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Advocacy in LGBTQ+ Cancer Care: Historical Resilience as a Model for Further Efforts in Psycho-Oncology

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Cover Page Footnote

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As a community, the lesbian, gay, bisexual, transgender, queer (LGBTQ+) population has shown tremendous resilience in overwhelming adversity, particularly when confronted by crises in community health. Disproportionately elevated incidences of cancer are impacting the LGBTQ+ population at epidemic levels, and yet the literature on proper care and advocacy efforts in psychology remains meager. The National LGBT Cancer Network communicates the concerns associated with increased cancer-related diagnoses and deaths that LGBTQ+ populations disproportionately confront, particularly in the prognosis of the lung, breast, anal, liver, and cervical cancers (Healthy People, 2020). Various risk factors could contribute to these increased diagnoses, including systemic barriers to insurance and healthcare and increased risk-related behavior in sexual and gender minority (SGM) populations. In addition to concern surrounding the sociocultural factors contributing to this progressive uptick in cases, research on LGBTQ+ individual's experiences receiving cancer care reveals it is often less than satisfactory (Jabson & Kamen, 2016).

In response to this growing concern, the field of psychosocial oncology often referred to as psycho-oncology, has begun to compile research to inform policy and develop LGBTQ+-affirming, culturally conscious, community-centric standards of care. The American Psychosocial Oncology Society (APOS) defines the profession as "a cancer specialty that addresses the variety of psychological, behavioral, emotional and social issues that arise for cancer patients and their loved ones." (American Psychosocial Oncology Society [APOS], 2021). Conceptualizing and exploring the history of LGBTQ+ healthcare is vital in informing these burgeoning advocacy efforts in psycho-oncology, as the current medical and psychosocial systems that provide care to LGBTQ+ people retain institutional biases and disparities in care from an establishment that once pathologized their identities (Bayer, 1987; King, 2019). Additionally, the significance of the AIDS crisis within the community has created a large body of research on AIDS-specific care and advocacy practices during the Gay Liberation Movement that is useful in understanding LGBTQ+ trauma, community support, and resilience (Institute of Medicine, 2011). This paper aims to review the historically significant literature on LGBTQ+ people's experiences with health care, which will then provide the necessary context and supplemental data to illuminate current practices in LGBTQ+ cancer care and inform the next steps in advocacy.

Origins of LGBTQ+ Health Psychology: Pathologization of Sexual and Gender Minorities

The inaugural edition of the American Psychological Association's *Diagnostic Statistics Manual (DSM)*, which has long served as the most widely accepted set of diagnostic criteria in the United States and now utilizes the fifth revised version,

included a diagnosis of homosexuality alongside substance abuse and sexual disorders, all of which existed in the overarching category of sociopathic personality disturbances (American Psychiatric Association, 1952). Conversely, gender dysphoria-related experiences were not included in the two inaugural publications of the *DSM* but first appeared in the *DSM-III* in 1980 with the introduction of a diagnosis of transsexualism, an antiquated term used to describe being transgender, to the manual (Yarbrough et al., 2017). The medical and psychological pathologization of Queer identities was vital in shaping public perspectives on LGBTQ+ people and being ingrained into institutional practices for care that continue to permeate health institutions 70 years later. Analysis of the history begins to reveal a through-line that fetters many of the contemporary disparities in treatment and lack of advocacy efforts in the field of psychosocial oncology back to systemic decisions and societal attitudes shaped in 1952. The consequences of stigma in healthcare, conceived through prejudice that continues to perpetuate harmful beliefs and actions, must be identified and named to facilitate greater recognition of the importance of continuing advocacy efforts.

Conversations around SGM individuals were incredibly limited in the United States before their introduction to the *DSM* in 1952. However, intense social stigma already permeated both daily interactions and systemic sentiments and, to this day, private, consensual same-sex conduct remains criminalized in 71 countries as of 2021; 15 of those jurisdictions also criminalizing transgender and gender-expansive identities (Human Dignity Trust, n.d.; King, 2019). In the United States, individuals continued to be legally persecuted and imprisoned for same-sex conduct until the affirming ruling of *Lawrence v. Texas* in 2003 (*Lawrence v. Texas*, 2003). This win overturned laws specifically targeting same-sex behavior as violations of the Due Process Clause of the Fourteenth Amendment (*Lawrence v. Texas*, 2003). When these societal norms are considered, the pathologization of homosexuality can be viewed as a predicted evolution fueled by a long narrative of stigma and bigotry and facilitated by an American Psychological Association (APA) board that was egregiously unrepresentative of minority perspectives and contribution. However, while decriminalizing homosexuality and transgender identities was vital in facilitating new sociopolitical norms, those norms functioned to legalize "homoerotic actions," or the act of engaging sexually with someone of the same gender, while continuing to condemn sexual minority identities (King, 2019).

Operationalizing gay, lesbian, and bisexual identities as mental health problems set in motion a massive shift in perspective, from what was once considered a punishable deviant behavior to a problem that materialized intrinsically within the individual; the behavior became the symptom of a deeper problem, which was widely accepted as an affliction that could be treated and even cured with psycho-medical intervention (King, 2019). Unfortunately, this psychology-led shift in concentration, from behavior to identity, also contributed

to a dramatic increase in social stigma towards the LGBTQ+ community. In addition to people with sexual minority identities, transgender people have also experienced similar medical pathologization. Unlike homosexuality, the umbrella term Gender Identity Disorder (GID) has become gender dysphoria and remains a current part of the diagnostic manual (American Psychiatric Association, 2013). This change occurred in the most recent revision of the *DSM* and intentionally replaced the term disorder with dysphoria to align with a contemporary clinical understanding of gender (APA, 2013).

Additionally, this shift reflected the medical and psychological communities' efforts to remove stigma-loaded terminology associated with diagnosing someone's identity as disordered (American Psychological Association, 2013). The importance of this adjustment cannot be understated, as a diagnosis of gender dysphoria continues to be required medically and for insurance purposes in order to provide accessible gender-affirming medical care. However, this curative perspective applied liberally to the SGM population, used discriminatory and problematic practices to solidify heterosexism and cisnormativity as a kind of medical diagnostic control; a harmful systemic stereotype used to support thousands of SGM people being subjected to violently harmful practices and inequitable treatment both personally and professionally (Bayer, 1987).

Early Attempts to Move Away from Stigmatization in Psychology

Attempting to force individuals to adopt a cisgender or heterosexual identity was conducted through various conversion therapy methods, including psychotherapy, hormone alteration, drug-based aversion-conditioning, electroshock, castration, and lobotomies (APA, 2009; Feldman, 1966; Katz, 1976; King, 2019). In 1957, Dr. Evelyn Hooker, a seasoned psychologist tenured at the University of California Los Angeles, published *The Adjustment of the Male Overt Homosexual* (Hooker, 1957; Milar, 2011). This study challenged the widely held belief that nonclinical gay men were pathologically divergent from heterosexual men by having expert clinical adjudicators attempt to decipher what 30 test results were from gay men and which 30 were from straight men. These tests, including Rorschachs, thematic apperception tests (TATs), and the measure of academic progress (MAPs), were indistinguishable from one another and showed no inherent pathology in gay men (Hooker, 1957). A breakthrough moment in LGBTQ+ health and psychology, Hooker (1957) returned to the assumption presented in the *DSM* that homosexuality was inherently related to psychopathology, and through empirically valid, ethical research practices, the claim was not supported. The respect and allyship exhibited in this research are widely supported by those who knew Dr. Hooker; one of Dr. Hooker's companions, Christopher Isherwood, later shared, "She never treated us like some strange tribe, so we told her things we had never told anyone before"

(Dunlap, 1996, p. 19.). Hooker (1957) is chronicled as one of the first American psychological studies to support the depathologization of homosexuality, and Dr. Hooker continued her advocacy efforts late into her career, heading up a study group on male homosexuality with the National Institute of Mental Health and supporting the repeal of laws concerning sodomy (Milar, 2011).

This work continued primarily through the efforts of Kinsey, Ford and Beach, and Hooker, whom LGBTQ+ rights activists supported as they began publicly confronting and challenging anti-LGBTQ+ practices in the early 1960s (Institute of Medicine, 2011). However, those methods of attempted conversion therapy have become inextricably intertwined with the history of LGBTQ+ psychology and health, as many of these once-standardized practices were the basis of the first public institutional discussions acknowledging sexual orientation and gender diversity. The pathologization of non-heteronormative identities persisted in various forms for 30 years until the diagnosis of ego-dystonic homosexuality was removed in 1982: the repercussions and trauma inflicted by this pathological categorization proved significant (King, 2019).

Ongoing Consequences of Psychological Pathologization. In addition to pervasive criminalization, *DSM* diagnostic criteria were weaponized to support various exclusionary and oppressive legal decisions. For example, the military was allowed to refuse LGBTQ+ people (Policy Concerning Homosexuality, 2006), job discrimination was permitted based on sexual orientation and gender identity (*Bostock v. Clayton County*, 2020), and same-sex marriage was barred for another half-century (Defense of Marriage Act, 1996). In each of these cases, the US Supreme Court found these laws unconstitutional, but discriminatory legal decrees persisted. An apparent trickle-down effect has occurred through various systems and institutions that affected the health and everyday life of LGBTQ+ people. A 2013 Gallup poll reported that LGBTQ+ adults were 8% more likely to lack a personal doctor than non-LGBTQ+ adults (29% versus 21%; Gates, 2014). Notably, the margin was even more remarkable for LGBT women, with 29% of the population reporting they did not have a primary care physician compared with 16% of non-SGM women (Gates, 2014). This poll found a correlation between lack of insurance and having a consistent doctor with financial instability that much of the SGM population faces. This economic disparity is synthesized by the data produced by Charlton et al. (2018), which showed that sexual minority people were almost twice as likely to have been both unemployed and uninsured in their adult lives than their sexual majority complements. Badgett et al. (2019) found that the LGBTQ+ community as a whole experienced a collective poverty rate of 21.6%, which was almost 6% higher than the cisgender-heterosexual (cishet) population. Not only is this barrier to healthcare access proven dangerous, as individuals in the LGBTQ+ population have been shown to be at increased risk of a variety of medical concerns (heart disease, eating disorders, violent victimization and injury, and

cancer), but the disparities in socioeconomic status and related issues in insurance access are additional stressors that must be considered in a history-informed analysis of LGBTQ+ health care (Carlson & Bultz, 2003).

The American Psychological Association (2018) documented that uninsured adults reported experiencing significantly higher baseline stress levels than their insured counterparts (5.6 vs. 4.7 respectively). Disparities in stress levels also occurred in populations with chronic health conditions and those who lived in urban areas instead of rural or suburban locals (APA, 2018). Thus, under the intersectional framework model, an individual's LGBTQ+ identity, as well as other elements of their identity such as their economic positioning, past and current ability status, and their race will intersect and interact in a way that puts LGBTQ+ people in a notably disadvantaged situation in the medical field.

The Beginning of the AIDS-Epidemic in the U.S. and its Effect on LGBTQ+ People

Outside of the pathologization of LGBTQ+ populations, the most significant and informative aspect of understanding the history of Queer medical care is inarguably the AIDS crisis. While significant stigma previously existed around LGBTQ+ people, never before had an institution as saturated with historical homophobia and transphobia as the medical field was confronted with a health epidemic that disproportionately affected that population (Institute of Medicine, 2011). A year before the psychological depathologization of same-sex attraction, the first known case of what would eventually be known as AIDS was identified in a gay man in 1981 in New York (Gottlieb et al., 1981). While it is known that HIV and AIDS affect people of all sexual orientations and genders, the prevalence of this novel disease in the Queer community resulted in an almost immediate medical and social correlation between the two. Prior to adopting medical terminology for Acquired Immune Deficiency Syndrome (AIDS), the U.S. population at large referred to the affliction as Gay-Related Immune Deficiency (GRID). While short-lived, this terminology can be seen everywhere from medical and psychological studies of the early 1980s to publications in *The New York Times* that describe the beginning of the epidemic, focusing on the rampancy of this disease in gay men but reassuring the cis het populations that they need not worry about being infected themselves (Altman, 1982). This transphobia and homophobia were additionally fueled by the intentional dissemination of misinformation by conservative religious institutions, a majority of which were Christian-based (Wood, 2008). The breadth and magnitude of this problem were highlighted by the actions of Randall Tobias, the AIDS coordinator for the Bush Administration, who used his political position to disseminate misleading statements and false data circulating in the evangelical church that perpetuated the belief that condoms were not an effective means of

preventing the transmission of HIV, thus placing unmerited blame on LGBTQ+ communities' behaviors (National Research Council, 1993). GRID was initially thought to be a series of previously unknown forms of cancer, but as medical knowledge of the disease increased, and greater society became aware of the means of transmitting AIDS, notable shifts in treatment, particularly inpatient care, began to occur.

Similar to the world's current experiences with the 2020 Coronavirus pandemic, information on AIDS was constantly evolving and changing as more was revealed about the virus. A wide breadth of literature exists on the impact of the media on public opinion, and these effects are apparent in the data produced by psychosocial scholars of the time. O'Donnell et al. (1987) researched healthcare workers in various work positions who interacted with AIDS patients. A majority of the survey sample, which consisted primarily of women (76%) from eight healthcare facilities across Massachusetts, reported that they received a majority of their information on interacting with AIDS patients through news media or hospital in-service education (O'Donnell et al., 1987). This education correlated with a general feeling that they lacked sufficient knowledge to provide care to AIDS patients and the development of "AIDS-phobia" in care practices (O'Donnell et al., 1987). O'Donnell et al. (1987) included the results of this AIDS-phobia index, which documented various homophobic beliefs held by medical personnel that incited valid concern over access to safe and compassionate treatment for LGBTQ+ people with AIDS. Almost half of the respondents noted that they felt: hospital workers should not be required to work with AIDS patients (42%), working with AIDS patients is a high-risk profession (53.9%), and if they were diagnosed with AIDS, they would worry that others would assume they were homosexual (43.5%) (O'Donnell et al., 1987). This social homophobia, or discrimination experienced daily, has measurable repercussions: LGBTQ+ people and those living with HIV/AIDS experienced increase harmful language, excessive precaution to the point of no contact, and blame for their diagnosis by medical professionals (National Women's Law Center [NWLC], 2014). Medical discrimination continues to be perpetuated on transgender and gender-expansive people in particular: 20% reported being forced to contend with harsh and abusive language from their healthcare clinicians, as well as being blamed for their health problems (NWLC, 2014). While healthcare workers' experiences are essential to document and explore, this data becomes vital in contextualizing LGBTQ+ patients' experiences in receiving care for AIDS and the revolutionary advocacy efforts from the LGBTQ+ community that bloomed in response.

Psychological Reverberations of the AIDS Crisis. Research conducted at the height of the AIDS crisis produced data showcasing a significant psychological toll in addition to the physical symptomatology brought on by advancements in the disease. Morin et al. (1984) were one of the first major studies to acknowledge and

further explore the psychological impact of AIDS on gay men, focusing on those at risk as well as those who had been previously diagnosed. Within the gay community, a myriad of significant stressors and subsequent mental health effects were noted in response to a positive AIDS diagnosis, including fears about death, guilt, resentment, and concern about one's gay identity, perceived and experienced stigmatization, lack of understanding medical treatment options, severe depression, and decreased social support coupled with a significant increase in dependency needs (Morin et al., 1984). The summation of this complex intersection between systemic and interpersonal discrimination and subsequent mental and physical health detriments, as outlined above, has since been labeled as AIDS-related stress (Huang et al., 2020). This highlights the relationship between the lived experiences of someone with HIV/AIDS and the sizable mental and physical repercussions of that trauma (Huang et al., 2020). Additionally, Morin et al. (1984) document the effects of worry and AIDS-related stress on asymptomatic gay men, which correlated with psychosomatic experiences such as generalized anxiety, obsessive thoughts, and panic. Large populations of gay men were experiencing increased psychological distress, which correlated with progressively compromised immune systems and decreased social engagement and functioning (Morin et al., 1984).

In discussing the effects of AIDS on the LGBTQ+ community, both acutely and over time, Levine (1989) astutely described how such cataclysmic events could throw a community's antecedent sociocultural structures and norms into upheaval, leaving survivors to confront the lasting effects of trauma both within themselves and as a broader community. This discussion of collective trauma, or the loss of support and solidarity within a community, is critical in understanding the psychosocial experiences that many Queer people report, specifically those who lived through the AIDS epidemic and experienced the deaths of people within the community (Institute of Medicine, 2011; Levine, 1989). Martin et al. (1989) denoted AIDS as a community stressor because data showed primary sources of stress related to AIDS concerned the deaths of loved ones and the potential for one's illness or death. In addition, three years of interview data on 634 gay men in New York City reiterated their hypothesis that these dual aspects of community stress were related to choices in sexual behavior, substance use, and psychological distress (Martin et al., 1989).

In terms of contemporary research, continuing to investigate the interplay between mental health and successful HIV/AIDS treatments have shown that mental illness, specifically depression and substance abuse (which consistently occur at higher rates in the LGBTQ+ populace), are indeed correlated with decreased compliance with potent antiretroviral therapy (ART) and subsequent treatment failure (Pence, 2009). Medical noncompliance in the LGBTQ+ community is important to explore, as it is a harmful consequence of AIDS-related trauma, namely the aforementioned medical discrimination and the mistrust

perpetrated by the corrupt and dangerous use of Zidovudine, commonly referred to as "AZT," as a treatment for HIV/AIDS (Farber, 1989). A cancer medication discontinued because of its extreme toxicity, AZT was liberally used as a treatment for HIV/AIDS despite the medical community's knowledge that the drug was killing patients faster than the natural disease progression (Farber, 1989). Celia Farber exposed the corrupt science and bureaucratic homophobia behind the use of AZT in her groundbreaking article, "Sins of Omission" (1989), which revealed the continued use of AZT despite knowledge of its ineffectiveness as a long-term treatment, as exhibited by the medication's significant negative side effects such as catastrophic anemia and devastating bone marrow suppression (Farber, 1989). Burroughs Wellcomes manufactured AZT, which cost \$8,000 a year, making it the most expensive medication ever produced at the time and establishing a socioeconomic barrier to care for marginalized communities experiencing the highest risk (Farber, 1989). As a whole, the body of literature paints an empirically consistent picture that supports the validity of LGBTQ+-specific health concerns, including decreased access to adequate and informed healthcare, increased stress, and lowered mental and physical well-being. The integration of psychological perspectives on LGBTQ+ patient care during the AIDS crisis was particularly vital, as it genuinely revealed the impact that increased sexual and gender minority stress, or the relationship between harm experienced, expected prejudice, internalized prejudice, and identity concealment in LGBTQ+ people, had on physical health. (Lewis et al., 2012; Meyer, 1995).

LGBTQ+ Health Care and the AIDS Epidemic: Novel Approaches to Advocacy

Research on LGBTQ+ care began to mobilize these findings into advocating for the amalgamation of psychosocial care into the medical healthcare fields. This call for change has persisted as a decades-long process in the field of health psychology, spearheaded primarily by LGBT psychologists such as Steve Morin, Ph.D., who first became involved in advocating for the removal of LGBT identities from the *DSM* and then again became embroiled in LGBT psychological advocacy at the institutional, state, and national levels during the AIDS epidemic (Noriega, 2014). The history of LGBT psychology in the United States is relatively compact, spanning just under 70 years. Then, moving to redact homosexuality as a psychological diagnosis did not eliminate homophobic practices or address discrimination in psychological care in the handful of years between the *DSM* alteration and the peak of AIDS. Within ten years of the first suspected cases of HIV/AIDS in the United States, 206,563 diagnoses and 156,143 deaths were reported (amfAR, n.d.). Larry Kramer, the co-founder of the Gay Men's Health Crisis (GMHC) and prominent author, playwright, and gay-right activist described the realities experienced by the LGBTQ+ community during the peak of the AIDS

crisis in his play, *The Normal Heart*: "We're all going to go crazy, living this epidemic every minute, while the rest of the world goes on out there, all around us, as if nothing is happening, going on with their own lives and not knowing what it's like, what we're going through. We're living through war, but where they're living, it's peacetime, and we're all in the same country" (Kramer, 1985, p. 85) The LGBTQ+ population was ravaged by HIV/AIDS, and disparities in available care, medical discrimination, and barriers to information and treatment have led to disproportionate diagnoses and deaths in Black and Latinx transgender women especially (Clark et al., 2017). This incongruity persists in recent data, with transgender women making up 84% of the 2351 new HIV diagnoses between 2009 and 2014. Of these women, 51% were Black, and 29% were Latinx (Clark et al., 2017).

As a result of these continuing disparities and the tragic impact of AIDS on the LGBTQ+ population specifically, the community fomented a collective advocacy effort to address the psychosocial needs of their loved ones being affected by this outbreak (Institute of Medicine, 2011). While psychologists continued to conduct the necessary research for advocacy at the national level, LGBTQ+ people came together, despite collective trauma, social stigma, discrimination, and potential violence, and reestablished support structures of their own (Institute of Medicine, 2011). Members of the LGBTQ+ community offered psychological and social support services, and self-help groups run by peers were regularly offered to encourage increased self-care, well-being, and empowerment (Institute of Medicine, 2011). LGBTQ+ activists came together to fund and conduct community-based research on potential treatments and cures for AIDS and inaugurated various coalitions and committees to address the multifarious inequities in accessing quality LGBT care (Epstein, 1996).

One of the most well-documented self-advocacy efforts of the LGBTQ+ community at this time was ACTUP!, or the AIDS Coalition to Unleash Power (ACT UP NY, n.d.). The inception of this action group was to organize a march on Wall St. to protest the exorbitant cost of AZT and lack of treatment accessibility (ACT UP NY, n.d.; Aizenman, 2019). ACTUP! continues to be an active organization that utilizes various advocacy techniques, with its roots in spreading awareness and enacting systemic change (Aizenman, 2019). One method of protest closely associated with ACTUP! are "die-ins": a method of civil disobedience primarily inspired by the non-violent occupation tactics of Black and African American people during the Civil Rights Movement; die-ins included a group of individuals suddenly congregating in a public space, theatrically pretend to die, and then subsequently departing (ACT UP NY, n.d.; Aizenman, 2019). These tactics were instrumental in informing the public of the realities of the AIDS crisis and combating a discriminatory system that was killing thousands (ACT UP NY, n.d.).

Additionally, the importance of community and solidarity between LGBTQ+ people was partially established through the participation of lesbians in AIDS-related efforts. This was seen most clearly in lesbian involvement in organizations like ACTUP! and their willingness to provide care for gay men living with AIDS when healthcare workers refused to (Lister, 2018). By employing a more holistic investigation of the LGBTQ+ healthcare experience, personal and structural barriers to access were confirmed; this work also importantly acknowledged that intersecting membership in other marginalized groups, such as racial and ethnic minorities and low-income groups, experience increased and often auxiliary obstructions as a result of additional societal stigma and discrimination (Halkitis & Cahill, 2011; Institute of Medicine, 2011).

AIDS and Minoritized Groups: Why Advocacy Must Continue. In 2018, AIDS continued to affect gay and bisexual men at an alarmingly disproportionate rate (over 69% of all new HIV diagnoses in the U.S. in 2018; Centers for Disease Control [CDC], 2020). The U.S. Census Bureau reported that Black and African American men made up 6.4% of the whole population in the United States in 2019 (U.S. Census Bureau, 2020). However, Black and African American gay and bisexual men disproportionately accounted for 25% of total HIV/AIDS diagnoses by the following year (CDC, 2020). This disease remains tightly intertwined with the LGBT population; the introduction of pre-exposure prophylaxis (PrEP) is 99% effective in preventing an initial HIV infection (CDC, 2020). However, as previously discussed, LGBTQ+ people are less likely to have health insurance than heterosexual people, and without this coverage, PrEP can cost as much as \$13,000 out-of-pocket, which is not an option for many individuals (Badgett et al., 2019; Diamant et al., 2000; San Francisco AIDS Foundation, 2020). The disproportionate numbers of AIDS diagnoses in racial minority communities, particularly Black and Latino gay men, bisexual men, and transgender women, and exhibits the confluence of racism, poverty, and homophobia in AIDS prevention, diagnosis, and treatment of LGBTQ+ people of color (CDC, 2011; Rodríguez-Díaz et al., 2015; Zamudio, 2004).

Advocacy efforts remain necessary, particularly from psychologists and psychotherapists, who have played a crucial role in connecting the homophobia and discrimination LGBTQ+ peoples experience in the medical field with LGBTQ+-specific mental health concerns that could plausibly be alleviated through changes in care practices and psychological support methods (Halkitis, 1999). Clinical support is critical when one considers the biological consequences of minority stress on LGBTQ+ people. Figueroa et al. (2021) recently produced data supporting the supposition that everyday minority stress can result in elevated cortisol levels associated with compromised health due to cortisol dysregulating stress response systems. The byproducts of homophobia and transphobia in the United States produce quantifiable health problems in a population already disproportionately

affected by health concerns; LGBTQ+ care needs to continue to evolve to combat the effects of sexual and gender minority stress instead of further contributing to them. In these efforts, it is prudent to look to the unprecedented resilience and tenacity exhibited by the LGBTQ+ community at the height of the AIDS epidemic; the community-support model, as well as the rise of self-advocacy, are both highly successful and merit close examination as a potential model for future advocacy efforts in LGBTQ+ health psychology.

The LGBTQ+ Community and Cancer

Special Considerations in LGBTQ+-Affirming Cancer Care: What is Missing?

Examining the history of LGBTQ+ healthcare and related advocacy efforts is necessary, as the LGBTQ+ community now faces another surreptitious health threat receiving far less recognition. A dangerously overlooked public health concern across the LGBTQ+ community is cancer, estimated to have affected approximately 135,000 LGBTQ+ people in 2020 alone (American Cancer Society, 2020). The emergence of a specific subsection of clinical psychology has run parallel to LGBTQ+ health psychology efforts, from identity pathologization and through the AIDS crisis, not intersecting until recently. Psycho-oncology is a specialty that primarily focuses on managing psychological symptoms during and after treatment, helping to navigate survivorship, managing the psychological needs of patients who are in end-of-life or palliative care, and conducting research on preventative behavioral measures and mental health risks of various treatments (Holland, 2002). The genesis of psycho-oncology did not occur until the middle of the 1970s, mainly as a result of coexisting stigma against individuals with cancer and those with mental illnesses (Holland, 2002). Stigma acting as a barrier to both medical and psychological support, even in the context of comorbid diagnoses, strongly mirrors the experiences of LGBTQ+ people during the AIDS epidemic.

While a diagnosis of cancer does not carry the same immediate LGBTQ+-related stigma and prejudice, LGBTQ+ people are being diagnosed with cancer at a far higher rate than their heterosexual counterparts and receiving different standards of care and outcomes in treatment. LGBTQ+ people contend with an increased risk for a variety of cancers: men who have sex with men (MSM) living with HIV experience anal cancer 30 times more than the entire male-identifying U.S. population, lesbian women experience higher incidences of breast, cervical, and ovarian cancers, and the LGBTQ+ population as a whole experiences higher rates of lung cancer as a result of increased substance use (Buchting et al., 2015). Until recently, population-based research on the instance of cancer in the transgender population has not existed. Boehmer et al. (2020) was the first study of this kind, finding transgender men were twice as likely to have received a cancer diagnosis than cisgender men, but that no statistical prevalence was found to

distinguish cancer diagnoses in transgender women from cisgender women (Boehmer et al., 2020). The contagion factor of AIDS, particularly before definitive information was gleaned on its transmission process, as well as the overwhelming number of deaths in a short period largely within one community, continues to draw attention from academics. This work in psychology continues to be undeniably necessary, as many people with HIV/AIDS continue to lack access to biomedical and behavioral support, and advocacy efforts are life and death (Wolitski et al., 2007). In addition to this work, concerted efforts must be made to investigate LGBTQ+ cancer care through a psycho-oncological lens.

Contemporary medical knowledge has understood that cancer is not contagious; however, the LGBTQ+ community continues to be diagnosed at disproportionate rates. This could result from a whole host of factors, including increased risk behavior in the community, lack of proper medical access, and enduring homophobia and transphobia in the medical field. Through an intersectional theoretical approach, psycho-oncology can arguably provide a particularly novel perspective on these risk factors before and during treatment, acting as an aid in mitigating them, both in addressing the mental health of LGBTQ+ cancer patients person-to-person and in making systemic changes to support the Queer community.

A Call to Action for Clinical Support in LGBTQ+ Healthcare

Clinical Psycho-Oncology: An International Perspective has become the seminal publication on the necessity of psycho-oncology in cancer treatments. Grassi et al. (2011) emphasize the variability of people's ability to adapt to the psychological distress that accompanies a cancer diagnosis. This publication advocates for culturally appropriate care and empirically validated psychology practices to be standardized in cancer care for all patients (Jacobsen & Wagner, 2012). While a cultural humility and awareness model should be the benchmark for all psycho-oncology practices, it is crucial for minority populations, as the psychosocial issues that minority populations face in the medical system and their lives likely diverge considerably depending on the ways their various identities intersect. The needs within the LGBTQ+ community are diverse and greatly influenced by additional factors, yet, statistically and consistently, LGBTQ+ people continue to face higher rates of cancer and associated emotional distress. Jabson and Kaman (2016) found that sexual minority individuals (i.e., lesbian, gay, and bisexual) reported a higher frequency of poor satisfaction with cancer care when compared with a heterosexual population (with control measures for additional demographic variables and clinical interventions). In this way, history repeats itself with the same problems that devastated the LGBTQ+ community during the AIDS epidemic. A myriad of systemic inequities persist in the healthcare networks, including lack of clinical

training and knowledge on LGBTQ+-specific care, assumption of patient's heterosexuality, and discrimination for over 50 years have conglomerated into a heterosexist standardized system of care that can be harmful to the community (Dahan et al., 2008; Jabson et al., 2011; Jabson & Kaman, 2016; Schatz et al., 1994).

Transgender cancer patients experienced similar discrimination, with over 50% of respondents on the 2015 National Transgender Discrimination Survey reporting having to educate their healthcare providers on transgender care (Levitt, 2015). Additionally, to respond to increased cancer incidence in the transgender population, Ceres et al. (2018) advocated for conducting an organ-based screening protocol, operationalized as universally screening transgender individuals based on any biological body part present, regardless of their current hormone use or engagement with various gender-affirming transition methods. While increased cancer screenings in the LGBTQ+ community are necessary for disease prevention, organ-based routine guidelines and other procedures and treatments have the potential to be invalidating and triggering for transgender or gender non-conforming people (Ceres et al., 2018). Having mental health professionals trained in oncology-specific psychological support and culturally competent with LGBTQ+ mental health needs is necessary for ensuring adequate care is available for LGBTQ+ cancer patients as they navigate a system with a long history of community-specific trauma.

These experiences with discrimination and stigma place LGBTQ+ cancer patients in a position to decide whether or not they disclose their LGBTQ+ identities to their providers. Doing so could facilitate more appropriate care practices and support measures, or it could inadvertently put them at greater risk (Kamen et al., 2017). Such uncertainty contributes additional stressors to the process of receiving care for cancer that is not experienced in the same way by cis/het people. In addition, fear of stigmatization and past negative experiences with discrimination has been shown to increase delays in LGBTQ+ people seeking medical intervention, which aids in further contextualizing the higher rates of cancer diagnoses within the community (Institute of Medicine, 2011). To achieve a lasting change in making cancer care LGBTQ+-affirming, Thomas J. Pier, clinical oncology social worker at the Simms/Mann-UCLA Center for Integrative Oncology, stresses the importance of creating an environment in which Queer individuals and their families feel comfortable and supported in disclosing their LGBTQ+ identity (Diamant & Pier, 2013). For the field of psycho-oncology, this includes ensuring there is a clinician on staff who is trained in LGBTQ+-affirmative psychotherapy. This involves being knowledgeable on how sexual and gender minority stress and stigma impact SGM people's mental health, as well as being aware of the literature on identity development, the coming out process, the experiences of religious SGM people, the differences between same-sex couples,

and heterosexual couples, and psychotherapy and support for gender non-conforming people (Kamen et al., 2015; Lisy et al., 2018; Pepping et al., 2019). While the profound lack of literature addressing the psychosocial aspects of LGBTQ+ cancer care does not necessarily speak to a lack of practitioners in the specific field, the data does suggest an overarching tendency for LGBTQ+ people's identities to become invisible during and after receiving a cancer diagnosis and subsequent care (Jabson & Kaman, 2015; Pepping et al., 2019; Quinn et al., 2020).

Review and Analysis: LGBTQ+ Advocacy Practices in Cancer Care

Kohnke (1980) defines advocacy in healthcare as "the act of informing and supporting persons so that they can make the best decisions possible for themselves" (p. 76). Providing multidimensional, comprehensive support in navigating treatment and survivorship is an essential element of SGM cancer care, as LGBTQ+ people's marginalized identities can accompany additional needs and concerns in dimensions of mental and physical health (Burkhalter et al., 2016). Notable declines in cancer diagnoses are occurring yearly across the United States, and the general rate at which people with cancer diagnoses are dying has decreased 27% over the past 26 years (McDowell, 2019). However, this decline is not occurring universally across sociocultural groups, and marginalized peoples, including the LGBTQ+ community, continue to experience health inequities that leave them at risk despite the shifts happening in the field as a whole (Alcaraz et al., 2019). Alcaraz et al. (2019), an article included in 2019 American Cancer Society's Cancer Control Blueprint series, calls for dual efforts to be made in continuing to address population-specific health disparities while additionally focusing on cancer-specific injustices that affect the behavioral, environmental, health care, and social factors in addition to biological predispositions.

Much like AIDS, cancer is a disease affecting the whole person while simultaneously being affected by the sum of their experiences in medical centers and beyond. A shift towards a more holistic approach to cancer is supported by the success of the community-based efforts of LGBTQ+ people during the AIDS crisis and suggests focusing on acknowledging and addressing multiple levels of need in care. The Shanti Project, a San Francisco-based HIV and cancer agency, was one of the first organizations in the US to provide services to individuals living with HIV/AIDS and has utilized mutual aid principles since its inception (McHugh, 2021). The concept of mutual aid is based on the practice of people giving each other what they need without supervision or support from the state; this manifested in Shanti providing peer counseling and end-of-life care, trained advocates, support groups, and providing care guidelines for medical professionals working with people with AIDS (McHugh, 2021). These Queer-led advocacy efforts that started

during the AIDS crisis recognized the importance of community and personal support in healthcare. This can be operationalized and recontextualized to address one of the major oversights of contemporary LGBTQ+ cancer care: treating the disease but not the person.

Public Perception and Care: Involving the Masses in Making Change

Contemporary care for cancer patients has continued to become more integrated and tailored to the specific needs of the individual, a dramatic shift in less than half a century from a disease that was rarely spoken about above a hushed whisper and often carried an assumption of associated pain, suffering, and death (Bultz, 2016). This evolution closely parallels how the media coverage and discourse about AIDS have changed over time; a disease that was once denied and condemned by the media was recontextualized as "everyone's problem" beginning in 1992 (Stevens & Hull, 2013). This completely reframed the discussion about HIV/AIDS, supporting a massive shift away from targeted LGBTQ+ shame and towards a more informed and compassionate understanding that anyone could be living with AIDS (Stevens & Hull, 2013). Additionally, as highly active antiretroviral antibody therapy (HAART) became an adequate standard of treatment for AIDS in the mid-1990s, the media continued to be a highly influential resource to relay this information and encourage its use: 1996 marked the first year that new AIDS cases declined in the United States (Stevens & Hull, 2013). While the relationship between media coverage and cases declining is correlational and influenced by a myriad of other changes, the shift in public perception of AIDS and subsequent social and medical implications were supported by opening up the conversation about a disease once labeled taboo (Stevens & Hull, 2013). Similarly, the discourse about LGBTQ+ cancer care can continue to work towards more open dialogue as a means of advocacy.

The comprehensive introduction of psycho-oncology clinicians as a standard component of cancer care has proven to be an essential shift for the betterment of all patients; quality of life, palliative care, survivorship, coping skills, and psychosocial symptom management have all been successfully targeted by a multidisciplinary, psycho-oncology based evolution (Bultz, 2016; Carlson & Bultz, 2003). However, it is vital to acknowledge that LGBTQ+ patients and other minority groups have additional and frequently sui generis needs that must be met to receive that same comprehensive care. The disparities in statistical frequency of the disease, coupled with data that supports the lack of satisfaction and comfort LGBTQ+ people experience in oncology, supports the necessity of a multifaceted approach to advocacy in psychosocial cancer care.

Considerations for Professional Psychological Organizations Committing to Advocacy

The APA's 2020 statement on priorities in advocacy includes working to advance health equity in marginalized and at-risk populations, including communities that also need that support: children, immigrants, tribal communities, veterans, and those living with HIV/AIDS (APA, 2020). Addressing the essential psychosocial needs of these groups in the context of healthcare is a necessary aspect of ensuring an ethical provision of care and working towards the elimination of socioeconomic barriers to mental health care. The bulletin itself also reflects the current state of the literature on the advocacy for LGBTQ+ cancer care in the APA: extremely limited or discussed briefly in an article's conclusion. This problem is evident in the 2011 publication of the *MD Anderson Manual of Psychosocial Oncology*, the most current edition of the comprehensively utilized guide on conduct in psycho-oncology; sexual orientation is discussed once and promotes data that has since been heavily contradicted that suggests homophobia does not affect cancer care experiences (Duffy & Valentine, 2011). Additionally, this discussion is included in the chapter "Sexuality and Cancer," in the context of a broader discussion of the effects of cancer treatment on sexual function and related mood and mental health concerns. The proximity of these topics within the publication increases the risk of providers conflating sexual functioning with sexual orientation. The former refers to physiological operations that affect one's ability to engage with their desired sexual actions, while the latter is an aspect of an individual's identity shaped by their sexual and romantic attractions and how those influence their behaviors (APA, 2020; Pathela et al., 2006; Wiegel et al., 2005). Coupling these topics proposes a commonality reflecting a common reductive belief that a person's sexual actions broadly define their sexual identity; this can lead to harmful minimizations concerning the differing psychosocial needs of sexual minority patients and their LGBTQ+ identities when faced with sexual functioning changes. Representation of transgender and gender non-conforming patients are also absent from the manual, and gendered language, consistent with that often seen in the medical field, is actively present in discussions of sexuality and body image in particular (Duffy & Valentine, 2011). At an educational and procedural level, the advancements made in how the field of psycho-oncology understands LGBTQ+ cancer care must become more widely distributed and discussed to fulfill the APA's 2020 advocacy goals concerning health psychology.

At an institutional level, the American Psychosocial Oncology Society (APOS) has instituted a Health Equity and Cultural Diversity Special Interest Group (SIG) captained by Charles Kamen, Ph.D., and Amy Zhang, Ph.D. The mission of this SIG is expounded on the APOS website as "advanc[ing] the knowledge and practice of psychosocial cancer care for all members of society by

eliminating barriers to inclusion and alleviating disparities" (American Psychosocial Oncology Society [APOS], 2020). Specific goals of the division focus on increasing awareness of socio-culturally specific measures and care techniques, increasing diversity in the field, supporting additional research on disparities in oncology, and working towards creating community-centric, culturally conscious research methods to ethically increase the data pool on historically underrepresented populations (APOS, 2020). The language used in these objectives, particularly the emphasis on cultural consciousness and community-based engagement, bears a striking resemblance to advocacy efforts made by LGBTQ+ psychologists and community organizers during the AIDS crisis. This is not to suggest that the responsibility of advocacy fall onto the shoulders of LGBTQ+-identifying psycho-oncologists and the community, but instead necessitates an intentional shift in the primary populations being studied (typically white, heterosexual, cisgender populations) to look at community-specific concerns through methods that are approved of and informed by the population being served (Melton, 2018).

This Health Equity and Cultural Diversity SIG goal is well-founded, as a lack of large-scale research grossly limits advocacy efforts for LGBTQ+ health psychology; a substantial body of empirically validated data is necessary to ensure widespread change, particularly at the systemic and institutional levels (Frost, 2017). Dr. Kamen, one of the co-chairs of this unit, is at the forefront of the social justice and advocacy efforts for psychosocial inequities experienced by sexual and gender minorities receiving cancer care. Through his association with the University of Rochester and as the Chair of Health Equity Research at their Community Oncology Research Program, Dr. Kamen has quickly become a leader in conducting ethical research on LGBTQ+-specific cancer care that has been used to develop and inform new practices for healthcare workers that actively address harmful disparities in care.

The differentiation between health psychology research that can supplement future advocacy efforts and research designed within an advocacy framework is an important one, particularly in minority populations who have previously experienced trauma within the system. For example, Dr. Kamen's research is based on an understanding of the differing needs of the SGM population within cancer treatment and survivorship, as well as the discrimination and heterosexism that exists within medical and mental health care at large (Alpert et al., 2020; Jabson & Kamen, 2016; Kamen et al., 2015). Naming these disparities as they are (i.e., heterosexism, homophobia, discrimination) is a vital aspect of addressing a systemic problem that is targeting LGBT people; discrimination and microaggressions, defined by Dr. Derald Wing Sue as momentary typical interactions that communicate disparaging implications about a person because of

their membership in a certain group or community, are forms of violence against Queer people that warrant being addressed with appropriate urgency (Sue, 2010).

Tri-Level Advocacy for LGBTQ+ Cancer Care

Institutional Advocacy. A meta-analysis of the psychology-based literature informing advocacy in LGBTQ+ cancer care reveals three potential levels of advocacy: institutional, team-based, and individual. Throughout the course of this review, institutional concerns have been thoroughly addressed and primarily address institutional policies that disproportionately negatively affect LGBTQ+ cancer patients and their care. One of the recurring themes in data concerning SGM oncology patient's dissatisfaction with care was feelings of identity invisibility within the healthcare system (Jabson & Kamen, 2016; Kamen et al., 2015; Lisy, 2018; Margolies, 2014). These studies overwhelmingly support the need for new educational training programs for helping professionals in oncology (i.e., psychotherapists, social workers, occupational therapists) that specifically address culturally conscious practices for working with LGBTQ+ populations. This information can be additionally mobilized through revisions to the *MD Anderson Manual of Psychosocial Oncology*; limiting gendered language in discussing body image and sexuality and addressing the disparities in care experiences between LGBTQ+ and non-LGBTQ+ populations are important measures in ensuring clinicians have a baseline of accurate information. Understanding that LGBTQ+ people generally experience lower satisfaction of care supports further systemic advocacy for the continuing integration of culturally informed psycho-oncologists, which starts with universities, hospitals, and overarching psychological associations such as the APA and APOS investing in training programs run by psychologists and community leaders from historically underrepresented and marginalized communities on informed care practices (Alpert et al., 2020).

Stigma has long been a barrier to informed and comprehensive LGBTQ+ cancer care, both for the patient and for Queer psychologists, particularly women and people of color, whose work has frequently been overlooked or underfunded. This trend is present in the field's existing literature on advocacy; in collecting data on the LGBTQ+ experience, people of color and transgender individuals were consistently underrepresented in sample pools. Individuals with multiple stigmatized identities have reported experiencing increased levels of minority stress as a result of discrimination that is unique from heterosexism or racism individually or coalesced; the unique intersection of their identities creates experiences with discrimination that cannot be generalized from studies that primarily center on white subjects (Fattoracci et al., 2020; Kamen et al., 2019). Additionally, transgender women of color, specifically Marsha P. Johnson and Sylvia Rivera,

were the founding leaders of the LGBTQ+ liberation movement of the 1960s and 70s. These women identified the connections between the civil rights movement, LGBTQ+ discrimination, and poverty and spearheaded significant advocacy efforts in the United States. The history of LGBTQ+ socio-political advocacy is an essential consideration in shaping contemporary plans of action for psycho-oncology, particularly in light of the violence towards Black and Latinx transgender people in 2020 and the startling disparities in disease diagnosis, experiences with care, and survival rate for Black individuals (Alpert et al., 2020; Cook et al., 2008; Dess et al., 2019; Penner et al., 2015). The advancement of social justice and advocacy in LGBTQ+ and racial/ethnic minority cancer care are interrelated, although more significant research is necessary to accurately describe the specific connections and additional institutional advocacy efforts for Queer racial minority individuals (Kamen et al., 2019).

Team-Based Advocacy. At the team-based level of advocacy, the literature broadly supports actions that facilitate an environment in which LGBTQ+ individuals feel safe and comfortable in disclosing their sexual orientation or gender identity (Alpert et al., 2020; Jabson & Kamen, 2016; Kamen et al., 2015; Kamen et al., 2019; Margolies, 2014). In a general discussion of measuring cultural competence for psychologists working with SGM populations, Boroughs et al. (2015) summarized the key factors as confidentiality, maintaining a healthy therapeutic relationship, and being knowledgeable on sexual and gender minority concerns; a review of practitioners encourages empathy, self-awareness of bias and prejudice, and a personal understanding of the effects of internalized, interpersonal, and institutional homophobia and transphobia. Alpert et al. (2020) synthesize this in the context of advocacy for psycho-oncology care, suggesting the revision of intake forms to be inclusive of SGM individuals, asking about a patient's sexual orientation or gender identity using inclusive language (i.e., "partner" instead of "wife/husband"; "person" as opposed to "man/woman") (p. 20), and revising gendered spaces and practices. When coupled with institutional practices, these are empirically validated, actionable steps a cancer care team can make to address normalized exclusionary practices, thereby improving clinician/patient relationships and increasing identity disclosure (Alpert et al., 2020; Kamen et al., 2015; Kamen et al., 2019). Creating an environment that supports identity disclosure additionally encourages patients in same-sex relationships to involve their partner in the care process, decreasing feelings of distress related to disclosure and anticipated discrimination (Kamen et al., 2015). When coupled with training on cultural humility and awareness, disclosure would allow for more appropriate and targeted psychosocial support from clinicians, potentially addressing disparities in the cancer care experiences of LGBTQ+ people.

Self-Advocacy. The third element of advocacy in cancer care for sexual and gender minorities within the research is centered on the person going through

cancer care or navigating survivorship. The canon of research on resilience in the LGBTQ+ community is vast; the literature shows that Queer people exhibit a propensity for survival and even prospering in the face of many adversities (Meyer, 2015). Meyer (2015) discerns the difference between resilience and coping within a minority stress model as the "quality of being able to survive and thrive in the face of adversity" compared with the "effort mounted by the individual in response to stress" (p. 210). Per this operational identification, resilience within LGBTQ+ individuals and the community denotes a successful adaptation to a challenge or stressor, such as the community's response to the AIDS epidemic (Meyer, 2015).

While it is important not to adopt an assumption of resilience for every patient, the propensity of resilience in the LGBTQ+ community suggests psycho-oncologists support qualities of resilience in the individual during their care (Meyer, 2015; Pearlin & Schooler, 1978). In a qualitative study of 273 LGBTQ people with cancer diagnoses, one of the five themes that emerged was some LGBTQ+ individual's particular ability to act as self-advocates throughout their diagnosis and treatment: adapting behavior in response to disrespectful and discriminatory treatment, vocalizing one's specific needs as an SGM person, as well as intentionally using a cancer diagnosis as an impetus for increasing gratitude, grit, and self-compassion (Kamen et al., 2019). Clark and Stovall (1996) propose self-advocacy as a vital cornerstone of cancer survivorship, supporting empowerment practices and building coping strategies to address the psychosocial aspect of being diagnosed with cancer. By intentionally targeting communication, problem-solving, and negotiation skills, a patient can ensure they are informed about their diagnosis and able to communicate their needs, as well as being able to identify additional resources or seek alternative care if those needs are not being met (Clark & Stovall, 1996). While this study did not specifically focus on studying a population of LGBTQ+ people, the self-advocacy model can be facilitated by both the clinician and the patient themselves. More research is necessary on SGM populations with cancer to support its widespread integration, but the potential for increasing empowerment and resilience through learnable techniques is an encouraging call to invest in self-advocacy research.

A Look Back to Move Forward: Next Steps in Research and Advocacy

This historical review of LGBTQ+ experiences in healthcare and related advocacy efforts seeks to contextualize a discussion on the current advocacy efforts in LGBTQ+ cancer care. While a wealth of knowledge exists on LGBTQ+ disparities in health, particularly about HIV/AIDS, the literature on advocacy in psycho-oncology is considerably limited. This incongruity in the body of literature reveals itself to be highly paradoxical, as the LGBTQ+ community has consistently experienced cancer diagnoses and deaths at higher rates than their non-SGM

counterparts and reported lower satisfaction with their care (Jabson & Kamen, 2016). Discrimination and institutional stigma all frequently contribute to LGBTQ+ cancer patients' feelings of distress, which has been shown to have negative effects on mental and physical well-being. The disparities in care necessitate advocacy and social justice efforts across multiple levels, including institutionally, within care teams, and by the individual, but the small body of research is hugely limiting in expanding upon these advocacy needs. As psycho-oncology continues to advance, additional research is needed on the care and psychosocial support needs of the LGBTQ+ community, with a distinct focus on addressing the advocacy needs within the field. The perspectives of historically underrepresented groups, including transgender individuals and people of color must also be explored, as LGBTQ+ people of color are consistently the most affected by disparities in health care, and samples of primarily white, affluent individuals do not reflect the breadth of LGBTQ+ experiences. Cancer is a furtive epidemic in the LGBTQ+ community; increasing the body of research, informing policy with a focus on marginalized patients and clinicians, altering oncology departments to support SGM well-being, and encouraging self-advocacy are the next steps in a 70-year battle for equity in the field of LGBTQ+ health care and psychology.

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