as well as neglectful and sometimes harmful governmental policies relating to health care and the portrayal of People With AIDs (PWAs) in the popular media, created challenges. Whereas, actions by activist groups such as ACT-UP (AIDs Coalition to Unleash Power) at the exosystemic and chronosystemic levels led to changes in drug policies, allowed new medications to be accessible and increased longevity.

Most clients were able to manage their emotional, financial, and social difficulties by working with their volunteers. This includes taking control of their microsystems in the form of social, financial, and medical support. Additionally, clients experienced similar medical and emotional problems as their illnesses progressed, although they presented differently depending on the client's personality, demographics, and their environment. The services offered at GMHC allowed clients to make sense of their situation and to feel less alone as they experienced tremendous loss due to the death of friends and lovers or their own health declined.

This project is a pilot for a larger project that will use these archival data to explore the history of the AIDS crisis and how changes in the organizational structure of GMHC impacted on services and client satisfaction over time. In addition, it is our belief that this historical analysis of ecological systems will help us better understand the development of different age cohorts of LGBTQ+ individuals.

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