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Is AIDS chronic or terminal? The perceptions of persons living with AIDS and their informal support partners

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Abstract

Viewed as a terminal disease just a decade ago, HIV/AIDS is now often characterized as a chronic yet manageable disease. The goal of this study is to assess the perceptions of the course of the disease among persons living with AIDS and their informal support partners and to identify the themes that distinguish the differing perceptions of the epidemic. The findings from this research reveal that 41% of persons living with AIDS and 39% of their informal support partners perceive AIDS as chronic. By contrast, 37% of persons living with AIDS and 39% of the informal support partners perceive AIDS to be terminal rather than chronic. Among persons living with HIV/AIDS, those with lower levels of education and higher levels of perceived race-based discrimination were significantly more likely to view AIDS as a terminal rather than chronic condition. In addition, informal support partners in poor health were significantly more likely than others to view AIDS as terminal rather than chronic. Content analyses of the qualitative data revealed five broad themes related to the specific perceptions of AIDS, including medications, personal experience, cure, time/eventuality and education. The implications of these findings are discussed.

Introduction

The HIV/AIDS pandemic continues to evolve as a major public health issue with more than one million Americans currently living with HIV/AIDS (Glynn & Rhodes, 2005). According to the Centers for Disease Control and Prevention (CDC), the incidence of new HIV infections is relatively stable at about 40,000 annually, with a concurrent mortality rate of approximately 18,000 (CDC, 2005).

HIV continues to be spread primarily through sexual contact and men who have sex with men (MSM) account for nearly two-thirds of the cases (CDC, 2005). While MSM continue to account for the largest percentage of HIV/AIDS cases in terms of both prevalence and incidence, evidence indicates that this trend is shifting. Rates of new infections and newly diagnosed cases are increasing at an alarming rate among intravenous drug users, heterosexuals, women and people of colour (CDC, 2005; Karon et al., 2001). In 2003, for example, new HIV/AIDS diagnoses in communities of colour were twice that of whites; while African Americans constituted only about 12% of the total US population, they accounted for half of all newly diagnosed cases of HIV/AIDS (CDC, 2005).

From its emergence into the US public's consciousness in the early 1980s through the mid-1990s, AIDS was primarily viewed as a terminal disease, striking gay and bisexual men in the prime of their lives (CDC, 2002). Despite the initial short-term successes of nucleoside reverse transcriptase inhibitors (NRTIs) such as AZT and 3TC, the general prognosis from initial infection with HIV, through a subsequent period of viral latency to the ultimate development of full-blown AIDS and death, was an average of 8–11 years (Thornton et al., 2000; Troop et al., 1997).

In the mid-1990s the landscape of AIDS began to change rapidly. Two new classes of potent anti-HIV medications provided important new treatment options beginning in late 1995 and continuing through mid 1997 (Rabkin & Chesney, 1999). Protease inhibitors (PIs) were quickly followed by non-nucleoside reverse transcriptase inhibitors (NNRTIs) and when mixed with the previous generation of NRTIs, these cocktails were able to more effectively inhibit viral replication in the majority of persons living with HIV/AIDS (Rabkin & Chesney, 1999). These powerful combinations, collectively known as Highly Active Anti-Retroviral Therapy (HAART) came into widespread use in

the US in 1996 (CDC, 2002). Around the same time, in the late 1990s, a small number of people became identified as 'long-term non-progressors'; they either progressed very slowly or not at all to full-blown AIDS (Barroso, 1997; Cruess et al., 2003; Folkman et al., 1996; Ironson et al., 2002; O'Cleirigh et al., 2003; Thornton et al., 2000; Troop et al., 1997).

While deaths resulting from HIV/AIDS are still occurring, the AIDS mortality rate has plunged dramatically. AIDS mortality rates peaked in 1993, with about 80,000 Americans dying annually from AIDS (Baer & Roberts, 2002; CDC, 2002; Gallagher, 1997; Ostrow et al., 2002; Pequegnat & Stover, 1999). From 1999 through 2003, the annual US mortality rate from AIDS hovered at approximately 18,000 per year, roughly one-third of its 1995 levels (Glynn & Rhodes, 2005).

HIV/AIDS is by definition a disease fraught with ambiguity and uncertainty. According to the US National Library of Medicine and the National Institutes of Health, 'terminal' is an adjective used to describe that which is near, close to or in the final phase of reaching death. 'chronic', on the other hand, is used to describe ailments or diseases that have as their hallmark, presence over a long period of time and often, though not necessarily, of progressive severity (Medline Plus, 2006).

An epidemic that was initially described as terminal is now often characterised as a chronic yet manageable disease. Recent articles in professional peer reviewed journals include such statements as the following: 'The estimated 42 million people worldwide who are infected with HIV are living with a chronic disease ...' (Chesney et al., 2003, p. 1038); 'Human immunodeficiency virus infection is now commonly viewed as a chronic illness ...' (Cruess et al., 2003, p. 52); and, '... the advent of new treatments ... has helped transform HIV/AIDS from a quick fatal disease to a more chronic, albeit incurable, disease' (Demmer 2000, p. 12). Mainstream media also routinely characterizes HIV/AIDS as a chronic yet manageable condition. For example, recent quotes in major newspaper publications include: 'The drugs delay the progression of HIV, the virus that causes AIDS, turning the disease into more of a chronic condition' (Guthrie 2005, p. B1); and, 'In recent years, new therapies have turned HIV/AIDS into a chronic disease rather than a fatal illness' (Peterson 2005, p. H1).

While HIV/AIDS is now routinely characterized as a chronic disease, our understanding of the perceptions of the course of the disease among persons living with AIDS and their informal support partners is limited. Yet, their perceptions of the course of the disease may have important implications for HIV/AIDS treatment and prevention. To begin to address

this gap in our knowledge, this exploratory study examines the following research questions: (1) Do persons living with AIDS and their informal support partners perceive the course of AIDS to be a chronic or terminal condition? (2) Among persons living with AIDS and their informal support partners what background characteristics and experiences (e.g. age, race/ethnicity, income, education, discrimination and social support) are associated with the perception of the disease as chronic or terminal? and (3) What themes distinguish the perceptions of the epidemic as chronic or terminal among persons living with AIDS and their informal support partners?

Methods

Sample

The sample for this study consists of 154 dyads comprised of a person living with AIDS and a primary informal care partner, both 18 years of age or older. Each person living with AIDS self-identified as a gay male with an AIDS diagnosis. Documentation of the AIDS diagnosis per 1993 CDC guidelines was provided by each participant. Persons living with AIDS were excluded from the study if they were severely cognitively impaired. The informal support partner was defined as a partner or other family member, friend or neighbour who provided unpaid assistance, such as personal care, providing or arranging housekeeping or transportation, assisting with financial matters or providing emotional support. Informal support persons were not acting in a paid capacity or assisting the person with AIDS through a volunteer organization.

Potential participants for the study were recruited through announcements placed in community health centres and clinics, local churches, support groups and other community groups. In addition, the study was advertised in local newspapers and newsletters. Face-to-face interviews were conducted by graduate students in the social and behavioral sciences with experience working with HIV/AIDS populations. The interviews lasted 60–90 minutes and the persons living with AIDS and the informal support partners were interviewed in separate rooms but simultaneously to insure that members of the dyad did not influence each other's responses. The interviews were conducted at a time and location chosen by the person living with AIDS and the informal support partner, provided that privacy could be insured. Data were collected on standardized forms as well as through notes on the interview protocol. Each person living with AIDS and their informal support partner received a

US\$20 honorarium for participating in the interview. Confidentiality and human subject protections were maintained throughout all phases of data gathering and analysis.

Eighty-three percent of the participants living with AIDS were between the ages of 30 and 49 years, 7% were 19–29 years old and 8% were 50 years or older. Sixty-three percent were white, 15% African American, 7% Hispanic, 3% American or Alaskan Native, 1% Asian or Pacific Islander and 13% were mixed or other race/ethnicity. Twenty-six percent of persons living with AIDS had obtained a college or advanced degree and 48% had attended some college. In addition, approximately 15% had completed high school or its equivalent and slightly less than 10% had not completed high school or its equivalent. Nearly 90% of persons living with AIDS reported annual incomes of less than \$20,000; the remaining 10% reported annual incomes between \$20,000 and \$39,999. Slightly over half (54%) were single and 46% were partnered. In terms of health status, 6% of the persons living with AIDS reported their health to be poor, 42% fair, 33% good and 19% very good or excellent. Slightly more than 80% were taking antiretroviral (ART) medications at the time of the interview.

Three-quarters of the informal support partners were between the ages of 30 and 49, 6% were 19–29 years old and 20% were 50 years or older. Approximately 70% were white, 9% were African American, 7% Hispanic, 5% Asian or Pacific Islander and 10% were other or mixed race/ethnicity. Four-fifths of the informal support partners were male. Thirty-three percent had a bachelor's or advanced degree, 45% had attended some college, 19% had completed high school or its equivalent and 3% had not completed high school. More than half (56%) had an annual income of less than \$20,000. Seven percent had incomes over \$60,000 per year. Approximately 15% of the informal support partners rated their general health as excellent, 69% as very good or good, 13% as fair and just over 3% indicated that their health was poor. One half of informal support partners were HIV-negative, 43% were HIV-positive and the remaining 7% did not know their HIV status. Of those living with HIV, slightly more than three-quarters were on ART regimens.

Measures

The following variables were assessed in this study for both the persons living with AIDS and their informal support partners: age, race/ethnicity, education, income, health status, current HIV/AIDS medications, discrimination, social support and their perceptions of AIDS as a terminal or chronic health condition.

Sociodemographic variables were measured in standard format. Health status was measured by the Physical Self Maintenance Scale (PSMS) and the Instrumental Activities of Daily Living Scale (IADL). In terms of validity, both the PSMS and IADL scales have been found to be highly correlated with other measures of functional and instrumental health and behavioral and adjustment ratings (Lawton & Brody, 1969). Participants were also asked to indicate whether they were currently taking HIV/AIDS medications.

Based on questions from the National Work Study questionnaire, discrimination was measured by asking participants two questions: 'How often do you feel you are discriminated against on the basis of HIV or AIDS?' and 'How often do you feel you are discriminated against on the basis of race or ethnicity?' Responses were recorded on four-point Likert scales ranging from 1 = 'rarely or none of the time' to 4 = 'most or all of the time'.

Extent of social support was measured through seven items regarding the perceived availability of someone if the respondent was upset and wanted to talk, had an important personal problem, needed care if confined to a bed, needed to borrow money or get a lift to the doctor, needed guidance or needed advice in making a decision (Cronbach's alpha reliability coefficient = 0.85) (O'Brien et al., 1993).

The participants' perceptions of AIDS were assessed through a two-part question: 'Do you consider AIDS to be a chronic illness, a terminal illness or don't know?' Each participant was then asked, 'Could you please explain your answer?'

Data analyses

Distributions on all variables were examined to identify statistical outliers and to inform scaling decisions and the choice of analytic techniques. Proportions, means and standard deviations were computed for each variable. Most of the measures that were used had been developed and examined psychometrically in other studies and unless otherwise noted, the scales were created as indicated by the original work as described in the measures section. Distributions of these scale scores were examined and measures of internal consistency for each scale, using Cronbach's alpha, were computed. Next, categorical items (e.g. ethnicity, perception of AIDS) were examined for goodness of fit and/or tested for independence. Interval level items (e.g. age and income) were analyzed via independent samples *t*-tests.

The qualitative data were analyzed to identify manifest categories as well as latent content. Through several iterations of reading through the

Table I. Results of content analyses of perceptions of AIDS: Persons living with AIDS.

Category	Perception of AIDS				
	Total responses (%)	Chronic (%)	Terminal (%)	Don't know (%)	Both (%)
Medications	33	58	29	11	1.9
Personal experience	24	54	40	23	8
Cure	13	10	5	85	0
Time/eventuality	12	5	89	0	5
Education	4	43	43	14	0

Note: Because many responses fit into more than one category, overall response rates may not equal 100%.

qualitative data, responses were first content-analyzed to identify categories of responses. For example, if medication was used in a response, that response was placed in a 'medication' category, without initially being linked to the respondent's perception of AIDS as a chronic or terminal disease. Frequency rates were then recorded. Once manifest categories emerged, meaning units were discerned using the phenomenological method as developed by Giorgi (1985). In this method, the manifest objective reality is identified and the subjective meaning of an experience is allowed to emerge by surfacing the latent content through narrative analysis. Within identified categories there was variation in phenomenological perceptions and many participants cited multiple reasons why a particular perception was held; thus each reason was counted and the total response rate was potentially greater than the number of participants.

Results

Perception of AIDS

Persons living with AIDS were nearly evenly split in their views as to whether they perceived AIDS as chronic (41%) or terminal (37%). Another 17% indicated that they did not know whether they viewed AIDS as chronic or terminal, while approximately 5% indicated that it was both. Background characteristics and experiences among persons living with AIDS that were significantly associated with the

differing perceptions of AIDS included education and race-based discrimination. Those with more education were significantly more likely to report that they saw AIDS as chronic ($t(121) = 2.66; p = 0.009$), while those that reported experiencing discrimination on the basis of race/ethnicity were significantly more likely to view AIDS as terminal ($t(122) = -2.19; p = 0.03$).

Among informal support partners, 39% indicated that they felt AIDS was chronic, 35% terminal, 18% were unsure and 8% felt it was both chronic and terminal. When comparing informal support partners' background characteristics and experiences, physical health status was statistically significant in terms of their perceptions of AIDS. Support partners who were in poor health ($t(112) = -2.12; p = 0.036$) were significantly more likely to perceive AIDS as terminal rather than chronic.

Emergent themes in the perception of AIDS

Content analyses of the qualitative data revealed five broad themes related to the perceptions of the course of HIV/AIDS as chronic or terminal for both the persons living with AIDS and their informal support partners. The five themes were as follows: medications, personal experience, cure for AIDS, time/eventuality and education. Results of the content analyses for persons living with AIDS and their informal support partners are displayed in Table I and Table II, respectively.

Table II. Results of content analyses of perceptions of AIDS: Informal support partners.

Category	Perception of AIDS				
	Total responses (%)	Chronic (%)	Terminal (%)	Don't know (%)	Both (%)
Medications	38	55	28	16	2
Personal experience	27	62	40	33	10
Cure	18	21	50	21	7
Time/eventuality	18	14	50	25	11
Education	12	14	57	29	0

Note: Because many responses fit into more than one category, overall response rates may not equal 100%.

Medications

Both persons living with AIDS and their informal support partners cited ‘medications’ most often as the reason they perceive AIDS as either chronic or terminal. Among the 33% of persons living with AIDS that cited medication, 58% perceived AIDS as a chronic condition, 29% perceived AIDS as terminal, 11% were unsure and 2% viewed it as both chronic and terminal. Among the 38% of informal support partners who cited medications, 55% viewed AIDS as chronic, 28% as terminal, 16% were unsure and 2% as both chronic and terminal.

As one person living with AIDS explained, ‘I believe it is an illness that has just moved into a chronic state because of the [new] medications.’ Similarly, an informal support partner shared, ‘In the past, it [AIDS] was terminal but with medicines now it’s chronic...’ Interestingly, however, the toxicity, side-effects and cost of medications also impact perceptions of AIDS as terminal. One person living with AIDS explained, ‘If HIV doesn’t kill me, complications from the meds will.’ Another person living with AIDS shared, ‘The pills are killing you. They constantly deteriorate you over time... they have new medications that work for a while but quit working. I’m on my fourth combination.’ Another person living with AIDS shared, ‘Until meds more affordable, it’s terminal; meds are expensive.’

One support partner who was unsure if AIDS was chronic or terminal stated, ‘The new meds, if they work, will help it be chronic instead of terminal.’ The support partner went on to explain that in many cases the medications are not effective and AIDS is terminal. Other comments were also illustrative of the ambiguity that many felt in terms of the potential impact of medications on the course of HIV/AIDS. For example, one support partner who felt AIDS was both chronic and terminal explained, ‘We don’t know that today’s medications may work or that they may not cause more serious problems.’

Personal experience

Belief in the chronicity or terminality of AIDS was often predicated on personal experience, either through one’s own illness, personal behaviors or attitudes or through caring for someone with HIV/AIDS. Among persons living with AIDS who drew upon personal experiences, 54% viewed AIDS as chronic and 40% as terminal. Twenty-three percent of the respondents who cited personal experiences as impacting their perception of AIDS were not sure if they considered it chronic or terminal and 4%

perceived it as both chronic and terminal. Among the 27% of informal support partners who cited personal experience, 62% viewed AIDS as chronic, 40% as terminal, 33% didn’t know and 10% viewed it as both terminal and chronic.

One person living with AIDS who perceived AIDS as chronic stated that, ‘If it were terminal, I’d be dead. I think I was infected in 1984... do the math.’ As another person living with AIDS shared, ‘[I] used to think of it as terminal, almost died, then “came back”—proof that it is chronic.’ One person living with AIDS stated he believes that AIDS is chronic, with one caveat: ‘... depends on where you live—support and services are limited where my parents live in Kansas.’

Another person living with AIDS shared, ‘For some people it is terminal because they don’t take care of themselves, they engage in the same behavior they engaged in when they were HIV-negative.’ Personal attitudes were also held to be responsible for the course of AIDS as chronic or terminal, as is evident in the words of one person living with AIDS, ‘Depends on the person’s mindset. Get HIV, get sick, die. Others, fighters—chronic.’

An informal support partner stated that a ‘cousin’s ex-husband was diagnosed with HIV [about] ten years ago and is still alive.’ Another support partner echoed this thought, ‘... not terminal anymore if you take care of yourself.’ By contrast, several informal support partners viewed AIDS as terminal based on personal experience, as exemplified by the following response. ‘I lost a son—it’s terminal.’ Another informal support partner shared, ‘Anyone infected with HIV I knew is dead.’

Several persons living with AIDS and their informal support partners indicated personal experience was why they believed AIDS to be both chronic and terminal. For example, a person living with AIDS shared, ‘My experience has shown me that it’s chronic but I’ve never seen anyone cured. Everyone I know that has had it is either chronically dealing with it or is dead.’ Likewise, one informal support partner stated, ‘[I] know a lot of people who died from it. Don’t believe it is always terminal.’ Another informal support partner who was unsure if AIDS was chronic or terminal explained, ‘I had a family friend who married a guy who had AIDS and she died really quick—he’s still alive.’

Cure

Among persons living with AIDS, 13% stated ‘a cure for AIDS’ impacted their perceptions of whether AIDS was terminal or chronic. Among those that cited ‘cure’ as influencing their perceptions, 10%

hoped for a cure and indicated that AIDS was chronic, 5% indicated that there was no cure and AIDS was terminal and, interestingly, 85% of those that raised the issue of cure were unsure if AIDS was chronic or terminal.

Eighteen percent of the informal support partners cited 'cure' as affecting their perceptions of AIDS. Among the informal support partners, half reported that no cure existed and thus they viewed AIDS as terminal, 21% indicated they were hopeful that a cure would be found, which supported their perception of AIDS as chronic, 21% citing a potential cure were unsure if AIDS was chronic or terminal and 7% viewed AIDS as both chronic and terminal.

Several respondents cited the lack of a cure for AIDS as a reason why they perceived AIDS as a terminal disease. More than one respondent simply stated they believed AIDS was terminal because, 'There is no cure'. Another person living with AIDS indicated that he felt AIDS was terminal because, 'They haven't found a cure and no one is looking for a cure'. At other times their perceptions were implied; one man living with AIDS asked, 'Can you name any person that has been cured?' One informal support partner stated, 'There's no cure, people will die from it.' Another shared, 'We don't have a cure; the "cures" we've gotten are worse than the disease.'

Several respondents who felt AIDS was chronic indicated that they held hope for a cure. As one informal support partner shared, 'I do believe that we will find a cure for it'. A person living with AIDS also said, 'I think that there will be a cure, and it is probably in a flower in Hawaii.' The ambiguity of living with AIDS is also seen in responses where respondents were unsure of how they viewed AIDS, specifically in terms of a cure. A person living with AIDS said, 'I used to think you got it [AIDS] and died—but now I don't know—I may be around for the cure if they find one.' Some informal support partners held similar views as exemplified by this response: 'I would like to think they would find a cure and I'll be around when that happens.'

Time/eventuality

Time and eventuality has as a central feature of living or dying in relation to time—the present contextualised in terms of the past and the future. More specifically, there was a thematic sense of an inevitable, inescapable reality and the eventuality of an outcome. Time and eventuality were cited by 12% of persons living with AIDS and 18% of informal support partners as supporting their

perception of the AIDS epidemic. Among the persons living with AIDS, 89% of persons who cited time and eventuality felt that AIDS was terminal, 5% indicated that time and eventuality supported their view of AIDS as chronic and 6% as both chronic and terminal. Among informal support partners, time and eventuality supported their perception of AIDS as terminal (50%), chronic (14%), don't know (25%) and both chronic and terminal (11%).

Persons living with AIDS and their informal support partners who perceived AIDS as a terminal disease most often talked specifically about the eventuality of death, despite advances in medications. One person living with AIDS said simply, 'Treatment is better but the end result is the same.' Another informal support partner held a similar view: 'Even when the medications hold it off, you eventually will die.'

A person living with AIDS who viewed AIDS as chronic simply said, 'More people are surviving now.' An informal support partner who felt AIDS is chronic shared, 'Because it will be years before the ultimate result of death.' And, another stated, 'Now I would say a chronic illness because people aren't dying like they used to a few years ago.'

Education

Only 4% of persons living with AIDS and 12% of the informal support partners shared that their perceptions of the course of the disease were influenced by information they gained through education. Among persons living with AIDS, 4% explained that education and information influenced their perceptions; among these 43% perceived AIDS as chronic, 43% terminal and 14% were unsure. Among the 12% of informal support partners that stated that information and education impacted their perceptions, 14% viewed AIDS as chronic, 57% as terminal and 29% were unsure.

Most of the individuals' explanations of their perceptions that were explicitly based on information they received had been told by a healthcare provider or via information they received in the healthcare setting. For example, one person living with AIDS who viewed it as chronic shared, 'Says that on my medical papers—pretty chronic.' Several informal support partners also gave similar explanations such as: 'They told me here at [this health clinic] that it is a chronic illness.' Some holding the view of AIDS as terminal also indicated they had been told by a healthcare professional. For example, as one person with AIDS shared, 'I've been told from professionals since day

one that I'm going to die. Some say that I only have a short time.'

Discussion

The findings from this exploratory study suggest that many persons living with HIV/AIDS and their informal support partners do not share the widely held view that HIV/AIDS is a 'chronic yet manageable disease'. While 41% of persons living with AIDS and 39% of informal support partners perceive AIDS as chronic, another 37% of persons living with AIDS and 35% of informal support partners perceive AIDS to be terminal rather than chronic. In addition, nearly one-fifth don't know whether they consider AIDS to be chronic or terminal and over 5% perceive AIDS to be both. Those living with HIV/AIDS who have lower levels of education and higher levels of perceived race-based discrimination were significantly more likely to view AIDS as a terminal rather than chronic condition. In addition, informal support partners in poor health were more likely than others to view AIDS as terminal.

As mirrored in the findings in this study, HIV/AIDS is by definition a disease fraught with ambiguity and change. When discussing the long-term survival of gay men living with AIDS, Thompson (2000) concludes that the 'narrative accounts suggest that long-term survival with HIV likely require a tolerance for ambiguity and an ability to reconstruct the future, skills which may co-vary with economic/career opportunity, social supports and individual resilience.'

Although the AIDS mortality rate has declined precipitously in recent years and many are living longer with HIV/AIDS, a significant numbers of persons are still dying (Oram et al., 2004). Furthermore, the rate of morbidity and mortality is higher among certain subgroups of persons living with HIV/AIDS, including non-whites and the poor (Karon et al., 2001). The way these factors interact with limited education and race-based discrimination may provide important insights into how they affect both perceptions of HIV/AIDS and lived experiences.

In this study, among persons living with AIDS and their informal support partners, five broad themes emerged in the narratives describing whether they perceive of the course of AIDS to be chronic or terminal: medications, personal experiences, cure, time/eventuality and education. Medications were cited most often as the factor influencing the perception of the course of HIV/AIDS as a chronic disease. Yet, it is also important to recognize that a substantial number of persons living with

AIDS and their informal support partners viewed AIDS as terminal as a direct result of medications and their side-effects. The ways in which such perceptions of the disease impact health behaviors (e.g. medication adherence) and lead to more effective treatment-related outcomes are important and timely issues that warrant further study. Furthermore, among persons living with AIDS who attribute a positive meaning to their illness, Farber and colleagues (2003) found significantly higher psychological well-being and longer term survival as compared to those who attributed a negative meaning to their illness.

The difficulty in differentiating AIDS as a terminal versus chronic disease may also, in part, result from the ambiguity in the definition of these terms since they are rarely defined in the medical setting for those living with HIV/AIDS and their loved ones. For example, the participants in this study often used nearly identical language to convey differing perceptions of the course of disease. Furthermore, as evidenced by the participants' accounts, the lived experience of HIV/AIDS may not fit well with the dichotomized categories of 'terminal' or 'chronic' and perhaps is better characterized as both chronic and terminal.

Currently, the quantity of information available on HIV/AIDS is daunting, with the knowledge base rapidly changing. However, education provided by healthcare professionals was least often cited by the persons living with AIDS and informal support partners as influencing their perceptions of the course of the disease. While 87% of physicians feel they discuss treatment objectives and trade-offs, only 50% of patients agree (Zuniga, 2006). Such research suggests that further training is needed to help healthcare professionals assist people living with AIDS and their support partners understand the changing nature and the complexities of the disease. While medical practitioners tend to interact with AIDS through the theoretical lens of their practice specialization (Kleinman, 1988), a biopsychosocial family-centered approach is likely needed to discuss perceptions of the illness with patients and their support partners, with time allotted during routine office visits to provide such education (Duffus et al., 2003).

Cross-sectional data on the experiences and perceptions are reported in this study and some of the associations observed may be due to selection effects of those that participated. Although this research suggests important areas for further study, there are several limitations that need to be considered. More research is needed to determine the extent of changing attitudes and perceptions of HIV/AIDS since these data were collected. In addition, research

with larger sample sizes is needed to test the interaction between the variables reported here, as well as to test the influence of other potential confounding factors (e.g. major life stresses and depression) as they may impact the findings. The persons living with AIDS in this study all identified as gay males living in a large, urban center in the Pacific Northwest, which likely differs from other populations living with HIV/AIDS.

Many persons living with AIDS are surviving longer and often with uncertainty about their future. The results of this study suggest that persons living with AIDS and their informal support partners have diverse ways of understanding the course of HIV/AIDS, with many viewing it as chronic, others as terminal and some expressing sheer uncertainty about the course of the disease. These findings highlight the importance of a renewed emphasis on training for healthcare professionals to better equip them to discuss the everyday lived experience of HIV/AIDS.

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