

Development of an Instrument to Measure Volunteers' Attitudes Towards People With AIDS

CONNIE SCHONDEL AND GLENN SHIELDS, Department of Social Work, Bowling Green State University, Bowling Green OH 43403-0284

ABSTRACT. An instrument to measure volunteers' attitudes towards people with AIDS was developed. A 37-item questionnaire was initially determined to have content validity. The questionnaire was administered to a random sample of youth services volunteers ($n = 150$) and to members of an AIDS volunteer organization ($n = 247$); results of a factor analysis produced five subscales. Reliability of the constructed scale was determined. The initial construct validity of two of the subscales was established. Results of this research are promising, and further testing and refinement of the instrument could provide a method to empirically measure attitudes of volunteers who work with people with AIDS.

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INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) is one of the ten leading causes of death in the United States. It is estimated that approximately one to two million people have already been infected with the Human Immunodeficiency Virus (HIV), the agent that causes AIDS (Coolfont 1986). By 1992, diagnosis of 300,000 to 480,000 cases of AIDS is anticipated in the United States alone (U.S. General Accounting Office 1989). According to public health officials, increased attention to the need for medical and social services for people with AIDS (PWAs) is of paramount concern.

Reports in the media concerning AIDS and HIV illness have drawn a great deal of public attention and evoked a broad range of lay and professional reaction (Furstenberg and Olson 1984). Widespread concern about the disease has firmly established it as a public health problem. However, as with most diseases, the concerns which mold the specific reactions to this disease come from many sources. As with tuberculosis, cancer, epilepsy, and sexually transmitted diseases other than AIDS, reactions to AIDS are affected not only by scientific information and rational appraisal, but also by myth, superstition, and stigma.

If the CDC (Center for Disease Control) predictions concerning the number of individuals infected with HIV are reasonably accurate, an increased demand for health-related services for those infected can be anticipated. The steady increase in the reported AIDS cases will require a matched increase in the number of professionals, para-professionals, and volunteers to meet the medical and psychosocial needs of PWAs (Poullard and D'Augelli 1989).

Lopez and Getzel (1984, 1987) have written extensively about the use of volunteers in the community to provide services to PWAs. Poullard and D'Augelli (1989) suggest that as more people with AIDS and HIV infections are treated, training focusing on volunteers' attitudes toward PWAs and HIV illness will be necessary. These researchers further indicated that volunteers will be confronted with major difficulties. These difficulties cover a wide range of factors including societal stigmata about such characteristics as sexual orientation, social class, race, ethnicity, and

gender. Therefore, effective care of PWAs occurs only to the extent that volunteers are prepared to anticipate their reactions to clients, and to face the differences and similarities they share with them.

Since volunteers have direct contact with PWAs, their families, and their friends, it is important to know and understand volunteers' attitudes. The purpose of this study was to develop an instrument which measures volunteers' attitudes towards AIDS and people with HIV infection. Through understanding the volunteers' attitudes, we can develop training programs which help volunteers to more appropriately confront the issues associated with AIDS and increase the quality of care prescribed to PWAs.

MATERIALS AND METHODS

Scale Development

The item pool for the development of the instrument was derived from a review of literature about AIDS (Devore and Schlesinger 1987, Furstenberg and Olson 1984, Dunkel and Hatfield 1986) and from in-depth interviews with volunteers who work with PWAs and people with HIV infection.

On the basis of the initial qualitative data collection (Schondel 1989), 50 questionnaire items were constructed. The actual language of the interviewees was used whenever possible in designing the questionnaire items. These items were then presented to two feedback groups. One group consisted of six volunteers who were involved in a support group. Three health care professionals, knowledgeable about AIDS, who had been working with PWAs (or HIV infected) for over a year, made up the second feedback group. Group members reviewed all items for length, clarity, readability, meaning, and the level of comfort with each item. The results of the pretesting were used to revise the wording of some of the statements and to eliminate others. Items were scored on a 1-5 Likert Scale with 5 indicating strongly agree and 1 indicating strongly disagree. According to the feedback groups, 37 of the original statements identified a range of relevant volunteer attitudes towards AIDS and PWAs.

In addition to the 37-item pool, two pre-existing instruments, Templer's (1970) Death Anxiety Scale and Hudson and Ricketts' (1980) Index of Homophobia were incorporated into the data collection questionnaire to

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determine construct validity. Based on the review of the literature of AIDS and the themes which emerged from the in-depth interviews, fear of death and fear of homosexuality seemed to be major components of attitudes toward AIDS.

Sampling Procedure

To arrive at a sample, two local non-profit organizations and their volunteer memberships were selected for a variety of reasons. Columbus AIDS Task Force (CATF) was chosen because: 1) it is one of the primary service organizations providing AIDS-related services; 2) it has a large volunteer membership, predominantly males; and 3) it is considered a self-help voluntary organization. Big Brothers/Big Sisters (BB/BS) was selected because it represents a more traditional service-oriented volunteer organization, and it has a volunteer membership with a large number of male volunteers.

The unit of analysis was the volunteers from each organization. According to the most current volunteer listings, CATF had 328 volunteers and BB/BS had 900 volunteers. The entire CATF volunteer membership was included in this study. The sample size for BB/BS was limited to 150 volunteers who were selected by a systematic random method of sampling. Data included 247 CATF volunteers (75.3%) and 94 BB/BS volunteers (62.6%) who returned completed questionnaires.

Data Analysis

The initial analysis of data for both groups involved the use of descriptive statistics (frequencies, means, standard deviations). This provided a description of the demographic characteristics for each group of volunteers. The second major step in the analysis involved the use factor analysis (principal component) on those items related to AIDS. Factor analysis provided a data reduction method for discovering clusters of interrelated variables (Kim and Mueller 1978). Varimax rotation was utilized in order to further define the factors. Variables (items) with a correlation coefficient of 0.40 or higher were selected as those contributing most to the meaning of the factors.

Chronbach Alpha coefficients were computed on each subscale in order to measure the internal consistency reliability. The resulting reliability coefficients were analyzed to ascertain the homogeneity of the subscales. Pearson Correlation test was computed on the constructed subscales and the theoretically-related Death Anxiety Scale and the Index of Homophobia scale for the two sets of data, separately and combined. The final procedure involved the *t*-test which was computed in order to compare the two group scores on the emergent "Attitudes Towards PWAs" subscales and the theoretically-related instruments in order to determine whether the constructed subscales were able to discriminate between the groups.

RESULTS

Demographics

The BB/BS sample consisted of approximately equal proportions of white, middle-class men and women. This sample represented the more "traditional" volunteer in a social service setting. On the other hand, the CATF sample was made up of white, middle-class male volunteers.

Their history of volunteerism, which was less than that for the BB/BS sample, was consistent with the onset of the AIDS epidemic.

Factor Analysis

A principal component factor analysis of raw data with varimax rotation revealed that five factors were present. Items on each factor with loadings of 0.40 or greater were identified (Table 1). The number of factors, or subscales, retained was based on the comprehensiveness of the factor and the scree plot which indicated five factors with eigenvalues greater than one. Each of the subscales was subsequently labeled based on a specific content rationale. The following subscales, or factors, were identified.

The first factor in the "Attitudes Towards PWAs" scale was labeled "Comfortableness With Proximity to Gay/HIV Positive." This subscale consisted of 14 items. In general, most of the items contained content concerning one's level of comfort in being in close contact with either gays and/or individuals infected with HIV. The issue of AIDS, particularly as it has been associated with homosexuality, has aroused fears such as contagion and homophobia in many people.

Factor two, "Societal Responsibility," was composed of four items in which normative responses to AIDS were expressed. The fundamental theme inherent in these items concerned the major role government and its social institutions are to play in fighting AIDS.

Factor three, "Comfortableness with Death," was composed of items related to death and dying and one's ease in talking about it. Since it is an incurable disease, AIDS provokes in many the fear of death and dying. In our society, most members are ill-prepared to cope with death, especially if it occurs in younger individuals. In addition, many other psychosocial losses are associated with the progression of the HIV disease.

The fourth factor, "Societal Perception to Terminal Nature of AIDS," contained items which generally expressed the social view of AIDS as terminal. The items in this subscale seemed to be similar in content to those in the "Comfortableness with Death" subscale, however, content of these items relates to a social response to AIDS rather than an individual response.

The final factor, "Societal Denial of Problem," was composed of items in which respondents viewed society's response to AIDS as minimal. It has been documented that a general lack of financial, societal, and governmental support exists regarding the AIDS epidemic. This apparent lack of action has been pervasive and has contributed to the growing problem of AIDS in this country.

The labels assigned to the five subscales which constitute the "Attitudes Towards PWAs" scale are reflective of the personal and social issues related to AIDS (Table 1). These include fear of contagion, homosexuality, death and dying, and society's reactions to AIDS, all of which are essential components of people's attitudes toward this disease. The subscale labels provide for informative classification areas for the major issues raised in the literature.

Reliability

The alpha coefficients for the "Attitudes Towards

TABLE 1

Factored subscales for "Attitudes Towards PWAs."

Factor Names and the High-Loading Variables	Loadings
Factor I: "Comfortableness With Proximity to Gay/HIV"	
1. I wouldn't want to live next to someone who has AIDS.	0.74
2. AIDS should prove to people that homosexuality is unnatural.	0.80
3. AIDS is not my problem.	0.59
4. The confidentiality of people who are infected with the HIV virus should be protected.	0.64
5. Employers should be able to fire someone infected with the HIV virus.	0.73
6. AIDS will not affect me personally.	0.58
7. AIDS should be reason enough not to be gay.	0.81
8. People with AIDS should be quarantined.	0.80
9. I wouldn't want to work next to someone infected with the HIV virus.	0.79
10. Casual contact with a person infected with HIV would not put you at risk of getting AIDS.	0.66
11. Taxpayers should be responsible for the cost of humane care for people with AIDS who cannot afford to pay for treatment.	0.47
12. A humane society should not allow PWAs to die without providing humane care.	0.55
13. It is unfair that the AIDS epidemic has hit the gay community so hard.	0.52
14. I wouldn't want to touch a person infected with the HIV virus.	0.73
15. I'm more wary of gay people since the AIDS epidemic.	0.69
Factor II: "Societal Responsibility"	
16. The government should be more active in disseminating information about AIDS to the American people.	0.82
17. AIDS education should be taught in the schools.	0.69
18. If a person gets AIDS, it is their own fault.	0.46
19. Employers should be responsible for providing inservice training about AIDS for their employees.	0.45
Factor III: "Comfortableness with Death"	
20. I feel comfortable being around anyone who is going to die.	0.72
21. I wouldn't know what to say to a person who is dying of AIDS	0.63
22. I feel comfortable talking to someone about dying.	0.80
Factor IV: "Societal Perception to Terminal Nature of AIDS"	
23. A person with AIDS should be treated like anyone with a terminal illness.	0.41
24. Because AIDS is terminal, merely mentioning it makes people cringe with fear.	0.80
25. People with AIDS die a terrible death.	0.48
Factor V: "Societal Denial of Problem"	
26. AIDS is not my problem.	0.42
27. The media has exaggerated the spread of AIDS.	0.74
28. A person with AIDS should be treated like anyone with a terminal illness.	0.43

PWAs" subscales ranged from 0.931 to 0.403, which reflect a strong to moderate inter-item correlation. More specifically, the "Comfortableness with Proximity to Gay/HIV Positive" (0.931), the "Comfortableness with Death" (0.714), and the "Societal Responsibility" (0.699) were the three most reliable subscales of the "Attitudes Towards PWAs" scale. The least reliable subscales were the "Societal Denial of Problem" (0.482) and the "Societal Perception to Terminal Nature of AIDS" (0.403).

Subscale Validity

Once the reliability of the subscales was ascertained, it was necessary to determine the validity of the "Attitudes Towards PWAs" scale. Based on the field tests and the utilization of a panel of experts, face and content validity were determined to exist. In order to assess the construct validity of the constructed scale, two existing instruments, Templer's Death Anxiety Scale (1970) and Hudson and Ricketts' Index of Homophobia (1980), were incorporated

into the questionnaire. Both appeared to be related to attitudinal components that comprise the meaning of AIDS. Therefore, it was expected that there would be an inverse relationship between the Index of Homophobia scores and the constructed "Comfortableness with Proximity to Gay/HIV Positive" subscale scores. Likewise, it was expected that there would be an inverse relationship between the scores on the Death Anxiety Scale and the constructed "Comfortableness with Death" subscale scores.

The scores on the Death Anxiety Scale and the Index of Homophobia were correlated with the scores on the five "Attitudes Towards PWAs" subscales for the two samples and for the total group. According to the correlation matrix, the vertical axis represents the five "Attitudes Towards PWAs" subscales, and the horizontal axis represents the Death Anxiety Scale and the Index of Homophobia (Table 2). In each cell, correlation coefficients are provided for the two sample groups and for the total group.

The Death Anxiety Scale showed significant correlation

TABLE 2

Correlation matrix between "Attitudes Towards PWAs" and Death Anxiety Scale and Index of Homophobia.

Subscales		Death Anxiety Scale	Index of Homophobia
"Comfortableness with Proximity to Gay/HIV Positive"	BB/BS	0.043	-0.755*
	CATF	-0.023	-0.583*
	Total Group	0.019	-0.835*
"Societal Responsibility"	BB/BS	0.018	-0.327*
	CATF	-0.015	-0.243*
	Total Group	0.010	-0.535*
"Comfortableness with Death"	BB/BS	-0.238*	-0.327*
	CATF	-0.243*	-0.177*
	Total Group	-0.202*	-0.462*
"Societal Perception to Terminal Nature of AIDS"	BB/BS	0.182	-0.129*
	CATF	0.091	-0.078*
	Total Group	0.108*	-0.139*
"Societal Denial of Problem"	BB/BS	0.131	-0.304*
	CATF	-0.004	-0.274*
	Total Group	0.031	-0.387*

*Significance <0.05

with the constructed "Comfortableness with Death" subscale (Table 2). Further, the two samples and the total group correlation coefficients indicated an inverse relationship, with the CATF correlation coefficient being stronger (-0.244) than the BB/BS (-0.238) and the total group (-0.202) correlation coefficient. In general this means that the CATF volunteers scored higher on the "Comfortable with Death" subscale and were less anxious about death/dying than the BB/BS group. Also, there appeared to be a small but significant positive correlation (0.108) between the total group scores on the constructed "Societal Perception to Terminal Nature of AIDS" subscale and the Death Anxiety Scale. In other words, the more anxious the volunteers were about death/dying, the more they thought society viewed AIDS as a terminal condition.

As was anticipated there was a strong negative correlation between the Index of Homophobia and the constructed "Comfortableness with Proximity to Gay/HIV Positive" subscale for both samples and the total group (Table 2). This means that the higher the scores on the "Comfortableness with Proximity to Gay/HIV Positive" subscale, the lower the scores on the the Index of Homophobia scale would be. The BB/BS group results indicated that they were less comfortable being in close contact with gays and people infected with HIV, and were much more homophobic than the CATF group (Table 2). The Index of Homophobia was significantly correlated with all the "Attitudes Towards PWAs" subscales. An

inverse relationship existed for both samples and for the combined groups on all the AIDS subscales except for the "Societal Perception to Terminal Nature of AIDS" where only the total group had a weak, negative correlation with the Index of Homophobia. The higher the scores on the Index of Homophobia scale, the less positive they were about the following: being in close contact with gay/HIV positive, holding society responsible for prevention and treatment of AIDS, and being at ease with issues related to death.

The results, comparing CATF and BB/BS groups on the subscales comprising the constructed scale, were as predicted; that is, the CATF group scored significantly higher on each subscale than the BB/BS volunteers (Table 3). Hence, the following can be said of the CATF group as compared to the BB/BS group: they were more comfortable being around gays and individuals infected with the virus; they were more adamant about the role that governmental institutions should play in fighting the spread of AIDS; they were more comfortable dealing with the issue of death and dying; their perception of society viewing AIDS as terminal was stronger; and their view of society's perception of AIDS as minimizing the epidemic proportions and the insidious nature of the disease was much stronger (Table 3) These results suggest that the constructed scale has the power to discriminate between groups who are choosing to work with a stigmatized population, their illness, and the issues related to the condition, and those who may be representative of the general population.

TABLE 3

Comparison of Columbus AIDS Task Force (CATF) and Big Brothers/Big Sisters (BB/BS) on the "Attitudes Towards PWAs."

Group	Mean	SD	T score
"Comfortableness with Proximity to Gay/HIV"			
BB/BS	57.234	9.670	-15.584*
CATF	73.951	6.204	
"Societal Responsibility"			
BB/BS	15.064	2.623	-9.754*
CATF	17.984	2.016	
"Comfortableness with Death"			
BB/BS	8.351	2.067	-10.221*
CATF	11.069	2.497	
"Societal Perception to Terminal Nature of AIDS"			
BB/BS	11.415	1.432	-2.439*
CATF	11.911	2.196	
"Societal Denial of Problem"			
BB/BS	11.564	1.954	-5.323*
CATF	12.2823	1.966	

*Significant <0.05

DISCUSSION

With few exceptions, most groups and societies view illness and disease as negative phenomena. The AIDS epidemic evokes strong personal and social responses. The five factors identified in the data and the results comparing the two groups on these factors support the literature contention that AIDS and HIV infection are indeed viewed as an epidemic of stigma. In addition to seeing illness (AIDS) as a type of deviance, fear of homosexuality (homophobia), fear of contagion, and fear of death and dying are other stigmatized issues associated with this disease. These associations negatively influence societal and individual response to PWAs.

Whether illness is seen in purely physical terms or at an emotional level, it involves discomfort and disruption. When people are sick they are usually totally or partially unable to maintain their daily routines (Devore and Schlesinger 1987). For these reasons, illness, or disease, has been described as legitimate deviance. Because of its disruptive effects, all societies and social groups define the rights and obligations related to being ill, and develop mechanisms to control illness and its social consequences (Devore and Schlesinger 1987). Closely related to the concept of illness as deviance is the concept of the sick role which was formulated by Talcott Parsons (1951). Parsons identified four key elements: 1) since people do not choose to be ill, they are usually not held responsible for their illness or disease; 2) while ill, people are excused from carrying out their responsibilities; 3) exemption from the responsibilities is contingent on the sufferer's recognition that illness is an undesirable state not to be maintained; and 4) the sick person is obligated to seek competent help (Devore and Schlesinger 1987).

Friedson (1970) suggests that Parsons' view of illness focuses on acute illness, assumes the availability of a cure, and does not allow for analysis of what happens to those who are chronically ill. These criticisms are especially relevant when discussing AIDS. Goffman (1963) suggests the notion of stigma (a spoiled identity) as it relates to those who are chronically ill. Those with physical handicaps, incurable illness, or illness for which they are held accountable develop a negative sense of self and are often treated negatively.

HIV infection has been perceived as a terminal disease which can be transmitted by specific behaviors and still is most prevalent among gay men and intravenous drug users. The items which make up Factor I "Comfortableness with Proximity to Gay/HIV" reflect this definition. This results in a dual stigma; first, from the identification of AIDS as a lethal disease; second, from the identification of AIDS with people and groups already stigmatized prior to the onset of AIDS (Herek and Glunt 1988).

In addition to Factor I, Factor II "Societal Responsibility" and Factor V "Societal Denial of Problem" represent further construction of AIDS-related stigmatization. Individuals are able to distance themselves from AIDS by defining the illness as an affliction of others. For instance, during the early history of this disease in the United States, reports about AIDS referred to "risk groups," thus allowing most Americans to see themselves as removed from the disease and protected from it (Herek and Glunt 1988). Furthermore, the results comparing the two groups in this study support the notion that in general the public does not readily identify with the risk groups, nor do they see as great a need for governmental interventions.

The second critical issue raised by AIDS is homophobia.

Since the AIDS epidemic has predominantly affected the gay community up to this point, attitudes, beliefs, and feelings about homosexuality have played a significant part in the reaction to HIV infection. Homophobia is the irrational fear of love and affection between members of the same sex. Homophobia and the discrimination it produces permeates our society. The disease AIDS has been seen as a gay disease by non-gay people and as a disease of outcasts by those in the societal mainstream. Some of the publicity about AIDS has strengthened the association between homosexuals and the disease. In addition, some religious leaders see the disease as God's punishment for the sin of sexual perversion which results in forfeiting any claim to society's concern (Furstenberg and Olson 1984). Data from this study support the association being reported in the literature about AIDS and homosexuality. Respondents in the more traditional service-oriented volunteer group, BB/BS, were more homophobic than those in the CATF group. The latter represented volunteers whose membership is a primary service organization that provides AIDS-related services. Furthermore, the more traditional volunteer group's scores on Factor I, II and V suggest less tolerance of those who are gay and/or HIV infected, less need for a social and governmental response to AIDS, and to a lesser degree identify with those infected with AIDS.

The third major issue raised by AIDS is the fear of contagion. The fear that HIV infection can be transmitted through the air or by casual contact with the skin has been a common misconception since HIV was identified as infectious. There is much about HIV and AIDS that is unknown, and many individuals question whether there is enough known about its transmission to state that contagion by proximity is impossible. Even though the U.S. Public Health Service (1986) has issued guidelines for precautionary measures which focus on the prevention of infection, the fears expressed by health care workers of being contaminated and of transmitting the contamination to family and friends reflect how little is known about HIV infection. In this respect, the fear of AIDS may resemble fears aroused by earlier epidemics. The analysis of data from this study supports the literature contentions that fear of contagion is a major AIDS-related issue. Factor I "Comfortableness with Proximity to Gay/HIV Positive" subscale, for example, suggests that fear of AIDS is linked to one's proximity to gay individuals and/or PWAs. There have been incidences where co-workers have demanded that a person with HIV infection be isolated or fired. Funeral directors have refused to embalm the bodies of those who died from AIDS (Collins 1983). There have been legislative bills introduced to incarcerate gays "until and unless they can be cleansed of their medical problems" (Beauchamp 1983). The number of calls to health departments and to the federal AIDS hot line indicate a high level of public anxiety (Seligman and Gasnell 1983). The results comparing the two groups on Factor I suggest that the panic of contagion is not limited to AIDS patients, but is transferred by many to all gay men. This has exacerbated the stigmatization for the entire gay population.

Among the issues raised by AIDS none appears to be more frightening than the fear of death and dying. No

person has been known to recover fully from AIDS. The average life expectancy following a diagnosis of AIDS ranges from six months to twenty-four months. Separate from the fear of contagion, but linked to it, is the fear of death and of the person who is dying—as if death might also be transmitted. This is not an uncommon dynamic, especially among health care providers who place a high value on beating death (Dunkel and Hatfield 1986).

Two of the identified subscales in this study, Factor III and Factor IV, support the connection being made between AIDS and death and dying. Working with a person who is dying challenges unresolved feelings concerning one's own mortality. Individual death is considered in relation to oneself, or how one handles the conflict surrounding mortality by denying the existence of death through denial of the personhood of the individual who is dying of AIDS. This conflict can be heightened by the untimely death of a young person, which is normally the case for individuals with AIDS.

According to Ryan (1991) there are few, if any, adopted policies to manage high stress and grief overload associated with providing care to PWAs. Likewise, there are currently too few trained social workers to provide essential services. Volunteers could presumably fill these current and projected gaps in service. The effective and efficient recruitment, training, and retention of volunteers will be vital in order to meet the increasing demand for services.

As a result of this initial research, an instrument is now available to help empirically test attitudes towards people with AIDS in the context of volunteerism and service to PWAs. The results of administering it to potential and/or current volunteers can provide information vital to the educational and training components of a volunteer program. A major finding of the study was the significant association between AIDS and homophobia, which has implications for volunteer training.

Even though the results show the instrument to have content and construct validity, further refinement of the scale is necessary. Two of the subscales require modification, and testing of additional items to ascertain reliability and useability is necessary. Likewise, the instrument should be administered to additional samples of volunteers. The outcome of these administrations will provide information about the psychometric properties of items across a wide range of respondents, which will hopefully expand the general applicability of the instrument.

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