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Structuring Support for Volunteer Commitment: an Aids Services Program Study

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Since the AIDS epidemic began over a decade ago, the bulk of services for people living with HIV in the community setting have been provided by volunteers. Volunteers are confronted with the stigmatized status of people with HIV and must learn to manage multiple crisis issues. This paper describes research on volunteerism in a buddy program for people living with AIDS and the perceptions of volunteers about the structural supports of the volunteer program. Issues around perceptions of stress and the relationship between bereavement and volunteering are explored.

Introduction

In just over a decade, the human immunodeficiency virus (HIV) pandemic has moved from a newly discovered virus found in a handful of people to a health disaster affecting perhaps as many as 12,000,000 people worldwide. The combination of new infections and the natural history of the disease among those already infected makes the decade ahead look inescapably worse (Mann, 1991).

The advent of AIDS, coupled with a trend in the 1980's towards cuts in social service programs and a reliance through-

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out the country on volunteerism to meet human needs, provoked a volunteer response of a magnitude unheard of in recent years (Arno, 1986). The initial response to AIDS was greatly a community based volunteer response (Rowe and Ryan, 1987) and still remains largely a volunteer response with program supports and professional managers.

The evolution of the response to AIDS has led to the development of volunteer organizations, many of which are large, complex and multifaceted. Volunteer activities have been as varied as exploring alternative medical therapies (Callen, 1988), providing a full range of services including professional direct care services (Gay Men's Health Crisis, 1991), and social and political advocacy (Shilts 1987). In that the role of volunteers has been central in the response to AIDS, it is important to know more about ways managers of programs and professional social service providers can foster structural supports to volunteerism.

This study provides descriptive data about the use of volunteers in the provision of direct services to people with AIDS. AIDS has been described as a "holocaust" (Kramer, 1989) because it has destroyed entire community groups within the United States, and has the potential to devastate entire countries, particularly in the developing nations of the world. In the face of this growing disaster, building volunteer community supports is imperative. Social workers at all levels of practice, especially within AIDS service organizations, need to familiarize themselves with methods of building support for volunteer programs.

Volunteerism & Stigmatized Groups

The literature on volunteerism explores various issues in the structural support of volunteers. In a study of one AIDS services program, Velentgas and others (1990) report that volunteers expressed satisfaction with their contributions and the program supports. Volunteers can successfully play a variety of roles in service provision when programs structurally support those roles (Mech and Leonard, 1988). However, the needs of clients must be clearly known for volunteer services to be most effective. For example, in a study by Filinson (1998), families of Alzheimer's patients sought support and education rather

than tangible services from volunteers, contrary to program expectations. Matching volunteer roles with client needs and agency programs fosters successful volunteer experiences.

The early identification of AIDS among gay men and soon thereafter among injection drug users quickly associated AIDS and social stigma (Sigelman, 1991). Hoffman (1963) noted the tendency to avoid stigmatized and devalued people rather than share in the devaluation by association. AIDS quickly became a metaphor for failure, particularly seen as a moral failure (Sontag, 1989). Volunteers working with persons living with AIDS confront the "spread effect" of a courtesy stigma and its effect on the volunteer. The fact that AIDS has largely been perceived as a "gay disease" means that volunteers must learn to manage the courtesy stigma of homophobia. As the infections have spread among women and people of color, volunteers have been forced to confront issues of racism, sexism and classism and the stigma associated with each. The motivations of persons volunteering in AIDS work then includes persons who bring skills in stigma management often gained from their personal experiences.

The stigmatization of HIV illness had led initially to an under-funding of supportive services for people affected by AIDS. This stigmatization has also meant that traditional sources of support, such as from family, church, and friends, have often responded in a phobic and rejecting manner to people living with HIV. For these reasons, volunteers play a critical role in meeting clients' support needs. Recently as more money has become available, volunteers continue to be needed because of the increasing caseloads, the numerous biopsychosocial crises surrounding AIDS (Macks, 1987), the ongoing supports needed by persons living with AIDS, and because of the ongoing discrimination and stigmatization people living with AIDS experience (Sontag, 1989).

The presence of stigma highlights a critical issue for volunteer management. Volunteers must overcome their own possible negative reactions to people with HIV illnesses. These reactions may be a result of homophobia, racism, sexism or classism, but they may also be related to anxiety about relating to someone with a potentially fatal illness; questions about the possibility of transmission of infection; working with someone

who has chronic problems with substance abuse, mental illness or mental retardation; or responding to people with an oftentimes rapidly fluctuating mental and physical state (Dunkel and Hatfield, 1986).

In addition to their own issues about the client's stigmatized status, volunteers experience the "courtesy stigma" (Goffman, 1963) associated with working with people living with what yet continues to be a terminal illness. As one of the volunteers noted in the study, several of her friends questioned her motivation for volunteering with someone with a transmissible disease who would "just die anyway".

To understand and be able to nurture the volunteer experience, motivational issues are important. Ilsley (1990) defines volunteer motivation in two general categories, formal and informal:

formal—needs defined by programs; coordination by programs; volunteering is formally rewarded; traditional roles

informal—spontaneous expressions of service to a personally perceived social need; often without formal rewards.

The early response to the HIV crisis began with "informal" volunteerism primarily by gay men and lesbian women and has now become more "formalized" as funding and professionals are infused into service networks. Rowe and Ryan (1987) trace the evolution of the San Francisco AIDS Foundation as an example of this transition. Members of the gay and lesbian community began the response to AIDS because of their awareness of the growing need for support and realizing that as a stigmatized, devalued population, that the support would have to come "informally" from within their communities.

Many current volunteers in HIV services are there for informal rather than formal reasons. Schondel's (1989) study of volunteer motivations in AIDS service organizations found "self-help" a greater motivator than more formal rewards. However, as volunteerism in AIDS services has become subsumed in funded professional programs, volunteer supports have become more formalized and accountable to broader constituencies.

Volunteer services often spring from informal motivations fostered by the demand for social justice. As these services

become institutionalized, the more formal motivations, reflecting agency and program orientations, receive greater focus. There is a nationwide movement toward more extensive use of volunteers in response to many social problems (Ellis, 1985). Politicians often attempt to capitalize on this trend for diverse reasons.

In a study of several social service agencies' use of volunteers in Israel, Cnaan (1990) found a diverse set of reasons for agency use of volunteers and, as well, many reasons why people volunteer. Within the AIDS community, initial volunteers who responded because of informal motivations, merged with others who volunteered as AIDS services became somewhat more legitimized (and hence less stigmatized) and sanctions became formalized. Demographic changes that reflect the shift in communities most affected by AIDS also continue to change the volunteer scene.

As the face of AIDS has changed over the past several years, more women, children and people of color have become sick and in need of services. (It's not so much the face is changing but that more faces are being added). Women, for example, experience the social problems related to AIDS in unique ways (Lindhorst, 1988). Volunteers, who initially began Working with people living with HIV because of informal motivations usually related to their personal proximity to the gay male community, report feeling challenged by new needs reflected by this diversity.

Social services can support the informal motivations of volunteers and need not over emphasize a dichotomy between social change efforts of AIDS activism and professional service provision with formalized structures (Withorn, 1984). Empowerment based practice moves social work practitioners toward social change activities (Mancoske and Hunzeker, 1990) which may well lead to structuring support for volunteers' social change activities.

Guidelines for programmatic support for volunteerism have been developed by the Council on Accreditation for Services for Families (Council, 1982) and the Association of Volunteer Bureaus (Jacobson, 1978). Standards were established in the areas of planning, recruitment, screening, training, assignment,

supervision, evaluation and follow-up. This study examines one AIDS service volunteer based agency to explore how volunteer support is structured into program efforts.

Study Population

The purpose of this study is to describe the perceptions of program supports of volunteers at a buddy program which provides a one-on-one match between volunteers and persons living with AIDS. The study explores the perceptions of the volunteers as to what extent the program was implementing the program components which shape the structural supports of volunteerism. The target (focus) population studied were the buddy program volunteers in a local AIDS service agency with a core of volunteer services.

Data Collection

This cross-sectional survey was designed to elicit input from active or recent program volunteers. The survey consisted of both forced choice and open-ended questions about the volunteers' perceptions of the program's support structures based on program support components noted in the literature. This provided descriptive information about the actual implementation of the program per the perceptions of the volunteers.

The study instrument used was devised by the authors to measure perceptions and attitudes toward application of generic standards of volunteer support. It was devised for this study based on volunteer standards of national volunteer service organizations. In the absence of standardized, validated scales, the instrument was pretested by administrative professionals and agency based volunteer managers of related community programs. The anonymous, self-administered mailed survey was sent to all active volunteers and all those who had been volunteers within the past three years. The mailing list was part of the agency records. In total, 44 surveys were mailed.

Findings

Twenty-six surveys were returned—a 60% return rate. There was no follow up mailing done. Some of the volunteers were known by the authors to have moved from the area and some were deceased.

Respondents were primarily middle aged (73% were between 36–55 years of age), white (92%) males (88%) who identified themselves as gay or lesbian (85%). Some were currently living with a lover (42%) though many (50%) were single. Many were Catholic (48%). Most were college educated (52%) and many also had graduate/professional degrees (40%). Most lived in the area for more than 5 years (73%).

Half of those responding volunteered for only one person living with AIDS (PWA) and the other half had volunteered for more than one. Most volunteers (61%) had been working with their PWA for over 6 months at the time of the survey. About one third of the volunteers spent about 1–3 hours a week volunteering, about one third spent 4–8 hours a week, and the other third spent more than 8 hours a week with their PWA. Thirty-five percent knew 1–3 persons who had died from AIDS, 39% knew 4–10 persons, and 15% knew more than 10 persons. Many volunteered in other capacities in the community also.

Volunteer activities reported included fairly traditional supportive volunteer activities. Most volunteers provided supportive listening, entertainment, hospital visiting, transportation, shopping and contact with the PWA's family. Some volunteers also helped with cooking, funeral planning, cleaning and personal finances.

Volunteers were asked to describe the amount of personal stress they were experiencing. An "Index of Clinical Stress" (see Hudson, 1982 for related information on scale) was used to measure stress. These standardized scales have a high reliability alpha (greater than .90) and reported face, content and discriminant validity. Twenty-five of the respondents completed the Index of Clinical Stress. The majority (72%) reported minimal stress. Twenty percent reported feelings of moderate stress, and 8% reported feelings of high stress. Volunteers were most likely to report receiving support for their volunteer experience from structured program supports and from their friendship networks.

These findings of stress and its management are remarkable in light of the high stress built into the AIDS volunteer experience. Informal comments on open ended questions indicated possible explanations, such as stress was mediated by supports received from the program, that volunteering connected

people to the AIDS service community for support, and that people find helping others "therapeutic" in addressing their own concerns. It is also likely that this was testimony to the adaptiveness and creativeness of the volunteers. Many have learned to successfully manage stigma in their own lives and this strengthens them in volunteering with AIDS services. This area of questions would benefit from further study.

Findings Related to Program Supports

Traditional program supports for volunteers include planning, recruitment, screening, training, assignment, supervision, evaluation and follow-up (Council, 1982; Jacobson, 1978). The following perceptions and attitudes of volunteers in the AIDS services program indicate that formal supports are perceived as valuable, even by those who largely volunteer for informal reasons.

At the time of the survey, the program was operating from a reactionary and crisis management orientation, with no long range planning system in place. This is characteristic of many newly created community based volunteer agencies. Volunteers reported a perceived need for more formalized planning to address wide ranging needs. Confusion as to who was responsible for the planning process was noted in comments of some volunteers.

The accreditation standards (Council, 1982) recommend that volunteers resemble clients in social demographic characteristics. The program had a strong representation of the gay and lesbian community among its volunteers. The gay male volunteers were slightly greater in numbers than the reported gay male AIDS cases locally. Almost 20% of the volunteers were females which was considerably greater in numbers than female AIDS cases locally. The weakest area of demographic representation was evident with respect to race—30% of reported AIDS cases were among African Americans, and 8% of volunteers were African American.

Race itself may not have a major impact on the volunteer experience. In a study comparing black and white volunteers, Morrow-Howell (1990) found both groups perform similarly, their commitments were similar, and both felt similar levels of

satisfaction. However, race was felt important in the helping dyad. When people were matched by race, they reported feeling more satisfaction and had increased contacts. No similarly known empirical data on how sexual orientation matching impacts the volunteer experience is reported in the literature.

Volunteers felt screening efforts of the program were legitimate and essential. Screening for various issues, such as recent or multiple bereavement, motivations, commitment and how one handles one's own HIV status, were noted. Many volunteers reported strong social justice motivations for volunteering. This was also found among persons volunteering with rape crisis and battered women's programs. Black (1989) found volunteers with strong informal motivations were often feeling less support, less acceptance by paid staff, and their length of commitment was shorter. This seems to suggest that informal and formal reasons for volunteering, which can be examined in the screening process, may well be an area for program supports for informal volunteer motivations. This study's respondents felt supported for their informal motivational commitments by the program's philosophy and its staff.

The volunteers expressed a strong desire for specialized training in such things as substance abuse, bereavement and planning for death. The volunteers reported engaging in a variety of volunteer experiences which they needed specialized training. Additional training was generally reported as a priority need. Further study might help clarify if this is a measure of training needs per se or of feelings of a wider need for support in sensitive and complicated aspects of the volunteer experience.

Volunteers reported feeling assignment to PWAs was important. Such issues as neighborhood proximity, race, sexual orientation and social class were noted as important. Volunteers felt these concerns were addressed programmatically. Volunteers generally were pleased that assignments reflected their personal interests and stated desires. With the changing demographic characteristics of the HIV pandemic, an important program issue will be addressing the diversity of needs presented by persons affected by the pandemic.

The volunteers generally felt supervision provided by the program was available. Volunteer coordinators were generally

available and offered helpful and supportive advice. Most reported limited use of this formal support.

Evaluations of volunteers by the program were felt to be subjective and handled in an uncoordinated manner. Most volunteers had not received any feedback on their experiences. Most desired more feedback and felt it would enhance their volunteer experience.

Several aspects of the volunteer services with PWAS distinguish this service from other volunteer experiences. Assignment is to one client over several months to what is becoming years, includes much uncertainty, and generally ends with a bereavement process within the program studied. No formal follow-up process occurred. Forty-two percent of the respondents surveyed said they were unsure or definitely not going to request reassignment to a new PWA. A distinct trend was seen between volunteers whose PWAs were currently alive and those that had died. Only 1 volunteer in 9 whose client had died was definitely willing to be reassigned another PWA; whereas only 1 volunteer in 11 whose PWA was still alive was definitely unwilling to be reassigned.

This trend raises serious questions about the need for follow-up. It seems to imply that follow-up services are needed by the volunteers. It is unclear when or why this dramatic change in opinions about reassignment occurs. It is unknown why volunteer attrition occurs without adequate follow-up.

Though many volunteered in AIDS services for informal and personal reasons, they reported a need for stronger program supports emanating from a more formalized volunteer program. This study has shown that volunteers have positive attitudes about more formal program structures of support. Further empirical study of which program structures have the most impact on enhancing informal support motivations is indicated.

Implications for Social Work Practice

This study provides descriptive, exploratory data on volunteers in AIDS services organizations. Social work practitioners need to familiarize themselves with methods of supporting volunteers through managing service networks and by providing nurturing program supports. Services by volunteers and

program supports for them is critical as the climate of service provision changes because of the growing numbers of those affected by the HIV pandemic, the changing demographics of those affected by HIV, and the increasing professionalization and formalization of services.

The findings of this study show that further research is needed to determine the nature of the relationships between variables shaping the volunteer experiences and program supports for volunteerism. The findings of this study indicate a strong influence of informal volunteer motivations in volunteers at this AIDS service organization. The literature alludes to differences in program supports, and the findings of the perceptions of volunteers in this study indicate uniqueness in the experiences described. However, further development of program supports need to be explored and impacts evaluated.

As the number of people affected by HIV grows, and as the people affected become less homogenous, traditional AIDS service organizations are being confronted with questions about priorities, historical bases of support, and decisions about their abilities to work within the divergent communities being stricken with AIDS. How do AIDS service organizations, the majority of which grew out of the experiences and resources of the white gay male community, nurture the involvement of members of other communities (particularly people of color and women)?

Several obstacles can hinder this process. Within the organization, often only superficial and stereotypical understanding of the issues of racism, heterosexism, classism and sexism exists; in non-gay communities, the impact of undisguised homophobia and AIDS phobia prevent the effective recruitment and use of volunteers. The social work profession's commitment to struggling with these societal problems and our ability to formulate strategies to confront these issues is needed in the AIDS services arena.

The early response to AIDS services by volunteers built upon gay and lesbian communities' strengths in management of stigma. Volunteerism as a response to an epidemic is not without built in limitations. Efforts to impose this early volunteer model of AIDS services on women and people of color who

are affected by AIDS are unlikely to succeed (Arno, 1991). New models emerging from the strengths of diverse communities experiences in dealing with problems are the key to further successes in the mobilization against AIDS. An important role for professionals in advocating for coordination and planning for services exists (Mancoske and Hunzeker, forthcoming).

The grief and bereavement needs of volunteers are of importance in developing follow-up support services, but they also have other implications for AIDS service professionals. The majority of volunteers in this buddy program were gay men, some of whom were also HIV positive. Although only a small number at the time, some volunteers have gone on to be diagnosed with AIDS. Volunteers and PWAs have described the peculiar devastation they feel on the discovery that "one of us" has become "one of them" (or vice versa). Agency staff can play a key role in helping at this critical service juncture.

How will AIDS service organizations and professionals develop methods of coping with the shifting roles and statuses of volunteers who become clients? If the majority of people who volunteer as buddies have experienced the death of someone they felt close to because of AIDS, how will programs develop screening techniques that recognize this experience as a motivation, and yet discern when individuals have unmet bereavement needs? As the number of people living with AIDS continues to rise, and since members of the lesbian and gay community comprise the majority of volunteers, how will their grief affect their ability to continue serving in these roles?

More information is needed on how gay men and lesbians are coping with what has been likened to a war, or a holocaust (Altman, 1986), and more so, whether volunteering can be fashioned into a healthy coping response. As further money is spent on service programs, the seminal work and experiences of volunteerism in the response to AIDS is essential. In the face of the ever worsening pandemic, building on the strengths of the informal volunteer community response to AIDS will strengthen the mobilization against AIDS.

This study examined an AIDS service organization and its volunteers. It looked at the formal and informal characteristics of the volunteer experience and the program support structure

for volunteerism. With the changing HIV pandemic, service organizations are confronted with changes in their programs. Services which build on the strengths of the volunteer network will serve to empower those affected by AIDS, which are us all.

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