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# The Unintended Consequences of AIDS Survival

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*Oh my friends my  
friends forgive me,  
that I live and you  
are gone. There's a  
grief that can't be  
spoken, there's a pain  
goes on and on.*

– Herbert Kretzmer from *Les Misérables*

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# 1

## Introduction and Background

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On June 5, 1981, a cluster of rare infections in gay men in Los Angeles was first reported by the Centers for Disease Control (CDC).<sup>1</sup> From that ominous day, an outbreak of a new, unnamed pathogen that was later identified as the Human Immunodeficiency Virus (HIV) slammed already-stigmatized communities throughout the United States—predominantly gay men, injection drug users, heterosexual women, African Americans, and Latinos. New cases soon spread like wildfire around the globe. No plague in modern times has taken such a devastating toll on this country’s health, economy, and welfare.

Today, HIV/AIDS is in its 35th year and its impact will continue to be felt for decades. Millions have been struck by the havoc of this disease: people who contracted it as adults, those who have lived with it their entire lives, having been infected from birth, and the providers, caregivers, and support volunteers who are also truly survivors, even if they never contracted the virus. Each group—and many subgroups within them—has its own issues and characteristics, but many will likely have lifelong scars from the deep trauma, stigma, grief, and devastation of the disease, and all are a part of the family of survivors that live on with the legacy of the extraordinary fight.

At the outset of the epidemic, grassroots mobilization began almost immediately in urban centers, as government and institutional leaders were unable to provide answers to the questions surrounding this new disease. Nationwide fear of contagion, and of anyone in a high-risk population, led to some of the most damaging stigmatization in years. In San Francisco, one of the first instances of AIDS activism were photographs of the first men to fall ill posted on a pharmacy window in the Castro.<sup>2</sup> This became an alert to the neighborhood of the sudden crisis, as well as a call to action and a plea for help.

Before long, hospitals were flooded with the sick and dying. Funds were raised, and marches were organized. A huge AIDS “patient empowerment” advocacy movement was organized, uniting the courageous leaders in the fight against AIDS. In 1983, a powerful document known as “The Denver Principles” was released by activists to demand basic rights for people living with AIDS.<sup>1</sup> ACT UP (AIDS Coalition to Unleash Power) and its brilliant tactics of clamorous public demonstrations, including

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peaceful civil disobedience and witty, in-your-face media campaigns and graphics, was founded by Larry Kramer in New York City in 1987. In-depth scientific and medical knowledge was crucial, and providing it became an important ACT UP function. Activists became knowledgeable with complex scientific, regulatory, and economic information that provided critical defense with corporate, institutional, and governmental decision-makers. Soon, ACT UP chapters spread worldwide and became the face of outrage at society and systems that were blind to AIDS.

AIDS mobilization essentially created both a powerful force and an opportunity for people with common bonds to join together to handle an epidemic that threatened their very existence. They did this with grace and dignity, and sometimes anger and rage. The HIV/AIDS survivor mobilization that has begun in the last several years was largely informed by these early AIDS grassroots efforts.

Over the past 35 years, tens of millions of people around the world have lost their lives to AIDS-related causes.<sup>3</sup> In the United States—the focus of this report—698,000 people have died.<sup>4</sup> However, significant treatment advances have been made, as evidenced by the approximately 1.2 million people currently living with HIV.<sup>4</sup> In the United States, AIDS mortality is now at its lowest, having dropped 80% since peaking in 1995.<sup>4</sup> In addition, taking 1 pill a day can now virtually prevent the transmission of HIV to someone else. An HIV vaccine, the one thing that could truly end AIDS, has remained elusive, and there is still no cure. But focused community advocacy and hope, backed up by focused international research efforts, have resulted in theoretical strategies for developing a cure, and there are many clinical trials currently underway to test these hypotheses. The profound scientific advances that have been achieved, combined with ongoing research, have led a few localized US areas to envision a future without this devastating epidemic, and develop public health campaigns with the goal of bringing the infection rate as close to zero as possible.

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Great strides have been made already, and new HIV infections have stabilized in many groups. In certain populations, though, they continue to go up—for instance, HIV diagnoses increased 16% in young (aged 13-24 years) Hispanic/Latino men who have sex with men (MSM) from 2010 to 2014, while they decreased slightly in young African American and white MSM.<sup>5</sup> In addition, although increases slowed to less than 1% between 2010 and 2014, incidence of HIV infection among African American MSM increased 22% between 2005 and 2014.<sup>6</sup> We can see success with these statistics, but there is a long way still to go, and disparities continue—and so the fight against HIV continues.

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In addition to the ongoing scientific advances toward HIV prevention and a cure, there are other reasons to celebrate. Chief among them is the fact that hundreds of thousands of people living with HIV/AIDS are surviving well into old age—something never imagined at the onset of the epidemic—and their numbers are growing.<sup>7</sup> Some of these survivors have lived half their lives with HIV/AIDS. But even this miraculous achievement has a downside: long-term survival with the disease and receiving antiretroviral therapy (ART) has created some unexpected challenges.

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## 2 Overview

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This paper focuses on the unique story and aspects of HIV/AIDS survivorship in the United States, and the movement that this phenomenon has generated. It includes survivor needs-assessment information directly from the hardest hit communities, evidence-based behavioral and clinical research, theoretical and historical accounts, best practice program models, and finally advocacy and community mobilization efforts.

Since survivors are being addressed in this paper, it's important that a basic historical timeline of the epidemic is presented. In **Section 3**, the AIDS historical graphic contextualizes survivor trauma as well as positive milestones for readers who may be unaware of this history. Additional context in this section comes from epidemiological data from the first reported cases to survival rates, overlaying the milestones on the graphic. While it would be ideal to be able to provide an epidemiologic breakdown of HIV survivors and who they are—their age, sex, and race—to show how the epidemic has shifted and evolved, this is not possible, since specific data are not collected on who has survived and for how long.

People with HIV/AIDS who were infected prior to the advent of effective combination therapy in the mid-nineties and are still alive are considered “long-term survivors.” **Section 4** explains the historic advance that changed the course of the epidemic, allowing thousands of survivors to live into today. Also covered are the mortality curves as a result of both prophylactic and combination antiretroviral therapy that represent the historic breakthrough, which led to what was coined as the “Lazarus effect.” More information on the improvement of survival rates and life expectancy is also provided in this section.

**Section 5** breaks down the unintended consequences of HIV/AIDS survival. These include trauma, leading in many cases to addiction and other psychosocial and mental health issues, premature aging, effects on the body of ongoing immune activation, and practical living survivor stressors. It is our hope that reading about and understanding these unintended consequences of HIV/AIDS survival in this paper will help increase survivor and community awareness and stimulate research that could uncover critical interventions, and lead to policy changes. If long-

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term survivors are addressed adequately and rapidly, a critical challenge in the fight against AIDS can be overcome.

Finally, **Section 6** tells the community survivor story. While awareness still needs to be increased, many in the HIV community have been working to support long-term survivors dealing with the unintended consequences of survival. This section describes the initiation and development of survivor mobilization and advocacy, and offers examples of some best program practices and effective models in the support, care, and treatment of survivors.\*

\*Every effort has been made to include the most current information possible. However, because the field is so fluid, new material may unintentionally be left out of this paper.

# 3

## AIDS Survivor Historical Timeline and Epidemiological Data

Year	Event	Data
1981	June 5: <i>MMWR</i> reports 5 cases of a rare infection in young gay men in Los Angeles; additional reports soon lead to the labeling of a new disease: gay-related immune deficiency, or GRID <sup>1</sup>	In the period between 1981 and 1987, there were 50,280 AIDS cases reported, with the highest incidences among white males and men aged 30-39 years; 95.5% of people with AIDS died <sup>8</sup>
	December: First photographs showing "Gay Cancer" are placed in the window of the Star Pharmacy in the Castro district <sup>2</sup>	
1982	<i>Acquired Immune Deficiency Syndrome</i> was the name given to the largest and most devastating plague of modern times <sup>1</sup>	
	First congressional hearing on AIDS <sup>1</sup>	
1983	Denver Principles introduced <sup>1</sup>	
1984	Discovery and naming of HIV <sup>1</sup>	
1985	Ronald Reagan first mentions AIDS <sup>1</sup>	
1987	ACT UP founded <sup>1</sup>	
	First AIDS drug approved (AZT) <sup>1</sup>	
1988	ACT UP targets the FDA in massive civil disobedience and demonstration; FDA changes regulations to accelerate drug approvals <sup>1</sup>	Between 1988 and 1992, there were 202,520 people with AIDS, with white males and men aged 30-39 years making up about half of all cases; 89.5% of people with AIDS died <sup>8</sup>
1992		AIDS becomes the number 1 cause of death for US men aged 25 through 44 years <sup>1</sup>
1993	Expanded definition of AIDS <sup>1</sup>	Between 1993 and 1995, there were 257,262 people with AIDS, with men aged 30-39 years making up 45% of all cases, and the percentage of white men dropping to 42%; the total death rate dropped to 62% <sup>8</sup>

<i>Year</i>	<i>Event</i>	<i>Data</i>
1995	Effective combination ART studies first presented <sup>9</sup>	Number of AIDS cases reported in the United States passes 500,000 <sup>1</sup>
1996		First-ever decline in the number of new AIDS cases reported in the United States <sup>1</sup>
1997	Highly active antiretroviral therapy (HAART) becomes standard of care <sup>1</sup>	<p>Almost half of AIDS-related deaths occur in African Americans, making mortality almost 10 times that of whites<sup>1</sup></p> <p>Between 1996 and 2000, 264,405 AIDS cases were reported; men aged 30-39 years were still the largest group, but increases were seen in older men; African American men made up the largest group at 45%; the death rate dropped to 23%<sup>8</sup></p>
2007		US AIDS-related death toll passes 565,000 <sup>1</sup>
2008	<p>Timothy Brown, aka "The Berlin Patient," is the first reported AIDS "cure" case<sup>1</sup></p> <p>First evidence that HIV treatment may be associated with life expectancies up to 70 years<sup>1</sup></p> <p>September 18 is the first National HIV/AIDS and Aging Awareness Day<sup>1</sup></p>	
2010	First national HIV/AIDS strategy released <sup>1</sup>	
2012	PrEP pill for the prevention of HIV transmission approved by the FDA <sup>1</sup>	New treatment recommendations to treat all adults and adolescents with HIV regardless of viral load <sup>1</sup>
2013	Long-term survivor mobilization begins in San Francisco	42% of all <i>diagnosed</i> HIV cases were in people 50 years of age or older <sup>10</sup>
2014	Studies show life expectancy increasing in the US and Canada <sup>11</sup>	
2015	Rickabaugh et al reported data from the Multicenter AIDS Cohort Study (MACS) showing signs of aging in HIV samples equivalent to aging expected in people 14 years older <sup>13</sup>	The majority of people living with HIV/AIDS in the US are anticipated to be over 50 years of age <sup>12</sup>
2020		Estimated 70% of people living with HIV/AIDS will be over 50 years of age <sup>12</sup>

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# 4

## The Miracle of HIV/AIDS Survival in the United States

As we have seen, significant strides have been made in reducing the incidence of AIDS and increasing survival time for those living with HIV/AIDS. AIDS incidence hit its highest point in the early 1990s and then began to decline. New AIDS diagnoses peaked in 1993 specifically due to the expanded definition of the disease. Fortunately, combination ART that included a new potent drug class known as protease inhibitors began to have apparent effectiveness in the mid- to late-nineties. The greatest impact was among gay men and racial and ethnic minorities. There were, however, still increases in cases in women and cases associated with heterosexual transmission. The famous graphic showing the inversion of mortality rates to number of people taking ART was dramatic (see below: “The Lazarus Effect”).<sup>14</sup> And as mortality rates and AIDS incidence have leveled off over recent years, the number of people living with and surviving HIV has risen—exactly what you hope to see in an epidemic with effective and successful treatment in the short term.

HIV no longer carries the horrifying death sentence it once did if people know their status and get on treatment as soon as possible, and survival rates have improved steadily as treatments have proven more effective and more people are gaining access. If people are able to manage and stay on treatment—which is now easier than ever for many, with lower pill burden and simpler dosing—they can survive as long as their HIV-negative counterparts, although in some groups, including women, people of color, and injection-drug users, predicted life expectancy remains lower compared to the general population.

As mentioned above, however, there is a major caveat to increased survival rates, which some refer to as “the graying of the epidemic.” Long-term survivors diagnosed early in the epidemic are generally at least 45 years old now. With research showing *earlier* biological aging in addition to the higher risk of associated life-threatening comorbidities that are normally associated with people over 65, we are faced with what might be a particularly tenuous health situation for these survivors (see further detail in Section 5).

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## ***The Lazarus Effect***

In the mid-nineties, a remarkable breakthrough was made in HIV therapy. “Highly-active antiretroviral therapy” (HAART), a treatment approach using very potent antiretroviral drugs in just the right combination, was shown in studies to bring virus levels to “undetectable” levels in the majority of patients for a sustained period. This was commonly referred to as the Lazarus effect, from the biblical story of Jesus miraculously raising the dead Lazarus from the grave. For those who had survived the first years of the epidemic, it did seem like a miracle.

Health improved, weight and energy were restored, and many were able to return to a seemingly normal existence. For the first time in the epidemic’s history in the United States and developed countries, the mortality rate dipped sharply. Hospital AIDS wards began to see fewer terminally ill AIDS patients. AIDS hospices closed and AIDS service organizations shuffled their program priorities. Some survivors returned to work and school with a “new lease on life.” Others, however, struggled to regain balance, having seen their community and loved ones decimated, and having fought their own way through against a backdrop of continued stigma and other life challenges. Survivorship is not always easy.

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Over the next 2 decades, the pharmaceutical industry sought out, discovered, and developed over 30 drugs to target HIV. The advance is unprecedented in medical history, including new drug classes, once-daily pills, and fixed-dose tablets that make taking the drugs simpler. Now, most people with HIV have choices, and doctors can tailor effective medications to individual needs.

Nonetheless, the epidemic rages on. More than 100 people are infected every day in the United States.<sup>15</sup> Stigma and complex social justice issues still tangle the success that has been made.

New people living with AIDS are learning their own particular survival skills. The issues for each survivor—whether a long-time HIV survivor, an uninfected caregiver, or a perinatally infected young adult—have similarities and differences, but all share one constant: a focus on surviving and thriving with HIV.

What defines a “survivor”? In some diseases, like cancer, living for 5 years is what makes a survivor. We generally refer to *long-term HIV survivors* as those who were diagnosed prior to the advent of effective ART in the mid-nineties. These survivors are given special honor in our communities not only because they have miraculously lived *decades* with HIV/AIDS, but also because so many of them are thriving today. Further, many have committed much of their lives to fighting to make change within the system.

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There are also long-term survivors who were infected at birth and are as old as the epidemic itself. Some tell of living through unimaginable stigma and loss for most of their young lives, in practical isolation and with little community support. This is another type of survivor who must be recognized.

Many other veterans of the AIDS movement have expressed an affiliation or affinity to the growing HIV/AIDS survivor movement. Uninfected men and women, family members, partners, caregivers, and community members fought for so many lives, many on the front lines of support, care and treatment, often providing the only strong backbone for those suffering to rely on.

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## The Unintended Consequences of HIV/AIDS Survival

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While there is no argument that the promise of long-term survival with HIV/AIDS is to be celebrated, it is not without its own significant challenges.

### *Spencer Cox and the Medius Report*

In the new millennium, the HIV treatment paradigm shift made long-term survival possible for tens of thousands of people. But the transition into this new treatment era wasn't seamless. In the gay community, it seemed to be a time of celebration for many, but others had difficulties. Not everyone with HIV achieved treatment success and many had to fight for newer, more effective antiviral drugs. For almost everyone, whole networks of friends, as well as jobs and homes, had been lost. In the new era of survival, the trauma and stress of the past was unintentionally swept under the rug, which may have led some survivors into loneliness, depression, and self-harming behaviors.

In 2004, Spencer Cox, a veteran ACT UP New York activist, began noticing these mental health issues and substance abuse behaviors among survivors (particularly gay men in their 40s through 70s), and questioned if the growing problem might be related to survivor trauma and posttraumatic stress. Cox and others founded the Medius Institute for Gay Men's Health, a remarkable project "dedicated to improving the health, well-being, and longevity of gay men." It was the first project to recognize and begin research into mental health issues, or unintended consequences of HIV/AIDS survival.

Tragically, Spencer also had issues with depression and drug addiction and at 44, in 2012, he died of an opportunistic infection because he had stopped taking his antiretroviral medications. As a leader in the ACT UP movement, his death was widely publicized and sent shockwaves through the AIDS community that wanted to make sense of his early death.

If there is a silver lining to this immense loss, it is the legacy that Spencer left through ACT UP, through Medius, and in his brilliant essay, "The Legacy of the Past: Gay Men in Mid-Life and the Impact of HIV/AIDS." The document provides an apt rationale for many of the questions and concerns of survivorship, and serves as an important framework for much of today's AIDS survivor movement.

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## ***Psychosocial and Mental Health Issues***

As survivors grow older they may experience an array of psychosocial issues—mental health issues that may overlap with social issues—such as depression, anxiety, isolation, and even suicidal thoughts or actions resulting from decades of unprocessed grief, physical illness, and trauma. While survivors say they have learned over time to live well with HIV,<sup>16</sup> some also have

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*Even the diagnosis of HIV itself has been called a severe traumatic event.*<sup>20</sup>

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shared stories of struggle and poor outlook from uncertainty about the future, inability to plan,<sup>16,17</sup> and even survivors' guilt<sup>18</sup> and “battle fatigue” from years of living with HIV. Long-term survivors also described trauma from stigma and personal loss, such as abandonment by family and friends or the death a partner or friends from AIDS.<sup>19</sup> Even the diagnosis of HIV itself has been called a severe traumatic event.<sup>20</sup> These issues may also be experienced by caregivers and should not be overlooked. Informal caregivers of people living with HIV had high burden, stress, and depressive symptoms<sup>21</sup> with self-reported depressive symptoms being linked to HIV caregiving-related stigma.<sup>22</sup>

It is becoming more evident how severely trauma impacts the mental well-being of long-term survivors. Traumatic events affecting people with HIV have been linked to an increased risk of developing posttraumatic stress disorder or PTSD, reported in studies to occur in 5%-74% of people living with HIV/AIDS compared with 7%-10% in the general population.<sup>23</sup> The studies were performed primarily in the United States and the range of reported PTSD prevalence indicates more intensive monitoring of PTSD needs to be done to truly understand how many people living with HIV are affected. To complicate matters, PTSD may coexist with other psychosocial issues including depression<sup>24</sup> or feelings of poor social support in HIV-infected women.<sup>25</sup> And again we see the role of stigma. When combined with other trauma, internalized HIV stigma was positively linked to the severity and course of PTSD symptoms.<sup>26</sup> PTSD and trauma have been mentioned as reasons people do not adhere to their ART regimen;<sup>27</sup> specifically, women experiencing recent trauma were 4 times more likely to fail ART.<sup>28</sup> The trauma seen in HIV/AIDS survivors is multifaceted and complicated and may be seen as similar to complex PTSD, a syndrome of repetitive or prolonged trauma first described by Judith Herman in 1992.<sup>29</sup>

The role of social support and the experience of social isolation described by long-term HIV/AIDS survivors is becoming better understood, but much more study is needed. In a group of people 50 years of age or older, and most living with HIV for 10 or more years, a majority said they did not receive enough support.<sup>30</sup> And stigma in this setting led to reporting feelings of rejection, concerns about disclosure, silence, and being stereotyped<sup>31</sup>—responses that could be socially

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isolating. More than half of people who felt a lack of support also described feelings of loneliness and depression,<sup>30</sup> and experienced more PTSD symptoms the longer they lived with HIV.<sup>32</sup> Social support may provide that all-important buffer to help moderate the severity of PTSD symptoms. But maintaining social support can be hard since long-term survivors may find they need to adjust family relationships or redefine their friendship group over time,<sup>33</sup> given the stigma and loss many experience.

A comparable problem is HIV-related disability resulting from physical and mental health symptoms or impairment, or difficulty completing activities of daily living that have been directly linked to challenges in maintaining social inclusion. However, until recently there were no tools to understand the relationship between disability and social inclusion. The Episodic Disability Framework is a new tool, the first designed to understand disability from the perspective of a person living with HIV and to study disability in relation to social inclusion.<sup>34,35</sup> Insights about how disability and social inclusion are connected may lead to better approaches to help survivors maintain important social connections with others.

### ***Physiological Findings***

Because of both effective medication regimens and the continued incidence of new infections in older people, we are seeing more people than ever who are older than 50 years of age with HIV. In 2013, 42% of the people living with diagnosed HIV were aged 50 years and older,<sup>10</sup> and that percentage can only be expected to increase. While this is happening, we find ourselves unprepared, though, as there are very little data available on HIV in those aged 65 years and older to inform the medical treatment, psychosocial support systems, and policy decisions needed to ensure that older people with HIV can continue to live healthy and fulfilling lives as they age.

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It is becoming increasingly evident that even with complete viral suppression, those aging with HIV are experiencing multiple comorbidities that can dramatically affect both their health and quality of life. Very shortly after Spencer Cox's completed his work with the Medius project, AIDS clinicians and their patients began noticing troubling physiological symptoms in survivors. In particular, they were finding signs of aging earlier than expected. Getting older was certainly a better prospect than dying, but researchers discovered that immunologic processes known as immunosenescence, or immune system deterioration, appear to be occurring in people with HIV.<sup>13,36</sup> It was also discovered that ongoing immune activation despite HIV control leads to a constant low-level inflammation, like burning embers in a fire.<sup>37,38</sup>

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And in 2015, Rickabaugh and colleagues reported data from the Multicenter AIDS Cohort Study (MACS) showing that blood samples from people with HIV showed clinical signs of aging equivalent to those 14 years older in the age-matched HIV-negative cohort.<sup>13</sup> These researchers believe that HIV causes increased methylation—something that occurs naturally with aging—and that this effect is additive with those of aging, essentially resulting in accelerated aging.

Existing research has enumerated the multiple comorbidities experienced—often earlier than we would expect in a noninfected individual—as people grow older with HIV. These include higher rates of dyslipidemias, hypertension, insulin resistance and diabetes, kidney and liver damage, osteoporosis, increased incidence of certain cancers, frailty, stigmatizing body shape changes, and neurological damage that can affect memory and executive functioning.<sup>37-39</sup>

Bringing together the potential impact of HIV on both physiological and psychosocial aspects of life, some researchers have started to examine geriatric syndromes in HIV survivors. Geriatric syndromes are types of conditions that clinicians use to define and describe progression in aging. Because geriatric syndromes are multifactorial—that is, they involve deterioration of not only clinical elements, but also psychosocial and environmental ones—and HIV also has highly complex effects, researchers have hypothesized and found that geriatric syndromes may be accelerated in HIV survivors.<sup>40</sup> This is just further evidence of the need to take special care when treating HIV survivors, clinically or with psychosocial support.

We are now seeing what is essentially the first cohort of long-term survivors, and they are facing a unique set of problems and resulting needs that must be addressed if some of our healthcare and social systems in areas with high HIV prevalence are not to be overwhelmed. More research is needed to inform the interventions needed to address these problems. But at the same time, we must remember and build upon the incredible resiliency that has so far defined HIV survivors, and study those resilience factors. In doing so, we can ensure that we are able to provide the clinical, sociobehavioral, and policy solutions that will ensure that those who survived the worst days of the AIDS epidemic are allowed to age with dignity, meaning, and purpose.

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## Survivor Response and Community Mobilization

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In 2013, 3 long-term survivors from San Francisco, all former ACT UP Golden Gate activists, were growing concerned about disturbing mental health trends in the community. Many of their friends, most of whom were also long-term survivors, seemed to be in a major funk—some for years. Depression had become all too common and so many people seemed isolated and lost, even in the vibrant city of San Francisco. There were other issues that arose as well, such as economic stress in one of the most expensive cities in the country. Many survivors were on strict disability plans and had no options but to stay where they were, and rents were skyrocketing. There was confusion and some community apathy about what to do, how to plan for any future that was left, how to reengage with the community, and how to become alive again.

These survivors were despondent and became worried about their future. As we recognized from our past history of activism, there was a need for an awakening; a kind of survivor community mobilization. It was time to gather together to listen and learn as much as possible, and work together to meet these new challenges posed by HIV/AIDS. Soon, a clearer idea of possible solutions would develop from a collective survivor response.

At about that time, the news of Spencer Cox's death came. And there were survivor suicides right in our own community. Lack of support for aging and survivorship issues from the AIDS service organizations we had relied on for so long was virtually nonexistent. There were no specific programs for long-term survivors in most city organizations or almost anywhere in the country, for that matter. It became clear that survivorship, and the unintended consequences associated with it, were not seriously considered in a community that clearly had other priorities.

In order to slow this destructive trend, survivors had to take charge and take matters into their own hands, as had always happened in this community. A steering committee of about 8 long-term survivors volunteered to organize and strategize each week in a small space at Castro and 18th, just 1 block but light-years away from the ACT UP Golden Gate meeting space. The meetings were incredibly emotional as each person told their survivor stories. The process of returning to community

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mobilization after so many years of little activity was difficult for the committee. In no time, though, an incredible reunion of survivors in the San Francisco community took shape, and issues poured forth as people told their stories, their voices were heard, and action was taken to begin addressing the future.

The first town hall forum for HIV/AIDS survivors was held in September 2013. More than 175 people came together in a packed room at the LGBT Center. Clearly, a nerve had been struck, and people wanted to speak out and wanted to be heard. Survivors reunited that night for a kind of cathartic experience, and left with vigor, renewed energy, and hope. Valuable information was collected from survivors about a myriad of issues, how lives had changed, and what needed to change in the city. In only a few months, after several town hall meetings and lots of press, there was a clear sense of long-term survivor mobilization and activity in San Francisco. It was evident that 1 identified issue— isolation—was being addressed just by taking these first steps and coming together.

### ***Survivor Policy Advocacy***

Survivor mobilization, advocacy, and energy has led to improvement in HIV aging focus in the San Francisco city government. A San Francisco Department of Aging & Adult Services subcommittee for seniors known as the Long-term Care Coordinating Committee has formed an active HIV and Aging policy workgroup. The workgroup has been tireless in coordinating a citywide HIV and aging needs assessment and policy recommendations report.

#### The recommendations include:

San Francisco HIV and aging needs assessment	Increased and sustained linkage to care
Affordable housing	Support for transgender inclusion in health services
Mental health and psychosocial services	Support for LGBT and Getting to Zero consortium recommendations
Medical and nonmedical training for geriatricians and HIV providers	Legal, financial, and employment services
Continuation of the HIV and Aging workgroup	Food security

A budget recommendation has also been approved by the city.

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## ***Survivor Support Services***

New social meeting groups have become very successful and are a model for engaging HIV/AIDS long-term survivors. The Elizabeth Taylor 50-Plus Network for Gay, Bisexual, and Trans Men at the San Francisco AIDS Foundation uses social media to keep hundreds of members engaged in social activities several times a week. Regular group emails keep members aware of a wide variety of social gatherings, volunteer opportunities, free entertainment options, and more.

*Honoring Our Experience* is a weekend, out-of-town retreat for all people affected by HIV. Experiential in nature, the facilitated retreat fosters engagement of the whole person: mind, body, and spirit. Participants share stories, music, reflection, walks in nature, writing, laughter, and tears. Joining together as one community in this retreat enables a unique healing experience through inspiration from each person's courage and resilience.

"HIV Long-term Survivors" is a closed Facebook group with thousands of members internationally, which is generating a lot of buzz and mobilizing HIV/AIDS long-term survivors all over the world.

Housing is a huge burden on older people with HIV, especially in San Francisco. Openhouse focuses on LGBT senior services and referrals and is a terrific resource for HIV seniors.

Building on the success in San Francisco, national projects designed to reach survivors across the country are underway. The Reunion Project, offered with support from Bristol-Myers Squibb and Test Positive Aware Network in Chicago, is a town hall "reunion" for survivors staged in selected host cities. A "reunion" is often the first time a group of survivors has met together to tell their stories of survival, feels part of a community, end isolation, and begin to hope. To set up a reunion, national organizers work with volunteers in the host cities to plan the summit program agenda and strategy tailored to the survivors in their city. Since starting the project in 2015, The Reunion Project Town Hall events have been held in Chicago; Palm Springs, CA; and Philadelphia. Increasing diversity is a primary goal for the future, and The Reunion Project is currently diversifying leadership and planning summits in South Florida and Atlanta. New funding will bring the summits to more cities in 2017.

The National Minority AIDS Council (NMAC), a major national AIDS organization, has begun a national service provider training program called HIV 50+ Strong and Healthy. The first training took place at the United States Conference on AIDS (USCA) in September 2016. It is slated to continue.

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## ***Research Efforts***

Mechanisms of the unintended psychosocial consequences of survival are complex and unique, and developing interventions and research are only beginning to shed light. As usual, there remain many more questions than answers. Noted researchers such as Rick Loftus, MD; Ron Stall, PhD, MPH; Adam Carrico, PhD; Michael Plankey, MD; and David Fawcett, PhD have brought to light a variety of behavioral factors mostly with HIV-positive gay men, and no doubt, their continued interest in the field may garner hope.

In New York City, the AIDS Community Research Initiative of America (ACRIA) is recognized as a leader and one of the first groups to dedicate research provider trainings and programming for older adults in HIV. In 2006, a comprehensive study of 1000 older adults living in New York City was published<sup>41</sup>: Research on Older Adults with HIV (ROAH) is the first study of its kind and focuses on psychosocial, societal, and mental health components in older HIV-positive people. A second extended, larger, and more comprehensive phase of the study “ROAH 2” will be starting in San Francisco, Atlanta, Chicago, Los Angeles, New Orleans/Baton Rouge, San Juan, Houston, Miami/Ft Lauderdale, and Washington DC. The longitudinal data collected through detailed surveys and focus groups in ROAH 2 will help build a comprehensive understanding of many of the issues older people with HIV face every day.

The Coachella Valley Community Research Initiative has leveraged Palm Springs’ unique concentration of older people living with HIV to start Project GRACIE (Geriatric Research of AIDS Comorbidities in the Inland Empire). The purpose of this project is to combine the efforts of loyal HIV providers to assemble a cohort of those aging with HIV—especially those older than 60—on whom very little data exist. As traditional longitudinal cohorts such as the Multicenter AIDS Cohort Study (MACS) and the HIV Outpatient Study (HOPS) see funding cut or eliminated, Project GRACIE will allow researchers to compare participants with their age-matched peers in order to assess the effects of HIV on aging. Simultaneously, researchers will be able to study interventions for aging conditions such as body shape changes and neurocognitive problems.

New, fascinating protocols and methodologies into behavioral and psychosocial interventions for older people are being planned. Many use newer methodologies that have seen success in other trauma-related diseases such as cancer and cancer recovery. These include eye movement desensitization and reprocessing (EMDR) and psilocybin-assisted group therapy. It is encouraging to see this level of interventional research being planned, especially since older antidepressants, counseling, and other dated interventions may not be sufficient to address the complicated and demoralizing trauma experienced by long-term survivors.

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Awareness of HIV/AIDS long-term survivorship is a dynamic process. New and existing research, workshops, trainings, committees, town hall forums, retreats, social media, and even 2 major acclaimed film documentaries, *Last Men Standing* and *Desert Migration*, are collectively a force that will hopefully bring an end to survivor suffering.

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# 7

## Conclusions

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Since awareness and mobilization within a community of HIV/AIDS survivors began less than 5 years ago in San Francisco, tremendous prospects for a healthy and happy life has become possible for thousands of people with HIV. Those survivors who have been fortunate to have access through groups, retreats, documentaries, town halls, AIDS conferences, or social media are coming out of isolation, working through the tragedy that was AIDS, and becoming active, engaged, and alive again.

But all HIV/AIDS survivors must take the next step into their future. In spite of the cards they were dealt, many are now living into their senior years, a kind of miracle no one anticipated when AIDS first struck. Now, after 35 years, a generation of survivors is trying to make sense of what they've been through, hoping and working to keep building a future that once seemed hopeless but now holds great possibility and promise.

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Matt Sharp, who was diagnosed with HIV in 1988, is a long-term survivor of HIV and celebrated his 60th birthday this year (2016). Co-founder of The Reunion Project, he is thriving as a community organizer, AIDS treatment activist, writer and teacher. He lives in Berkeley, California with his dog Bettie.

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