

Resistance and Resilience: The Untold Story of Gay Men Aging with Chronic Illnesses

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SUMMARY. Few studies have looked at the aging process in terms of sexual orientation, and none have focused on the role that chronic health concerns play in this relationship. This article begins a more comprehensive theoretical exploration of the connection between aging, chronic illness, and sexual orientation. The author employs his practice experiences as a social worker for chronically ill and aging gay men to highlight key issues for this population, including resilience in the face of crises; mistrust of the mainstream medical and social service institutions; and internally and externally located obstacles to receiving effective medical and psychosocial care. Effective intervention strategies to serve this population are presented. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]

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“Don’t get old, it’s terrible!” is the oft-repeated refrain of many of the clients at Senior Action in a Gay Environment (SAGE) in New York City. These clients are people 60 years of age and older who identify, either explicitly or tacitly, as lesbian, gay, bisexual, or transgendered. (LGBT People Living with HIV/AIDS become eligible for SAGE’s social services at age 50.) In keeping with the theme of this volume, this article will focus specifically on SAGE’s male clients.

So what are these men talking about when they utter the above lament? It can be said with certainty that they are not referring to their sexual orientation. The stereotype of the lonely, bitter, old “queen” has been debunked in most of the literature on gay aging to emerge in the 30-odd years since Stonewall (Wahler & Gabbay, 1997). In fact, as this article will illustrate, even individuals who apparently conform to such a stereotype, upon closer examination often reveal hidden reservoirs of courage and resiliency, born out of their early, unavoidable struggle with the “coming out” process.

It is argued that successfully negotiating the coming out process gives gay men a certain advantage over their straight counterparts because gay men are forced to cope with stigma and loss at a much earlier age (Kooden, 1997; Quam & Whitford, 1992; Pope and Schultz, 1991; Kimmel, 1978). Kimmel (1978) named this dynamic “crisis competence” (p.117). Both Kooden (1997) and D’Augelli (1994) suggest that crisis competence which results from negotiating the coming out process provides gay men with the basis for addressing all future life crises, including those connected to aging. Wahler and Gabbay (1997) indicate that relative satisfaction in terms of aging hinges upon the gay man, at the very least, being out to himself. This may account for some of the resiliency noted above in otherwise closeted individuals.

Most often, SAGE clients fall somewhere in the mid-range of a three-part spectrum of gay identity formation as conceptualized by Friend (in Kooden, 1997). At one end is the aforementioned stereotype steeped in internalized homophobia (the lonely, bitter, self-hating “queen”); at the opposite pole is the self-accepting, self-affirming gay man. Between the two poles reside those whom Friend describes as “passing”: gay men who have achieved conditional acceptance of their sexual orientation, but who remain closeted in some portion of their lives (where

they “pass” as straight), and maintain a more or less marginal connection with the gay community. The majority of SAGE’s clients fall into this midrange category, and it is these men whose situations this article will address.

GAY GERONTOLOGY

As Wahler and Gabbay (1997) point out, the study of gay gerontology is a recent phenomenon, currently spanning little more than three decades and comprising a miniscule body of work. At the time of their review, they found only 58 empirically based studies on the subject. Woolf (1998) notes that most of this research has focused on people 40 years of age and older with few studies conducted solely on individuals over 60. Most of these studies focus on “breaking down the negative myths surrounding older gay men” (Wahler & Gabbay, 1997, p. 5). There appears to be nothing in the literature specifically addressing the relationship between sexual orientation and the chronic health conditions associated with aging. This scarcity of information, both in scope and in content, creates a serious knowledge gap, not only in terms of gay aging, but also in terms of aging in general. As Kooden (1997) points out, “traditional developmental theory is based on an assumption of heterosexuality” (p. 22). Therefore, the developmental tasks necessary for gay men to successfully negotiate the passages, first into midlife and then into old age, with its incumbent physical deterioration, remain virtually unexplored and unarticulated. Yet it is apparent that many gay men have to some degree successfully negotiated these transitions despite the fact that they do not conform to accepted, heterosexually based developmental patterns, indicating the unique strengths and creative coping strategies of older gay men. Information culled from empirical studies of these special competencies would very likely benefit the aging population in general (Kooden, 1997; Wahler & Gabbay, 1997).

In this article, the author will draw from his experiences working with aging gay men at SAGE to illustrate some of the ways these men are dealing with their chronic health concerns, and how their histories as gay men may affect their coping strategies. The article will also examine some of the interventions SAGE has found particularly helpful in assisting its clients. Additionally, some of the obstacles to providing this assistance will be identified. Hopefully, this preliminary exploration will pave the way for the more extensive empirical research needed to create a healthier picture of aging for all gays and, by extension, for the

aging population in general. It must be noted that the majority of SAGE's population is white, educated, middle class, and urban. This demographic profile has been true for the vast majority of empirical studies of the LGBT population (Kooden, 1997; Wahler & Gabbay, 1997). It should therefore be kept in mind that the information presented herein is specific to a very small group of aging gay men.

AGING, LOSS, AND THE IMPACT OF AIDS

The lament from the beginning of this article (“Don’t get old, it’s terrible!”) usually refers most immediately to the physical aches, pains and decreases in functioning that are brought on by chronic conditions associated with aging: heart disease, arthritis, emphysema, diabetes, glaucoma, and hearing loss, to name but a few of the many things that also lead some SAGE clients to lament, “I never thought would happen to me.” On a deep level, these admonitions against aging refer to physical and emotional losses that declines in health bring on. These losses include those of freedom and autonomy that these individuals had previously enjoyed, as well as the social roles that gave them purpose and direction. In a very real and frightening sense, the aging processes of these men become, in their own minds and in the minds of a terrified ageist society at large, fused and thus confused with disease. Their sense of themselves as they once were is shattered. In addition to personal declines in functioning, the lament includes absences of friends, partners, parents, and siblings—those anchors of their social and historical context—lost through estrangement, relocation, their own ill health, or death.

Interestingly, all this begins to sound like what young gay men experienced at the height of the AIDS epidemic before the advent of combination therapy in the mid-nineties: the sense of incredulity, the suffering and loss, and the identification with disease. There is an important difference, however, between what those men went through and what gay men aging with chronic illnesses experience. That difference is the tremendous amount of support that gay men living with AIDS received from the gay community, fueled by a collective anger at the injustice being done them, as opposed to the indifference that ill and aging gay men have almost always encountered from the very same community. Ironically, many of the men who are now experiencing this indifference were at the forefront of the fight against AIDS. Many of these men lost whole friendship networks to that disease. A number of them are themselves

living with HIV. Now that the ardor of AIDS activism in the community has cooled, they are left to wonder how they survived and why. Older gay men living with HIV may be particularly affected by this dynamic. Harley, a 63-year-old gay man living with the virus put it this way:

I have had long relationships, 20 years or more, with men who were dying, and you never shake that. It never leaves you . . . I still remember them. I know the month they died. It's this terrible loneliness from all the people you knew that are gone, and watching people around you . . . die. And then you get this feeling of guilt, of why am I still here? (*Newsline*, 1996, p. 12)

Surprisingly, my experience with SAGE clients suggests that there is little bitterness expressed about the indifference of gay communities to them. The sentiment is more of resignation. Perhaps the loss of so many peers, a tremendous portion of a whole generation, and the ensuing survivor guilt lowers expectations. Internalized ageism may also be a factor. Several men have remarked that they never wanted to be around old gay men when they were young, so why should they expect younger gay men to feel differently now. The crisis competence referred to earlier may be another factor at work here. The image comes to mind, particularly in regard to older men living with HIV, of a group huddled bravely and stoically on an ice floe that is disappearing out to sea.

DOUBLE INVISIBILITY

When introduced to the services of SAGE, non-gay social service professionals as well as lay people often will want to know what distinguishes the needs of aging gays from those of the old in general. Why is SAGE a necessary organization? While this inquiry is usually prompted by genuine interest, the very asking of the question reveals the heterosexist assumptions that inform such inquiry. In fact, there is general agreement that most aging adults, gay or straight, face the same major concerns, and they mostly involve loss. These concerns are, as Quam and Whitford (1992) put it, "loneliness, health, and income" (p. 373). Underlying these common concerns is the stigma attached to aging. Just as a heterosexist society discriminates against gay people, so an ageist society discriminates against old people (Cahill et al., 2000). Witness the lack of positive terms for old people in our language and the plethora of derogatory ones: "geezer," "fogey," "dirty old man," "old fart," etc. (Genke, 2000; Engle, 1998). Expressions such as "You don't look your

age” and the reluctance to talk about age in general reinforce this devalued status, as does the enduring cultural obsession with procedures that inhibit looking old, such as plastic surgery, botox injections, and “anti-ageing” unguents. Systemically across the culture, the old are devalued, excluded and discriminated against. And this is perhaps even more the case for the older gay man residing in the youth-obsessed gay subculture (Cahill et al., 2000). As with homophobia, even for the most “self-actualized” gay men, the negative messages of ageism are unavoidably internalized not only by the young, but also by the old.

MARGINALIZATION

In her book *Justice and the Politics of Difference*, Young (1990) identifies what she labels “Five Faces of Oppression.” One of those faces she terms “marginalization.” Among those who experience this face of oppression are the old. Young describes marginalization as “perhaps the most dangerous [face of oppression because] a whole category of people is expelled from useful participation in social life [and thus faces] potential extermination” (p. 53) (at least, the author would add, in a metaphorical sense). “Uselessness, boredom, and lack of self-respect” (p. 55) constitute the internalized feelings Young identifies as being induced by this form of oppression. When the old speak of feeling “invisible,” it is this sense of marginalization, of metaphorical extermination, that they are describing. When old gay people speak of feeling “invisible,” their sense of marginalization reawakens and reinforces existing stigma from an early age when they first identified and/or were identified with homosexuality. Moreover, ageism denies, or at least conceals, the sexuality of the old (Genke, 2000; Huff, 1998). Thus, older gay men are not only rendered invisible because they are old, but also because as desexualized older people, their sexual orientation loses meaning within ageist culture.

AGEIST OPPRESSION WITHIN GAY COMMUNITIES

Sadly, this invisibility holds true, perhaps especially, in gay communities, where ageism may be even more pronounced. Cahill et al. (2000) cite “beauty standards that privilege youth” (p.18), whose sense of meaning and value is inextricably linked to “physical attractiveness and desirability” (p.18), as an obvious manifestation of this phenomenon. Berger (1982) notes young gay men who worry that they are “over the

hill” as early as age thirty. Cahill et al. (2000) go on to describe other more subtle manifestations of ageism in the gay community (and hence, perhaps more damaging to the self-concept of older gays). They point out that community discussions exclude old people and that senior issues are conspicuously absent from the mainstream LGBT political agenda. Furthermore, they assert that the ageism in the gay community is structural: gay organizations and institutions are age-segregated, outreach to the old is nonexistent (e.g., the lack of senior discounts to gay events), and the achievements of gay elders are rarely honored. With the exception of LGBT religious communities, few gay organizations are intentionally intergenerational.

It should be noted here that in the same way old people may collude in their own invisibility via their internalized ageism, old gay people may collude in their double invisibility via their internalized homophobia and ageism; this will hold true even if they have been relatively out in their younger years. Those who work with older gay men posit that old gay men tend to retreat back into the closet when they need to access mainstream service providers (Altman, 1999). The same retreat often occurs when they come in contact with heterosexual old people in senior centers and the like. In these settings, internalized homophobia is linked to an expectation of prejudice, since homophobia is generally more prevalent among older generations in this country, who have internalized the same homophobic messages as their peers, than it is in the population as a whole (Cahill et al., 2000).

CULTURAL IMPERIALISM

Young (1990) includes what she labels “cultural imperialism” among the Five Faces of Oppression discussed earlier (p. 58). The heterosexist culture which gives rise to homophobia is a vivid example of this phenomenon. In cultural imperialism, the dominant cultural group (e.g., heterosexuals) imposes on the oppressed group (e.g., gays) its experience and interpretation of social life while rendering the oppressed group’s particular perspective invisible and at the same time stereotyping that group and marking it out as the Other.

Those living under cultural imperialism find themselves defined from the outside, positioned, placed, by a network of dominant meanings they experience as arising from elsewhere, from those with whom they do not identify and who do not identify with them. (Young, p. 59)

Young (1990) invokes the words of W.E.B. Du Bois to describe the “double consciousness” that results from this imperialism. Even as the oppressed group is being negatively stereotyped by the dominant culture and is itself internalizing those negative images, it is also creating and sustaining its own affirmative culture that allows its members to develop a sense of positive identity. One example of this double consciousness is manifested in the phenomenon of “camp,” with which much of older gay culture is imbued. As Clark (1987) suggests, by enacting the effeminate stereotype, gay men appear to appease the dominant group even while enjoying among themselves the knowledge that they are “flaunt[ing] the lie of the stereotype in the face of the bigot” (p. 99).

Moreover, the cultural imperialism imposed on gay men by a heterosexist society seems to parallel that which an ageist gay community imposes upon its senior members. Within gay cultures, young gay men may be seen as comprising a dominant group who oppress, both actively and by unconscious omission, old gay men. This situation implies multiple layers of invisibility for old gay men: first as old within the larger society, second as old and gay within the larger society, third as gay within the aging community, and fourth as old within the gay community. If you add to the mix such factors as ethnicity, socioeconomic class, geographical situation, and chronic health concerns, then untangling the web of invisibility and shedding light on the experience and needs of this population confronts service providers with significant challenges.

INTERVENTION STRATEGIES: ONE AGENCY’S RESPONSE

SAGE’s mission is to provide a place where old LGBT people can feel supported, embraced and celebrated (Altman, 1999). Establishing, reestablishing, or maintaining a connection to the LGBT community by creating a sense of a surrogate family is a vital component of this mission. Depending upon the needs and circumstances of a particular client, interventions to achieve this goal can take various forms. For those gay men who have struggled most of their lives with unresolved issues around sexual identity, calling upon SAGE is often their first contact with a gay-identified organization, so that for SAGE to simply exist and be available is already a form of intervention. For most men, direct contact with SAGE results from a personal crisis, often health related: the need for home care, bereavement counseling, or access to entitlements.

Frequently, contact also is initiated by informed service providers who refer their clients to the agency. Other times, friends and even family members will do the contacting.

In addition to gay affirmative case management and clinical services, SAGE offers a wide range of socialization opportunities, including group activities, socials, activism, and volunteer options. Unlike SAGE social services, which are limited to people age 60 and above, socialization opportunities welcome adults of all ages, opening the door to potential intergenerational interaction. Empirical data has shown that integration into the gay community through active participation in social activities leads to greater life satisfaction for gay people. Individuals become more self-accepting, less depressed, and less fearful of aging (Quam & Whitford, 1992; Berger, 1982). As Vaillant (in Lambert, 2001) describes in *Aging Well*, his account of Harvard University's landmark longitudinal study on adult development, "Feeling safe, secure, and 'held' allows us to use more mature defenses" (p. 99). This would appear to hold true even for gay men of advanced age with little previous connection to the community.

Friendly visiting is one of the most significant interventions that SAGE provides. Volunteers are matched, according to interests and compatibility, with homebound or semi-homebound clients who lack social supports such as family or available friends. These volunteers agree to visit their "friends-at-home" weekly for an hour or two as well as to check in weekly by phone. If the client is ambulatory, the visitor can go out with him to eat, see a movie, attend a SAGE event, or just sit in the park and talk. Each summer, SAGE sponsors a picnic where friends and their visitors can meet and celebrate together. Often, if he is truly homebound, this is the only time the friend-at-home has the opportunity to attend an outside event. SAGE provides the transportation, and the staff and members of the board host the event along with the volunteers.

One of the important benefits of the friendly visitor program is the opportunity it provides for intergenerational contact and the resultant generativity that often ensues. The visitors are usually a generation or two removed from the friend they visit. They speak of how they are changed and affected by the work they do. Old, homebound gay men are presented with an opportunity to find meaning and purpose in this stage of life, and younger volunteers become the bearers of gay history in the same way families of origin carry their members' stories forward.

For those with more specific, concrete service needs, SAGE's Lend-A-Hand program provides volunteers on an ad hoc basis to help clients

with more practical matters. This may include escorting someone to a medical appointment, shopping, delivering a package, putting up a shelf, or installing a computer program, the kinds of things that family members or friends might do for their older relatives.

CASE EXAMPLE

Val was a closeted, 82-year-old gay man when he contacted SAGE. He was referred to SAGE by his psychotherapist, who had recommended increased socialization. Val was likable but rather reserved. He had resided in his spartan, meticulously neat walk-up apartment in the far reaches of one of the boroughs of New York City for more than forty years. Before retirement, he had done white collar work for an institution in Manhattan and was financially comfortable. Since the death of his beloved sister, he was estranged from his other siblings and their families and had been living an increasingly lonely and isolated existence. It was clear that his poor self-image contributed to this estrangement. He was easily hurt and built up strong and bitter resentments against his family for what he perceived as slights and neglect. Though he had never married a woman to “pass,” as many gay men of his generation had done, he had also never come out to his family or work associates. His gay contacts were limited to anonymous sexual encounters in men’s rooms and bars.

He was receptive to a home visit by the SAGE worker, and quickly agreed to accept a friendly visitor on a trial basis. Fortunately, there was a volunteer in Val’s neighborhood, a stroke of unusual luck for this remote location. The visitor was a warm and intelligent retired professional in his early sixties who provided the first open relationship Val had ever experienced with another gay man. Eventually, as their relationship grew, Val dared to venture to a few SAGE events at the LGBT Community Center in Manhattan. This was an act of courage for someone so closeted and an indication of the possibility of growth and change even in old age. That Val had sought out psychotherapy as this late stage in his life, even before contacting SAGE, also testifies to his resilience.

It became apparent to the worker during a reassessment visit a few months later that Val could use some home care services. His heart was deteriorating and a pacemaker had been installed.

He had blacked out and fallen several times. He was having increasing difficulty negotiating the stairs to his apartment. Shopping in his neighborhood was several blocks away. However, admitting that he was proud and stubborn, he refused all suggestions of home care.

When he left a message some time later with his SAGE social worker suggesting it was time to “consider” home care, it was clear to his provider that things had taken a serious turn. Unable to reach him, the social worker learned, with the help of the friendly visitor, that Val had been admitted to the hospital. He was clearly delusional. He told the social worker during a hospital visit that he had returned home briefly a couple of days before (which was impossible, given his physical condition), where he had discovered his apartment robbed and ransacked. Returning to the hospital, he said he found a note on his pillow telling him to leave, that “his kind” weren’t wanted there. He heard a voice whispering to him, “We know you’re gay!” The social worker was able to help Val acknowledge that most likely he had imagined these experiences, and that he was very scared. During this visit, he gave the social worker permission to reveal to the hospital personnel his relationship to SAGE. (Many SAGE clients do not want to be associated with a gay agency, so SAGE has an alternate name—which the worker had been using—to assure confidentiality.) To the SAGE worker, this represented a courageous act of coming out.

Val died a few days later. It would appear that the “holding” presence of a gay-identified social service agency in the person of a trusted social worker and a supportive gay volunteer had a lot to do with Val’s self-disclosure in the hospital. Certainly the quality of his last few years of life improved by the connection to the gay community, limited as it was, that SAGE provided him.

According to Friend’s (1991) model of sexual identity formation among older gay people referred to earlier in this article, Val would fall into the lower end of the category of “passing.” Though he did not marry, he lived a double life. He did not come out to friends or family; he limited his sexual life to anonymous secret encounters; and did not want the SAGE worker to reveal his association with him to other providers. His paranoid delusions in the hospital, while indeterminate in terms of a cause, vividly convey the strong hold that internalized homophobia had on Val.

While most of the clients at SAGE fall into this intermediate category of “passing” on the continuum of disclosure of sexual orientation, this does not mean that these men are without self-acceptance or gay affirmative sentiments. How one integrates a gay identity and manages disclosure is a complex, nonlinear, fluid process. Note that Val sought out psychotherapy at an advanced age and opened his door to SAGE services, hardly a template of despair. For many pre-Stonewall gay men, “passing” was a necessary and positive approach to managing stigma (Adelman, 1991). To be out unconditionally was not safe. The social message was clear: Sex between men was a criminal act; it was, according to mental health professionals, both abnormal and perverse; and mainstream religion saw it as sinful and worthy of hellfire (Altman, 1999; Kochman, 1997). Therefore, creating their own ways of living within safe limits, either as single gay men or as gay men in relationships, was a means of self-preservation. As Adelman (1991) puts it: “. . . the closets of the pre-Stonewall era provided comfort in a hostile environment by allowing one to have a positive image” (p. 30).

The legacy of passing can manifest in complex ways among aging gay men. For example, one of the major obstacles the author faces in working with aging gay men with chronic health conditions is their refusal to accept needed home care. Because old gay people like Val are more likely to live alone and have no informal caregiver to turn to (Cahill et al., 2000), this poses a real danger of self-neglect. In fact, a disproportionate number of neglect cases are composed of old gay people (Cook-Daniels, 2001). The self-reliance which had served gay men like Val well in the past as a survival mechanism becomes in the present a double-edged sword; It is both a strength and an obstacle to receiving necessary assistance.

Objections to accepting care can range from not being able to afford it, as in the cases of those ineligible for insurance benefits or entitlements, or in cases of those like Val who can afford it, to denial of need. Underlying these objections are the aforementioned value of self-reliance along with the not unfounded fear of discrimination. There are no home care agencies in New York City dedicated to caring for old gay people, and few provide LGBT sensitivity training to their workers (Altman, 1999). Consequently, when homecare is accessed, although the client’s health status and functioning may improve, the quality of that client’s life often deteriorates. One of the reasons for this is a feeling of being held prisoner in one’s own home by once again having to pass as straight. We find that gay couples often tell health care providers that their partner is

their “cousin” or “stepbrother.” In this way, the absence of gay affirmative care reinforces internalized homophobia and impairs psychosocial health.

CONCLUSION

As they age, most people develop chronic health conditions of some kind. Some of these conditions can be relatively benign and easily manageable, while others are severe and traumatic. People living with chronic illnesses may become more dependent on health care, government and social service institutions. They need more medical attention; they are hospitalized; they go to rehabilitation in skilled nursing facilities; they need home care; and they may need to apply for housing and/or health care benefits. For aging gay men, these institutions still symbolize the cultural imperialism of the heterosexist establishment. Accessing services can feel threatening and reawaken fears of discrimination experienced earlier in their lives. If older gay men have not successfully come to terms with their sexual identities, then they may avoid seeking the care that they need and fall into self-neglect and isolation, exacerbated by their identification with the ageist attitudes that society imposes.

Even as social service providers advocate for and with this population to access appropriate assistance and support, it is important to keep in mind the often discounted courage and resilience older gay men have shown all their lives in the face of institutionalized homophobia. It is equally important to notice these same strengths as older gay men cope, again in often not-so-apparent ways, with institutionalized ageism. Without this awareness, workers can lose sight of the full humanity of their clients, whose quality of life and self-determinism may then be jeopardized.

For their physical, mental and spiritual health, gay men aging with chronic health issues need to be helped to connect physically and emotionally to the gay community. SAGE has been engaged in just such work for 25 years, but it is able to serve only a fraction of the aging gay population. There appear to be no other organizations offering the range of social services, socialization opportunities, education and advocacy that SAGE provides. Moreover, SAGE’s expertise has been gained serving a predominantly white, urban, middle-class population, and most of the empirical research in gay gerontology, scant as it is, has

been done on this same cohort. SAGE has just begun the work of building a relationship with communities of color. While this holds enormous promise, the lack of culturally competent research in this domain presents SAGE, and indeed the entire LGBT community, with enormous challenges which must be met if social justice is to be served.

As baby boomers age, the need to address the health care and well-being of older gay men is being felt all over the country and all over the world. Their numbers and needs will only increase in the coming decades. While needs will change along with the socio-historic perspectives of clients, ageism and homophobia, it seems, will remain as formidable obstacles for the foreseeable future. Thus, if gay men are to have the rich old age they deserve, they will require services that will help them to feel “safe, secure, and ‘held’ ” (Lambert, 2001, p. 99) and to live meaningfully and productively. These services need to be developed from and supported by cogent empirical research. Such research will have enormous ramifications on the whole field of gerontology as the unique coping styles and strategies of a long-ignored population are identified and explored for the greater good of all old people now and in years to come.

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