ARTICLE

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The mothers: contesting health-illness status and cultural authority in the age of AIDS

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Despite the relevance and prevalence of research that produced knowledge about stigmatised groups and communities throughout the 1980s and 1990s, in the United States, studies that investigated the relationship between HIV/AIDS, intersectional stigma, and health-illness status among groups considered hegemonic are incipient—i.e., heterosexual, and white groups, who did not suffer stigma due to sexuality and race/colour, for example. In this study, such a gap is examined in order to observe the effects of stigma in non-exposed communities. Additionally, the article (i) explores the formation of a pioneering group of caregivers in New York City, the Mothers of Patients with AIDS (MPWA), created in 1986; and (ii) analyses narratives about health disease from a collective care agenda established by middle-aged and elderly mothers dealing with the challenges and needs of adult children and people with moderate and high degrees of dependence. This study is part of a larger project that investigated the emergence of non-profit organisations and gerontology care groups in the context of the HIV-AIDS epidemic in New York in the 1980s and 1990s. Documentary research was developed in the Florence Rush collection, made available by the Arthur and Elizabeth Schlesinger Library at Harvard University's Radcliffe Institute for Advanced Study. The selected materials bring together qualitative empirical sources from reports, personal histories, and interviews conducted by Florence Rush and other mothers, social workers, and health professionals. As the results attest, the narratives produced by Florence Rush's interlocutors during the AIDS health crisis make it possible to understand how social and cultural dynamics of recognising the disease did not result in autonomous, individual, and objective processes for exposing the pathological state. The strategic use of the term "cancer" instead of "AIDS" as an umbrella definition, and one less demarcated by aspects involving gender and sexual behaviour, evidenced the sociality of the illness. Conclusions show how negative representations were associated with AIDS—perceived as harmful, immoral, or deviant behaviours — and produced new meanings and demands among patients who feared stigmatising classifications in the midst of sexual panic until the commercial availability of the antiretroviral cocktail in 1997.

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Introduction

Pioneering studies demonstrated that, since the first years of the HIV-AIDS epidemic, people affected by the advanced stage of the disease dealt with fears and stigmas concerning the disclosure of the pathological state (Gilman, 1988; Pollak, 1988; Epstein, 1996; Epstein, 2007; Parker and Aggleton, 2003). Even after massive AIDS awareness campaigns over the last thirty years, improvement of drug classes, such as the most effective antiretrovirals and the cocktail, more specifically, challenges still remain in the diagnosis of HIV-AIDS, from a social and clinical point of view. From the social perspective, according to Bilardi et al. (2019), Gilbert and Walker (2010), Gabbidon et al. (2020), there are negative reactions to the HIV/AIDS status that greatly impact social relationships, as well as the anticipated perception of patients who fear compromising bonds established with the family, in the work environment, and in affective/loving relationships. According to the literature, the fear of exposure to stigma and forms of discrimination amplifies the demand for secrecy and management of the disease in terms that do not make it public or immediately recognised. Historically exposed groups, as well as those culturally marginalised and most associated with sexually transmitted infections (STIs), experience a high degree of perceived stigma and are more likely to not disclose their health status to people close to them and in the wider community (Madiba et al., 2021).

It is well-known that homosexual men, intravenous drug users, non-white immigrants, and sex workers were singled out at the height of AIDS deaths in the 1980s and 1990s as the main exposed groups (Rosenberg, 1989; Slagstad, 2021). Feelings involving worry, anxiety, fear, anguish, and depression were not rare among such groups. Furthermore, the presence of stigma was accentuated as other macro-structural issues of inequality and difference modulated the pathological status, such as those involving racial, ethnic, gender, sexuality, and age prejudice (Parker and Aggleton, 2003). Alternatively, the notion of intersectional stigma is useful, as it allows us to understand how processes of discrimination and prejudice link different social experiences from the same health issue—i.e., HIV/AIDS. In summary, as Karver et al. (2022) noted, the stigma-intersectional category makes it possible to pluralise the effects of stigma beyond structural social processes centered on sociodemographic variables, while relating to identities, marginalised health conditions, and the microsociological challenges faced daily. Through microsociological relations—also called "sociology of forms"—we incorporate Georg Simmel's sociological critique of Durkheim's concept of solidarity and the vision of society as a collective force greater than its individual reality. On the contrary, at the level of interactions between different social actors, microsociology gives importance and analytical magnitude to the relationships shaped by subjects, communities, and institutions. In sociology, this approach became known as "symbolic interactionism". With a powerful critique of functionalism, symbolic interactionism provided new theoretical bases for examining how structures of inequality can be produced, established, and modified by subjects as active agents in society.

Despite the relevance and prevalence of research that produced knowledge about stigmatised groups and communities throughout the 1980s and 1990s, in the United States, studies that investigated the relationship between intersectional stigma and health-illness status among groups considered hegemonic are incipient—i.e., heterosexual, and white groups, who did not suffer stigma due to sexuality and race/colour, for example. In this study, we sought to explore such a gap, inverting the classic logical correspondence between stigma and exposed groups, in order to observe the effects of stigma in non-exposed communities. By reversing the correspondence between stigma and traditionally marginalised communities, we sought to test the hypothesis that the disease also produced moral dilemmas and stigma among heterosexual segments that had been affected by AIDS.

In this article, we examine the formation of a pioneering group of caregivers in New York City, the Mothers of Patients with AIDS (MPWA), created in 1986. Specifically, we analyse narratives about health disease from a collective care agenda established by middle-aged and elderly mothers dealing with the challenges and needs of adult children and people with moderate and high degrees of dependence. This study is part of a larger project that investigated the emergence of non-profit organisations and gerontology care groups in the context of the HIV-AIDS epidemic in New York in the 1980s and 1990s. We conducted documentary research in the Florence Rush collection, made available by the Arthur and Elizabeth Schlesinger Library at Harvard University's Radcliffe Institute for Advanced Study. The selected materials bring together qualitative empirical sources from reports, personal histories, and interviews conducted by Florence Rush and other mothers, social workers, and health professionals, mainly in New York and, to a lesser extent, Ellsworth (Maine) and Kalamazoo (Michigan). As the results attest, the narratives produced by Florence Rush's interlocutors during the AIDS health crisis make it possible to understand how social and cultural dynamics of recognising the disease did not result in autonomous, individual, and objective processes for exposing the pathological state. The strategic use of the term "cancer" instead of "AIDS" as an umbrella definition, and one less demarcated by aspects involving gender and sexual behaviour, evidenced the sociality of the illness. This both exposed the way in which negative representations were associated with AIDS—perceived as harmful, immoral, or deviant behaviours—and produced new meanings and demands among patients who feared stigmatising classifications in the midst of sexual panic until the commercial availability of the antiretroviral cocktail in 1997.

During the first two decades of the HIV-AIDS epidemic in the United States, the high rates of early deaths among people of different age groups were accompanied by increasing demands involving long-term care and social support (Parker and Aggleton, 2003). Although pneumonia (pneumocystis carinii) and dermatological cancers (Kaposi's sarcoma) were the main opportunistic infections caused by the immunological suppression associated with the syndrome, physical-motor limitations and moderate degrees of dependence also produced significant effects on the functional capacity and autonomy of AIDS patients.

We problematise the work mobilised by the MPWA group and its intricate relationships around the discovery of AIDS. In sum, the archive shows how conflicts, disputes, and the management of care and death in a family and social context were marked by inequalities, prejudices, intergenerational relationships, and vulnerabilities. Similarly, we argue that the work undertaken by mothers was not solely focused on mechanical processes that required care and strictly medical-authority relationships centered on the disease. The work was, as the narratives attest, both mechanical and emotional (Bericat, 2016). A significant number of the veteran mothers on the front lines—who offered support to mothers who had recently arrived in the group—were facing losses and bereavements. Other "mothers," however, were daughters caring for their AIDS-stricken relatives. Illness, mourning, and death, therefore, produced new arrangements and axiological meanings for social relations insofar as they were key opportunities for the solidarity and cohesion of the group of caregiver mothers.

In sociological terms, and from the care of relatives and people affected by AIDS, the health-disease dyad was tenuous and was

not restricted to the narrative of the injury or the infectious agent as a type of neutral scrutiny, free of social and cultural connotations. Among segments directly exposed and with high degrees of social vulnerability—i.e., women, homosexual men, sex workers, intravenous drug users, immigrants, and African Americans—the language of pathology for viral status produced negative effects in the way in which AIDS was socially recognised as well as on ways of publicising and managing the disease (Epstein, 1996; Parker and Aggleton, 2003; Gould, 2009). This is because, culturally, such language was mostly linked to sexual practices perceived as harmful, immoral, and non-reproductive or the use of drugs injected intravenously (Pollak, 1988; Gilman, 1998; McKay, 2017; Ferreira and Miskolci, 2022; Mamo, 2023).

At the level of social interactions, such negative effects invariably weaken social support networks, weakening pre-established relationships in the family, at work, and in the community (Gould, 2009; Sievwright et al., 2022). In addition to the negative impact on networks and pre-established social ties in the family, for example, the management of health-disease status greatly impacted relationships and demands for care. This, on the one hand, brought together therapeutic anxieties and disputes around secrecy about serological status; on the other hand, it was also a mark of a historical moment in which new clinical terms and authority relations between patients, caregivers, and health professionals were forged (Karver et al., 2022).

Until the commercial availability of highly active antiretroviral therapy (HAART) in 1997, the care of people affected by diseases and opportunistic infections was complex, palliative, experimental, expensive, and unavailable to all social segments that depended on them. In the 1980s, in the United States, networks formed by philanthropic-charitable services and institutions emerged from hybrid coalitions among diverse social actors (Epstein, 1996; McKay, 2017; Mamo, 2023), namely, social movements and human rights groups, activists, health professionals, public policymakers, mixed institutions, government, and the third sector.

In that context, and under the impact of AIDS, we argue that the formation of social ties involved collective rituals about experiences of mourning and death. More specifically, death and mourning as collective events consolidated existential questions and solidarity mechanisms insofar as they constitute processes common to mothers. And they were conventionalised as part of the care rituals for adult children/patients affected by AIDS, experienced at the micro and macro sociological levels (Prickett and Timmermans, 2022). Alternatively, the bonds of trust created among mothers can be interpreted as those established in situations of commotion and collective effervescence when an illness or sudden catastrophe produces unexpected effects and brings immediately visible and challenging consequences (Douglas, 1996; Turner, 1969; Durkheim, 1995; Petryna, 2002; Collins, 2005a, 2005b). Such bonds emerged from a state of permanent adversity, organised by a biological principle—i.e., AIDS—in which both medical and scientific explanatory schemes were not enough to clarify the etiology of the disease and its prophylaxis or when the cultural frameworks that produced definitions for the disease were based on less secularised explanatory models that resulted in guilt, stigma, punishment, and contempt.

Although the production of ties among the mothers took place through the sharing of stories and familiarity with their experiences as caregivers, we consider that the pre/post-mortem mourning and the adversities faced daily with AIDS created the strongest community ties. These ties also comprised a web of indeterminate relationships that informed unequal positions of authority and symbolic contracts of trust (Prickett and Timmermans, 2022). Such adversities also illuminated gender asymmetries imposed on mothers unauthorised in their domestic functions and/or who dealt with stigmas arising from the illness of their adult children and from bereaved relatives, which were not overcome even after death.

First, and against the background of the emerging group of caring mothers in New York, we seek to establish new dialogs with the available academic literature on the HIV-AIDS epidemic, particularly the narratives that constitute sociological interfaces between health-disease status, long-term care, and authority relations. Second, and since the historiographical and sociological discussions about the MPWA group are incipient, this article proceeds by mobilising new documents and historical sources whose contribution to the contemporary history of the AIDS epidemic is substantive. In short, the article provides original contributions regarding (i) the relational impact of the epidemic and stigma on communities historically seen as hegemonic in the 1980s and 1990s (or less affected by AIDS); (ii) fear as a sociological force that influenced, for example, the production of diagnoses and the way people avoided certain terms to describe their health status; and (iii) the emergence of the "cancer" category among heterosexual women and anticipated perceptions of grief and prejudice.

Methodology

This study is part of a larger project that investigated the emergence of non-profit organisations and gerontology care groups in the context of the HIV-AIDS epidemic in New York in the 1980s and 1990s. Since 2019, we have carried out documentary research in the Florence Rush collection, made available by the Arthur and Elizabeth Schlesinger Library at Harvard University's Radcliffe Institute for Advanced Study (Rush, 1941). The archive was part of Florence Rush's materials relating to the Mothers of Patients with AIDS group, taking the 1980s and 1990s as a time frame, and encompasses yet unexplored historical materials for understanding the effects, mobilisations, and activism around the AIDS epidemic in the United States.

Data collection

The selected materials bring together qualitative empirical sources from reports, personal memoirs, and interviews conducted by Florence Rush and other mothers, mostly social workers, and health professionals, in New York and, to a lesser extent, Ellsworth (Maine) and Kalamazoo (Michigan). In sum, our sources were journalistic articles published by the press, letters, pamphlets, folders, campaigns, seminars, field reports, and activities organised with universities, philanthropic institutions, and social movements. As Florence Rush's archive incorporates materials that dealt with diverse topics throughout her life, we established four inclusion criteria: (i) materials only related to the HIV/AIDS epidemic; (ii) texts based on interviews and testimonies produced by MPWA; (iii) Florence Rush's personal statements and notes for newspapers and magazines; (iv) letters received and correspondence sent to activists, research foundations, friends and the manuscript of Florence Rush's unpublished book on the epidemic.

Data analysis

Data were analyzed using thematic and narrative analysis based on in-depth reading (Braun and Clarke, 2006; Gentles et al., 2015; Madiba et al., 2021). Thematic analysis, a procedure similar to content analysis (Vaismoradi et al., 2013), involves the search for repeated patterns of meaning from a broad set of data, originating from pre-selected texts. Thus, we performed (i) pre-analysis, (ii) exploration of the material, categorisation or codification, and (iii) treatment of results, inferences, and interpretation (Drisko and Maschi, 2016). Six analytical categories (or thematic subtitles) were explored: "fear", "shame", "prejudice", "disease", "AIDS" and
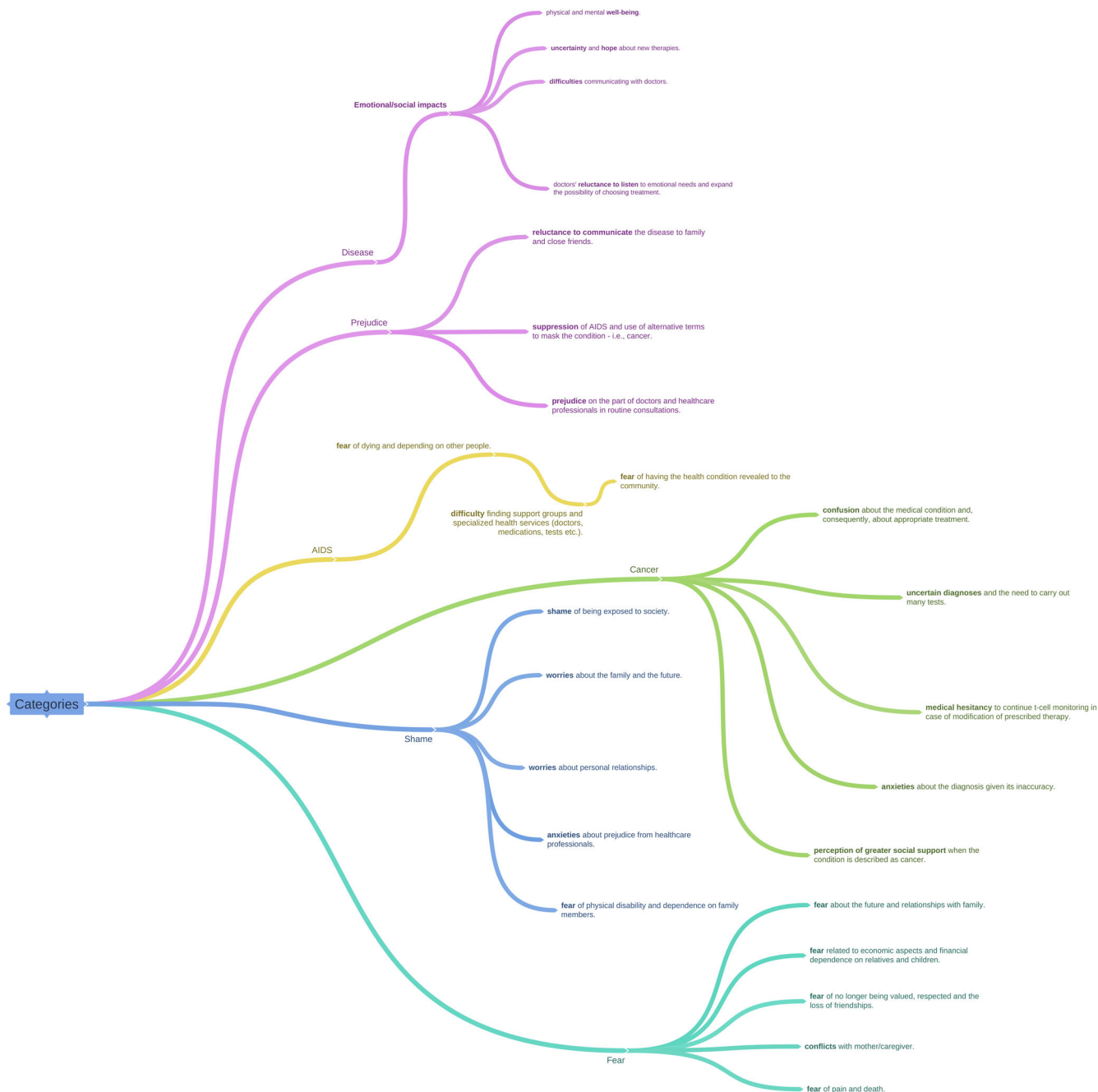
Fig. 1 Thematic analysis. Categories/thematic subtitles.

"cancer" (Fig. 1). Narrative analysis, in turn, incorporated some traditions of social research, such as, for example, oral history, privileging oral testimony as an instrument of access to reports and testimonies that, normally, are outside the official construction of history, or obscured by hegemonic readings of known social processes (Thomson, 2007; Ritchie, 2015; Kim, 2016).

Considering the scope of the qualitative analysis produced, we highlight some limitations of the analysed collection: (i) the empirical field is mostly limited to the reality of New York; (ii) the interviews obtained by Florence Rush did not follow a common script, through which it would have eventually been possible to recognise and explore variations and distinctions in the speeches elaborated by her interlocutors (mothers and caregivers, mostly); (iii) the file does not provide in-depth information about other groups of caregiver mothers in the historical period considered;

(iv) the integration of mothers' group activities with other groups and services, such as the PWAC and the GMHC, is incipient and poorly documented in the examined files.

Despite the four main limitations reported, we consider Florence Rush's collection to be a consistent documentary source for understanding the movement of caregiver mothers in New York. And it is equally relevant to the history of the AIDS epidemic in interface with organised social movements in health (and social gerontology, in particular) in the 1980s and 1990s in the United States.

The mothers of patients with AIDS group: coalitions around care, hope, grief, and death

July 8, 1988, is the second anniversary of the group of mothers, an event that should not go unnoticed. For me,

this birthday is particularly meaningful—I am the mother of a child with AIDS. The Mothers' Group is my lifeline to sanity and my connection to a reality I cannot walk away from. Fran Herman, a minister and psychotherapist, who has cared for mothers, is the founder of the group. Frank Donnelly, a psychotherapist, joined her to work with us. Fran and Frank gave us our Mothers' Group […]. We are mothers of adult children with AIDS. Our age ranges from forty to over eighty. We are working-class, white-collar, business, and professional women. We are widows, divorced and married; we are black, white, Hispanic, Catholic, Jewish and Protestant. Our sons and daughters, gay and straight, have AIDS and that's all that matters.

"Surviving and Thriving with AIDS," Florence Rush. *Newsline*, 1988. Florence Rush Archive. Harvard University, Schlesinger Library on the History of Women in America, PC320431.

In a 1988 article entitled "Surviving and Thriving with AIDS", published in *Newsline*, the People with AIDS Coalition (PWAC) newsletter, Florence Rush, a Jewish frontline AIDS mother, feminist writer, social worker, and recognised intellectual, reconstituted the brief history of the group of caring mothers in New York, which was celebrating its second year. The group, also popularly known as "AIDS Mothers" or simply "Mothers' Voice", provided care, advice, and a listening ear to more than 300 mothers who cared for adult children from 1986 to 1994. The group's activities were divided between "the mothers upstairs" and "those downstairs":

Downstairs, mothers of children with AIDS spoke of doctors, drug testing and T-cell counts. Upstairs, mothers whose children had died from the disease spoke of cremations, burials and patches on a memorial quilt. When they weren't talking, they cried upstairs and downstairs on Tuesday nights in the little brick building in Greenwich Village.

"AIDS Mothers' Undying Hope: Confronting the Dark at the Top of Stairs," ProQuest Historical Newspapers. *New York Times*, April 20, 1994. Microfilm collection. Harvard University, Widener Library.

In "AIDS Mothers' Undying Hope," an article published on April 20, 1994, in the *New York Times*, journalist Georgia Dullea uses the metaphor of the flight of stairs in the building where the services were offered, in Greenwich Village, New York City, to distinguish among the activities carried out by the group. For some mothers interviewed, such as Eileen Mitzman, [Going up the stairs for the first time was like walking into the shower in Auschwitz]. Rhea Parham, on the other hand, stated that the encounters with other mothers—[the friends, upstairs]—were a way of supporting and accepting what they felt, sharing the anguish and expectations, and surviving the pain. [The magic mother is the healer who can cure all illnesses], said Blanche Mednick, a social worker who headed the group until 1996. Mednick had also experienced a similar story when her son Brian died in 1992 of pulmonary complications resulting from AIDS: [When Brian died—and this is so peculiar—I was angry with the mothers downstairs. I knew that a magical mother couldn't heal him, but somewhere in my mind was the thought that ten magical mothers would help me save my son].

Florence Rush, in the first chapter of the manuscript of her book, *The Mothers: In the Age of AIDS*, described it this way:

Sometimes these mothers remind us of the Argentine women who displayed pictures of their lost children, "los niños desaparecidos," outside the presidential offices in Buenos Aires, after the so-called "Dirty War" of the 1970s. Traveling in small groups, with framed photos of their children, living and dead, mothers have been lobbying in Albany and Washington for the past two years. Mitzman's technique is to place a photo of her daughter, Marni, who was 26 when she died in 1991, on lawmakers' desks next to family photos.

The Mothers: In the Age of AIDS. A proposal. Florence Rush Archive. Harvard University, Schlesinger Library on the History of Women in America, PC32043.

Many mothers who were in the group, however, according to Susan Katz—a social worker and leader of the "mothers' group downstairs"—were not necessarily feminists or participants in organised civil rights movements prior to their AIDS experience. According to Katz, the activism embraced by the group was capable of providing a kind of alleviation of the anxiety and loss of control that the mothers felt, [allowing them to do something constructive about a process that was being deconstructed. […] The mothers who became activists are not necessarily those who call themselves feminists or those who took to the streets during the Vietnam War—some of them are 'ladies who lunch'].

[But first, they march,] said Rush. Carrying a banner over ten meters wide with the words "Mothers' Voices" written in blue, the mothers joined many other AIDS activist groups one morning in April 1994, the month in which the aforementioned article was published in the *New York Times*. The groups met at City Hall in New York City to demonstrate their dissatisfaction with a proposal to eliminate, or drastically cut, the Division of AIDS Services (DAS). [They say cut back!] chanted the ACT UP youth group; [We say fight back!], replied the mothers in the streets.

After 1994, the mothers' group left the small red brick building in Greenwich Village. Accompanying the People with AIDS Coalition, which had moved to the Chelsea neighborhood, the "upstairs group of mothers" migrated to the new premises while the "downstairs group of mothers" continued meeting in Rush's apartment.

One thing that separates mothers whose children have AIDS from those whose children have life-threatening illnesses is how the virus is transmitted. "We still don't deal with our own sexuality, with homosexuality, with ageing and drug addiction," said Mrs. Mednick. "That's what stops some mothers from taking to the streets or even telling relatives that their children have AIDS. They are ashamed. And the absence of services, support and care makes these mothers so strong and so vulnerable at the same time."

"AIDS Mothers' Undying Hope: Confronting the Dark at the Top of Stairs," ProQuest Historical Newspapers. *New York Times*, April 20, 1994. *Microfilm collection*. Harvard University, Widener Library.

Formed with the purpose of offering support to caring mothers directly and/or indirectly affected by the epidemic, the group also concentrated on programmatic actions designed to face a systemic lack of attention and care for bereaved people. The group also sought to offer support to people who spent their own resources on treating children and relatives with AIDS and coping with situations of stigma.

Children's names were sewn onto a memorial quilt panel, reported Deane Dixon, an upstairs mother who maintained the group's history. [It was a splendid bedspread, of satin fabric in midnight blue, dotted with 111 silver, pink, and gold lamé stars, one for each child]. The full names of all the children appear on the quilt, except for six who are identified only by their first names or initials. [When the mothers started meeting eight years

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ago, it was thought to be the only group of its kind in New York City. Today there are several groups for mothers, as well as groups for fathers and other family members. In each of these groups, there are lessons to be learned,] concluded Deane Dixon.

In addition to linking some of the mothers' group activities to the PWAC, in New York and in other cities, the group offered pioneering and multidisciplinary services aimed at older and very old people affected by the disease, led by social workers, specialists in gerontology, and activists. After moving to the Chelsea neighborhood and to the PWAC headquarters, part of the group started to hold activities that involved, for example, the recreational use of intravenous drugs and poppers, group therapies, condom distribution, prostitution, religiosity, service to communities formed by immigrants, etc., establishing a network that extended to eight regions—the Bronx, Brooklyn, Queens, Long Island, Staten Island, Westchester, New Jersey, and Manhattan.

As Rush noted, and despite what was going on in New York, there were many limitations to discussing sexually transmitted infections topics in small communities and towns, notably in more remote rural areas. This is because little was known about the impact of AIDS in these communities based on official data made available by the CDC. The social framing of sexually transmitted infections reinforced the conservative understanding that they essentially comprised sexual practices in urban areas, culturally associated with youth movements for sexual liberation and counterculture. These are sexual practices conceived as "harmful" and "morally questionable"—i.e., anal and oral sex—as well as the use of intravenous drugs. In non-metropolitan and rural regions, in addition to the invisibility of AIDS, discussions on sexuality, ageing, and health care issues, for example, were also incipient.

In the summary of her project submitted to the Winifred Foundation, the social worker wrote:

> I came to this project with the hope of breaking down the barriers created by homophobia and the stigma of AIDS that isolates mothers and grandmothers caring for a child who is sick or lost to AIDS. I also hoped that my book, with these mothers as examples, would help break down the stereotype of older women as old ladies who knit, cook, and happily sacrifice themselves to care for the sick and needy. I intended this book for all of us to recognize, respect, and pay homage to these older women for their painful sacrifices, courage, determination, and solitude in dealing with the complex issues that underlie this disease.
>
> AIDS is no longer a gay male disease. The new combination of drugs that emptied hospital beds, sent the sick back to work and cut AIDS funding, forced the AIDS community to focus on a new population of HIV—a population influenced by a culture that intensified shame and the disgrace associated with this disease. In fact, other than Kalamazoo, I've had little success in finding mothers with AIDS directly. Attempts to organize mothers, who are still the main caregivers, aim to help them come out of their lonely closet and openly participate in the political and social struggle against this deadly disease.
>
> The premature optimism of the media led to a lot of confusion. Headlines like "US Says AIDS Cases Dropped in 1996" encouraged a false security and complacency that diminished public concern, funding, and activism against AIDS. However, those who read the fine print and responsible medical journals learn that the disease is accelerating at an alarming rate and even many whose health has improved, after a year or more are falling ill again and dying. The epidemic has spread throughout our country and we are warned to be ready for what comes in the "long term."

Florence Rush Archive. Harvard University, Schlesinger Library on the History of Women in America, PC320431.

The use of terms such as "shame" and "stigma" and the constant correlation between the epidemic and a disease restricted to homosexual subjects highlighted the double challenge faced by social gerontology and the actions of non-governmental groups. First, and in the case of Rush, the challenge was making visible the collective aspect of the disease in the groups mainly formed by mothers and grandmothers that she visited in the small rural communities in Kalamazoo and Ellsworth, for example. The second challenge was to expand the number of mothers and grandmothers who participated, extrapolating the discussions about contagion, prevention, and care beyond the visible homosexual community—including the mothers and grandmothers who were caregivers, their sexual partners, and heterosexual relationships in general, comprising distinct and longer-lived age groups.

On January 25, 1991, invited by the Brookdale Center on Ageing, Florence Rush participated as a speaker at the conference "HIV/AIDS and Ageing." This was Rush's first time participating in meetings organised by the Brookdale Center. From that moment on, the work of Rush and her group of mothers became affiliated with that of two well-known social workers and gerontologists of the period, Joanna Mellor and Rose Dobrof. Between 1991 and 1993, Florence Rush and the mothers' group maintained initiatives and projects linked to religious institutions, social movements, and universities, such as, for example, "Hope and Remembrance" at the Central Synagogue, "Different Community Approaches to Loss", organized by the Lesbian and Gay Community Services Center, and "AIDS Training Project" at Rutgers University of New Jersey (School of Social Work/Center for Community Education).

On December 23, 1992, Rush was invited by social worker Marie C. Nazon to participate as a mediator at a conference, "The Future is Here. Growing Old with AIDS: AIDS and Ageing and the Years Ahead," organised by the Brookdale Center on Ageing. The conference resulted in a pioneering partnership of social organisations and organised civil movements with the mothers' group. This event, the second since the first in 1991, became a milestone for social gerontology and AIDS issues in the period, as it gained greater funding and visibility within activities co-produced by the People with AIDS Coalition and the mothers' group. In January 1996, the first issue of *Newsline* was entirely dedicated to social gerontology (Fig. 2). "AIDS and the Ageing" graced the newsletter's cover, with a lithograph of Virginia Woolf.

This edition featured personal narratives of mothers who were caregivers and key interlocutors of the mothers' group. Florence Rush had interviewed them on her field trips, and their testimonies showed conflicts and disputes regarding the management of the health-disease status, long-term palliative care, and relationships with doctors. As a main objective, and having the interviews produced by Rush as an analytical key, we sought to examine the oral narratives of four interlocutors—Eli, Marianitta, Jennifer, and Karen.

Analysing the fragments about serological status in the narratives of the interlocutors, we aimed to highlight the dynamics of concealment and visibility of AIDS—which, as we emphasised, were produced through euphemisms. First, we argue that disclosing serological status to people who are close (family, community, friends, health professionals, co-workers, etc.) and discussing its consequent management consisted not of mere

NEWSLINE

People with AIDS Coalition of New York — **January 1996**

"I remember how stunned I was when I found out. I was absolutely stupefied. I just sat there."

- Garland, Artist & PWA

AIDS and the Aging

Fig. 2 Florence Rush Archive. Harvard University, Schlesinger Library on the History of Women in America. Collection Identifier: MC 1096: T-352: Vt-160.

factual and empirical exposure but was linked to moral expectations that transcended the individual dimension of the disease. Second, and among women, age was conceived as a predisposing factor for clinical conditions similar to those common to AIDS, such as (anal/cervical) cancer and neurodegenerative diseases. Laura Mamo (2023), in her recent book, outlined an important story about the impact of anal cancer and the papilloma virus (HPV), developing a relationship with the discourses on risk, sexuality, and scrutiny of the female body at the end of the 20th century in the United States. From a clinical perspective, the narratives allow us to see that advanced age both obscured the possibilities for early diagnosis and, in sociological terms, expanded the alternatives for mitigating the disease, since in older patients and under specific conditions, the syndrome was treated as typical problems of old age. On the other hand, and following the clues given by the archives, we discuss that age also operated as a facilitator for those people who avoided being publicly associated with AIDS. That is, due to the ageing process, AIDS was embedded in a strategic web of indetermination in which euphemisms such as "cancer" or "pneumonia" gained centrality among heterosexual patients to lessen the impact of stigmas and prejudices.

The beginning of the end: Managing health-illness status, care, and authority

Eli, a white artist who lived in New York at the time, was born in 1942 in Chicago. Her experience with AIDS started after a blood transfusion in 1982. [I've been like this for 12–15 years. I only discovered [AIDS] when I contracted pneumonia and was hospitalised. I remember how shocked I was when I found out. I didn't receive any advice. I was admitted to a psychiatric hospital

against my will after the discovery of the condition]. Eli lived alone and, after a period of treatment at a psychiatric hospital, began to participate in the mothers' group as a volunteer, having been referred by a social worker.

According to Eli, in addition to the challenges of AIDS and the constant uncertainty about the evolution of the condition, there was the issue of ageing. From the point of view of medical care, Eli says that there were many limitations, as her doctor did not seem prepared to interpret the impairments typical of immunosuppression or old age: [How do you know what I am suffering from, whether it is AIDS or just related to the process of ageing? If I'm tired, is it because I'm an older person? Are some of the symptoms I suffer from, such as constant or occasional diarrhea or arthritic pain, related to HIV? How do we know this is what is manifesting itself or is it just the ageing process? And how do you treat me?] she asked.

These doubts, reproduced by Eli, were questions common to other people in the process of advanced ageing and old age who had pneumonia and severe asthenia. The latter, in particular, popularly characterised by episodes of muscle weakness, was usually attributed by biogerontology as a result of the organism's natural senescence. At each new consultation, Eli negotiated with her doctor new information and treatment methods for the disease. However, she was often advised to seek help from psychotherapists: [To a certain extent, my doctor helped me. Afterward, he would simply say there was nothing else to be done but maintain the T-cell count. But I wasn't taking those drugs [Zidovudine, Didanosine, Zalcitabine, etc.]. They hurt me. I am using medicinal herbs [herbal remedies]. He said that because I wasn't taking the prescribed drugs, it wasn't necessary to maintain the T-cell count. He doesn't think herbal treatments can be effective]. As in other situations, Eli's relationship with her doctor was conflicted and involved disputes over therapeutic authority. This was because Eli did not completely agree with the conventional treatment, reporting episodes of excessive fatigue and weakness and little openness to participate in the decision-making process. As the disease progressed, Eli observed an equally progressive loss of autonomy over her own possibility of choosing and bargaining for the treatment: [He [the doctor] said that it was either that [the treatment with the prescribed drugs], or nothing]. Eli passed away three years after the interview.

Marianitta, a 60-year-old Latina caregiver from Brooklyn who had lost her husband a few months earlier, said: [For two years Howard [Marianitta's husband] had anemia and other minor problems and we thought about doing the serological test, but they all seemed to be of the opinion that if you were in a monogamous relationship or weren't a drug user, it wasn't necessary. Testing was only recommended if you had injected drugs or were from high-risk groups. Apparently, my husband had a particular episode where his brain was affected. It was an infection and we never knew what it was. The insurance company called and asked if he had gone to see the doctor yet and I said, 'No. Because?' The attendant replied, 'because he wasn't completely open with me about what was going on,' and so I said, 'OK. Let's find a place and do the test.' And when we got back from the test, they called again and said, 'Did the doctor call yet?' and I said, 'No. We'll call him and go into the office.' And they said, 'No. Immediately go to the hospital.' They did a brain scan and found something. They never came to a conclusion as to whether it was a bacterial, viral, or fungal infection, but it did cause strokes and seizures. That was in July, and by October Howard was dead. A week later, we received the result and the test came back positive].

Howard was 69 when he died. Marianitta, consequently, had also been infected and was starting treatment with experimental antiretrovirals that were offered to patients without serious

impairments. Despite this, Marianitta argued that experimental treatments were new at the time and she had been frustrated in her attempts to be included in them. [Not all doctors dealing with autoimmune diseases were prepared to talk about AIDS and I had to negotiate to include my case in an experimental trial,] she added. [This disease is different. And if doctors are not interested in a disease that 'aimlessly' affects people, we always expect very little in terms of treatments]. She reported trying *Zidovudine*, also known as AZT: [I took it for about a week, but I got really sick. I went to my doctor and said, 'Look, this is making me sick. I can't eat and I like to eat'. And he said, 'If you don't take it, you will die']. Like Eli, Marianitta also found it difficult to communicate with her doctor, who was reluctant to include the case in a group of tests offered to patients with HIV-AIDS. In health services, in general, according to Marianitta, professionals either did not know about the advanced stage of AIDS or avoided talking openly about the subject: [In return consultations, silence. No nurse openly asked about the disease during triage, reserving the subject for the moment they entered the office. It was as if only the doctor could broach the subject. And that made me even more impatient].

Jennifer, 68 years old, black, and married, was one of the interlocutors whose contact with AIDS happened suddenly and, at first, almost imperceptibly. Jennifer was diagnosed positive for AIDS after the age of 50. [This is terrible. Because I experienced a lot of stigma as a black woman and I finally got over it—or learned to deal with it. And now this [AIDS]!]. Old age, in this context, converged with AIDS and with her previous experience of stigma based on her heritage. Jennifer was also the mother of two children, the oldest aged 44 and the youngest aged 40. As she reports, she avoided disclosing the disease to her children, keeping her HIV status secret from everyone but her mother. When the disease brought some more visible impairments, Jennifer preferred to tell her children that she had cancer without specifying the type: [I told them I had cancer. I want to sit down with them one day and tell them the truth. AIDS is like cancer, isn't it? There's not much to do and I'm aware of that. My doctor was clear about it. I'd rather it be known that I have cancer than AIDS. I am afraid of being rejected and not being able to see my grandchildren].

The strategic change in the way people who had contracted HIV identified the disease, shifting from "AIDS" to "cancer", was not just a question of nomenclature. It was symbolic and made the disease less stigmatised, sanitising the illness process and ensuring the bonds of support and solidarity among family members and people who could provide support and care. Thus, it was also a type of negotiation that involved moral expectations about pre-established relationships in the family and community. In addition to the pharmacological therapy recommended for her case, Jennifer admitted that she sought spiritual support in the church, as she came from a religious family—[My friends and family used to say that I should go, but that was something inside me and something I had to do. So, when I found out I had AIDS, I approached the church]. She also attended support groups at Iris House. [I know most of the girls there. They see life from a different perspective than mine; they are more open to sharing their experiences with the disease and we feel more supported]. Jennifer's visits to Iris House demonstrated, among other things, the importance of such services offered by philanthropic institutions in New York, particularly to people who experienced multiple processes of discrimination, prejudice, and stigma based on age, race, colour, ethnicity, health status, social class, origin, etc.

In the group of mothers, there was a kind of ritual to be followed. As Susan Katz, one of the downstairs mothers, said, [By caring for another mother's child while yours is still surviving,

going to the hospital and seeing the last stages of the disease, you are learning how to do it by getting a video prospectively]. This lesson was particularly important for mothers who were dealing with issues of the disease, but also for those who had recently discovered that their children or relatives were gay or drug users, for example. Thus, the learning accumulated by the group constituted key opportunities for understanding issues of health, sexuality, use of chemical substances, and mourning. According to Katz [The group is where AIDS stories begin. After a child or relative dies, stories are told and retold. Memories are created, bonds continue, and the story doesn't end]. The "AIDS stories" were not, therefore, facts limited only to experiences about illness and immunological suppression. Such stories were part of sociological processes that involved deprivation, violence, vulnerabilities, and discrimination.

As part of the ritual, the shared memories were the point of solidarity and sociality for the production of bonds through recognition of and identification with the narrated stories (Halbwachs, 1990). In sociological terms, sociality cannot be understood as a mechanical and natural element established among mothers based on essentially common purposes. As Erving Goffman (1963) and Randall Collins (2005a, 2005b) have found, sociality is ritually determined and involves situational co-presence, focused interaction, social solidarity, the sharing of sacred objects, and moral discomfort. These are also points that form emotional bonds or emotional solidarity in which people's harmony with experiences is the core of social interaction (Goffman, 1963; Collins, 2005a, 2005b; Bericat, 2016; Rose et al., 2022; Prickett, Timmermans, 2022).

From the ritual perspective, on the other hand, experience with caring for family members and people with AIDS anticipated social expressions of mourning, based on the possibility of learning from other mothers who had lost children and relatives about how to do it (Garcia, 2010; Kleinman, 1988). That is, considering that the discovery of the disease implied the understanding that there was no completely effective treatment until the commercial availability of the antiretroviral cocktail in 1997, death was the socially expected outcome, and funeral rituals were an inseparable part of the care process. In this regard, our approach follows the propositions elaborated by Natashe Dekker (2023), in which anticipatory grief follows a relational framework between the present and future. When caring for a relative suffering from a deadly and degenerative disease, mothers and relatives experienced losses in the present as the disease progressed: "With each change, they regret the skills or aspects of their relationships that were lost, they adapt to new circumstances, find new ways of relating and revise their expectations about the path ahead. Gradually these experiences bring the end of life into an increasingly tangible and imminent prospect. On the other hand, then, they become end-of-life-oriented. They anticipate this moment, bring it into the present, prepare for it practically and emotionally, and mourn the future losses that are expected and loom in the present. Anticipatory grief, then, is temporal and relational, encompassing the experience of losses in the present alongside losses that are yet to come" (Dekker, 2023, p. 703).

The dynamics of anticipatory grief were part of many stories, however, and were particularly strong in Karen's personal story as a caregiver for her mother, Tidy. Karen, a white lesbian social worker, started working with AIDS through a hotline that offered emotional support and counseling over the phone to people affected by the disease in the 1990s: [Many people work in the HIV world because, in some way, they are personally affected by AIDS in their lives. Perhaps they have lost partners, or friends or are HIV positive themselves. I started dealing with HIV-related issues when the city's AIDS Hotline first opened. I joined the first

team of people working directly on AIDS for the New York City Department of Health. Although the work soon became an obsession and I eventually opened and ran the city's first HIV ACT site, I did not feel personally affected by the epidemic].

Karen, however, could not have expected that her mother, Tidy, had contracted HIV from one of the blood transfusions she had undergone in recent years. As she related, [Within a year of starting to work on the AIDS Hotline, my mother started to lose weight, a little at first. Then she became very depressed and lethargic. She went to doctors who said nothing was wrong. She went to psychiatrists who told her that given her life circumstances—a severely cognitively impaired son, my brother Howie, who had lived at home all his life and was totally dependent on her for all his needs, and the fact that her only daughter was now a lesbian—she was doing great]. Despite this, and with the progression of symptoms of tiredness, confusion, and apathy, Karen considered the possibility that her mother had Alzheimer's: [So I called the appropriate organisations and the symptoms—disorientation, depression, weight loss, and possible immune suppression—they looked very similar. Finally, my mother went to visit the oncologist who had treated her for cancer three years earlier. I was at the test site when the phone rang. She said the doctor informed her that she had received a transfusion of infected blood from a person who eventually died of AIDS. I struggled to keep my attention on what she was saying, but I knew. I looked up and realised the entire team was there silently supporting me. I don't think I've ever felt more supported by a group of people than I did at that moment. But that was the beginning of the end].

From the evolution of the case to the conflicts and challenges with Tidy's care, Karen simultaneously dealt with the support and care that was offered to her brother, Howie, 34 years old. As the illness progressed, Karen observed that, [at home, Tidy withdrew from the world a little bit at a time]. As in the case of neurodegenerative diseases, discussed by Sharon Kaufman (2005), the care of family members and relatives with AIDS in an advanced stage created a kind of "indistinction zone" between the sociological categories of life and death. That is, as a result of the anticipation of mourning, the relationships established through care were also informed by the ambiguous feeling of loss (Dekker, 2023).

From the phrase "the beginning of the end," it is inferred that there was an anticipated perception of loss. That is, the notion of *end*, in the case of degenerative and fatal diseases, is not exactly the endpoint in which death is the outcome. We also consider that the *end* is part of procedural sociology in which the feeling of loss is the result of ruptures with everyday sociological schemes, not always resulting from complex relationships but significant at the level of common interactions. According to Karen, the *end* took place gradually, day after day, when Tidy seemed increasingly indifferent, with progressive degrees of physical-motor dependence: [At first, she stopped walking independently. So, she was incontinent, but she was still conscious enough to feel humiliated by being forced to wear diapers. It was really important to me to know how she was feeling, but she was having trouble communicating. Most of the time, she couldn't form a sentence or was trying to say something and no one could understand her. One day, when she was more coherent, she was able to talk about how she was doing. She said she couldn't stand the idea of people finding out she had AIDS. She kept saying it was so different when she had cancer; she wasn't embarrassed or worried about what other people thought. But if the people in her building found out she had AIDS, would they still talk to her, would they still appreciate and respect her, would they want to use the same washing machines? Howie would be placed in a long-term care facility if they knew?].

As Jennifer's story elucidates, "AIDS" and "cancer," however, were not random or indifferent terms. Tidy's demand that her disease be recognised as "cancer" can be seen as an immediate call for social inclusion, support, respect and the permanent discomfort and shame of being publicly seen as an AIDS patient. The use of the expression "cancer" (nonspecifically) also masked its etiology. Among women, cancers originating from sexually transmitted infections, such as HIV or HPV, constituted generational representations that associated them mainly with women over 40 years of age in the 1980s and 1990s. According to Mamo (2023), the increase in the number of diagnoses and the high incidence of anal cancer among women with HIV did not correspond to the proportional recognition of the cause in the field of health policies. The emphasis given to gay men (and men who have sex with men) by epidemiology formed a type of erasure and bet on women's bodies, as while they were made invisible, their bodies were also described in negative and stigmatising terms. In the case of anal cancer and HPV, specifically, such bets involved medical inquiries into promiscuity, prostitution, sexual abuse, unwanted pregnancies, etc. Likewise, the hypotheses raised about the form of contamination produced mechanisms of social containment and regulation of women's bodies anchored in two moral assumptions: excess sexuality and the risk of disease (Mamo, 2023, p. 105). In this sense, the narratives of the women analysed in this research suggest that not specifying the type of "cancer" was a dual linguistic and symbolic resource.

As in other cases, the description of AIDS-derived pathologies by the euphemism "cancer" made it possible to cover up moral dilemmas based on a disease historically associated with promiscuity, homosexuality, intravenous drug use, etc. Such strategic use was no different with Tidy. The refusal to make the diagnosis of HIV-AIDS public made the generic expression "cancer" popular among white, middle-class, and heterosexual people during the AIDS sexual panic. [She wanted everyone to know that she had cancer,] concluded Karen.

Conclusions
The narratives produced by Florence Rush's interlocutors during the AIDS health crisis make it possible to understand how social and cultural dynamics of recognising the disease did not result in autonomous, individual, and objective processes for exposing the pathological state. The strategic use of the term "cancer" instead of "AIDS" as an umbrella definition, and one less demarcated by aspects involving gender and sexual behaviour, evidenced the sociality of the illness. This both exposed the way in which negative representations were associated with AIDS—perceived as harmful, immoral, or deviant behaviours—and produced new meanings and demands among patients who feared stigmatising classifications in the midst of sexual panic until the commercial availability of the antiretroviral cocktail in 1997. It is known that public responses to HIV/AIDS differ from those established around cancer. As Roberts and Weeks (2018) noted, in the case of unknown diseases, as the example of AIDS illustrates, patients, doctors, and insurance companies also disputed the status of the disease in order to expand coverage for treatments and medical care or restrict them. Thus, the uses of AIDS and cancer make the category "health status" more complex, evidencing its polysemy which, in cases of undetermined illnesses, unified interests and disputes of different social actors.

New configurations of kinship were also produced as dependency reversed the logic of autonomy and authority, and the disease management encompassed a range of intersectional stigmas (Collins, 2005a, 2005b; Logie et al., 2019; Sievwright et al., 2022; Karver et al., 2022). As a kind of rite of passage, anticipated mourning promoted rearrangements in pre-established family

and community relationships. The relationship between past and present, considering moral ties, revealed feelings such as anguish, fear, and shame in relation to expectations about the future. Experiences with caring for relatives affected by AIDS involved conflicts and contradictions, with outcomes that did not always produce opportunities and learning, connecting a web of inde-termination that was informed by the fear of death from AIDS. As a process that does not end with death, dying from AIDS implies a perpetual management of secrecy among family, friends, and bereaved people. Despite the normative and moralising contours of the epidemic, mainly among communities considered exposed, affected heterosexual segments exhibited a similar fear of classification, normalisation, and recognition by the prevailing pathological vocabulary. Finally, the reports produced by mothers and patients can be understood as a more general part of an illness situation in which intersectional stigmas touch on aspects of gender, sexuality, race/ethnicity, and generation, still histori-cally present among patients and people affected by HIV/AIDS in different social and cultural contexts (Wolitski et al., 2009; Gil-bert, Walker, 2010; Overstreet et al., 2013; Arnold, Rebchook, Kegeles, 2014; Dourado et al., 2019; Gabbidon et al., 2020; Madiba, Ralebona, Lowane, 2021; Mamo, 2023).

Data availability
The datasets generated during and/or analysed during the current study are available from the corresponding author upon reason-able request.

References
Arnold EA, Rebchook GM, Kegeles SM (2014) "Triply cursed": racism, homo-phobia and HIV-related stigma are barriers to regular HIV testing, treatment adherence and disclosure among young Black gay men. Cult Health Sex 16(6):710–722

Bericat E (2016) The sociology of emotions: four decades of progress. Curr Sociol 64(3):491–513

Bilardi JE, Hulme-Chambers A, Chen MY et al. (2019) The role of stigma in the acceptance and disclosure of HIV among recently diagnosed men who have sex with men in Australia: a qualitative study. PLoS ONE 14(11):e0224616

Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3(2):77–101

Collins R (2005a) Interaction ritual chains and collective effervescence. In.: Von Scheve C, Salmella M, (eds). Collective emotions. Oxford: Oxford University Press, pp. 299–311

Collins R (2005b) Interaction ritual chains. Princeton University Press, New York

Douglas M (1996) Purity and danger: an analysis of concepts of pollution and taboo. Routledge, New York

Dourado I, Guimaraes MDC, Damacena GN et al. (2019) Sex work stigma and non-disclosure to health care providers: data from a large RDS study among FSW in Brazil. BMC Int Health Hum Rights 19(8):1–8

Drisko JW, Maschi T (2016) Content analysis. Oxford University Press, Oxford

Durkheim E (1995) The elementary forms of religious life. Free Press, New York

Epstein S (1996) Impure science: AIDS, activism, and the politics of knowledge. University of California Press, California

Epstein S (2007) Inclusion: the politics of difference in medical research. Chicago University Press, Chicago

Ferreira JP, Miskolci R (2022) "Reservoirs of venereal diseases," "MSM" and "PWA": continuities, ruptures and temporalities in the production of bioi-dentities in the context of the AIDS epidemic. Cien Saude Colet 27(9):3461–3474

Florence Rush archive. Papers of Florence Rush, 1941–1996 (inclusive), 1971–1996 (bulk). Schlesinger Library, Radcliffe Institute, Harvard University, Cam-bridge, MA; 1941

Gabbidon K, Chenneville T, Peless T et al. (2020) Self-disclosure of HIV status among youth living with HIV: a global systematic review. AIDS Behav 24:114–141

Garcia A (2010) The pastoral clinic addiction and dispossession along the Rio Grande. University of California Press, California

Gentles SJ, Charles C, Ploeg J et al. (2015) Sampling in qualitative research: insights from an overview of the methods literature. Qual Rep. 20(11):1772–1789

Gilbert L, Walker L (2010) "My biggest fear was that people would reject me once they knew my status…": stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg. South Afr Health Soc Care Community 18:139–146

Gilman SL (1998) Difference and pathology: stereotypes of sexuality, race and madness. Cornell University Press, London

Gilman SL (1988) Disease and representation: images of illness from madness to aids. Cornell University Press, London

Goffman E (1963) Stigma: notes on the management of spoiled identity. Simon & Schuster, New York

Gould DB (2009) The shame of gay pride in early AIDS activism. In.: Halperin DM, Traub V (eds). Gay Shame. Chicago University Press, Chicago, pp. 221–255

Halbwachs M (1990) A memória Coletiva. Vértice, São Paulo

Karver TS, Atkins K, Fonner VA et al. (2022) HIV-related intersectional stigma and discrimination measurement: state of the science. Am J Public Health 112:s420–s423

Kaufman SR (2005) And a time to die: how American hospitals shape the end of life. Chicago University Press, Chicago

Kim JH (2016) Understanding narrative inquiry: the crafting and analysis of stories as research. SAGE Publications, London

Kleinman A (1988) The illness narratives: suffering, healing, and the human condition. Basic Books, New York

Dekker N (2023) Anticipatory grief in dementia: an ethnographic study of loss and connection. Cult Med Psychiatry 47:701–721

Logie CH, Williams CC, Wang Y et al. (2019) Adapting stigma mechanism fra-meworks to explore complex pathways between intersectional stigma and HIV-related health outcomes among women living with HIV in Canada. Soc Sci Med 232:129–138

Madiba S, Ralebona E, Lowane M (2021) Perceived stigma as a contextual barrier to early uptake of HIV testing, treatment initiation, and disclosure; the case of patients admitted with AIDS-related illness in a rural hospital in South Africa. Healthcare 9(8):962

Mamo L (2023) Sexualizing cancer: HPV and the politics of cancer prevention. Chicago University Press, Chicago

McKay R (2017) Patient zero and the making of the AIDS epidemic. Chicago University Press, Chicago

Overstreet NM, Earnshaw VA, Kalichman SC et al. (2013) Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men. AIDS Care 25(4):466–471

Parker R, Aggleton P (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med 57(1):13–24

Petryna A (2002) Life exposed: biological citizens after chernobyl. Princeton University Press, New York

Pollak M (1988) Les Homosexuels et le Sida. A. M. Métailié, Paris

Prickett PJ, Timmermans S (2022) "If no one grieves, no one will remember": cultural palimpsests and the creation of social ties through rituals. Br J Soc 73:244–258

Ritchie DA (2015) Doing oral history. Oxford University Press, Oxford

Roberts JL, Weeks E (2018) Healthism: health-status discrimination and the law. Cambridge University Press, Cambridge

Rose N, Birk R, Manning N (2022) Towards neuroecosociality: mental health in adversity. Theory Cult Soc 39(3):121–144

Rosenberg CE (1989) What is an epidemic? AIDS in historical perspective. Dae-dalus 118(2):1–17

Sievwright KM, Stangl AL, Nyblade L et al. (2022) An expanded definition of intersectional stigma for public health research and praxis. Am J Public Health 112:s356–s361

Slagstad K (2021) The pasts, presents and futures of AIDS, Norway (1983–1996). Soc Hist Med 34(2):417–444

Thomson R (2007) The qualitative longitudinal case history: practical, methodo-logical and ethical reflections. Soc Policy Soc 6(4):571–582

Turner VW (1969) The ritual process: structure and anti-structure. Aldine Pub-lishing, New York

Vaismoradi M, Turunen H, Bondas T (2013) Qualitative descriptive study. Nurs Health Sci 15:398–405

Wolitski RJ, Pals SL, Kidder DP et al. (2009) The effects of HIV stigma on health, disclosure of HIV status, and risk behavior of homeless and unstably housed persons living with HIV. AIDS Behav 13:1222–1232

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The authors declare no competing interests.

Ethical approval

Ethical approval was not required as the study did not involve human participants.

Informed consent

Ethical approval was not required as the study did not involve human participants.

Additional information

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