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Psychosocial Support: A Crucial Component for the Successful Management of AIDS Volunteers

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Abstract

A multidisciplinary approach in the support of AIDS volunteers is discussed employing three dimensions: educational, social and psychological. This approach was developed by the Foundation for Interfaith Research and Ministry (FIRM) in Houston, Texas, to combat volunteer burnout and attrition often exhibited by volunteers when serving clients with AIDS and other chronic, debilitating diseases. An examination of the specific goals and tasks required of volunteer managers/coordinators to utilize this approach are outlined. Although these three components of support were implemented for AIDS volunteers, they can easily be modified to suit virtually any type of volunteer environment and are appropriate tools to enhance a variety of volunteer settings. Ideas and suggestions as to how this psychosocial model of support can be adapted for an organization's use are included.

Key Words:

HIV, AIDS, management, volunteers

Introduction

We are well into the second decade of AIDS. As with the first decade, the second persists in its unrelenting depletion of resources, finances and lives. As of Sept. 1993, the cumulative total of all people diagnosed with AIDS in the United States was 339,250 (Center for Disease Control, 1993). Of these men, women and children, 60% (204,390) have already died. Unfortunately, the current rate of AIDS diagnoses appears to be rapidly accelerating. The first 100,000 cases of AIDS were diagnosed eight years into the epidemic (CDC, 1989). The second 100,000 cases followed only 26 months later (CDC, 1991). The third 100,000 were documented 18 months later when the Centers for Disease Control (CDC) expanded the definition for the diagnosis of AIDS (Chang, Katz, and Hernandez, 1992). Indisputably, AIDS will remain a major public health

challenge for decades to come.

Along with this challenge comes the significant task of maintaining an active involvement of volunteers in the provision of services to people affected by HIV/AIDS. The professional role of the volunteer coordinator/administrator is critical to the ultimate success of those organizations which rely predominately upon volunteers for service delivery. This article presents the efforts of one such organization, the Foundation for Interfaith Research & Ministry (FIRM) in Houston, Texas. Described are the specific psychosocial support mechanisms instituted to surmount the challenge of maintaining long-term, compassionate and experienced volunteers. Although these mechanisms are discussed within the framework of FIRM's organizational structure, they can easily be adapted to accommodate virtually all types

of volunteer environments.

Program Summary

The Foundation for Interfaith Research & Ministry (FIRM) was created as a nonprofit organization in 1986 by clergy and lay people to provide educational and service programs in response to the expanding AIDS epidemic and to initiate other programs in the future. The underlying factors which led to the inception of the AIDS care team program, accompanied by the obstacles overcome in its implementation, are discussed elsewhere (Shelp, DuBose, and Sunderland, 1990). FIRM is responsible for recruiting, training and supervising volunteers organized into congregation-based care teams. The goal of the care teams is to offer friendship and support in the form of nonjudgmental care and companionship. In effect, the care teams become surrogate and extended families to those they serve. Examples of the types of services provided by the volunteers are social and emotional support, light housekeeping, limited transportation, shopping assistance, meal preparation and hospice care. In addition, case management and the Challenge/FIRM Co-op (a food pantry) are offered to clients who are in need of these services. All programs and services are provided free of charge.

Immediately following the recruitment of a new care team from the membership of a sponsoring congregation, volunteers are trained in several major areas. These areas include information on topics such as introduction to AIDS, infection control, psychosocial issues affecting clients and their loved ones, the provision of social and emotional support, care team organization and volunteer responsibilities. Applicable skills regarding basic nursing and hospice care for adults and pediatrics are later taught by a registered nurse.

Clients are referred to the agency by

physicians, nurses, social workers, healthcare providers, agencies, volunteers, family and loved ones, or are self-referrals. The service coordinator completes an intake and assigns a care team to each client. The volunteer coordinator then conducts an initial home visit to determine the appropriateness of the referral, to explain the role and function of a care team, and to assess any ancillary needs which may require supplementary referrals. The volunteers meet with their new client and create a schedule of visitation and assistance based upon a needs assessment. This schedule is consistently renegotiated as the disease progresses and the amount of assistance intensifies.

Unlike the traditional "Buddy" program where one volunteer is assigned to one client, the client is introduced to as many as six to eight volunteers who will be providing assistance. This team approach allows for a wider range of services available to clients. In addition, no one volunteer is overwhelmed by the expectation that he/she is the sole person responsible for providing the social, emotional and physical support of the duration of the client's life. Rather, volunteers are comforted knowing that they are part of a collective effort in the provision of services to their client.

Care teams typically consist of 15-20 volunteers and either one team leader or two co-leaders. A paid staff person is assigned to each team and functions in a variety of roles. Primarily, this volunteer coordinator is responsible for volunteer recruitment, continuing education, team supervision, volunteer support, assessment of client satisfaction and other administrative duties. Each volunteer coordinator is responsible for the supervision of 10-12 care teams and meets with each team monthly. The coordinator must also maintain an "open door" policy and be available daily to

respond to both volunteer and client needs as they arise. For an in-depth program description accompanied by training outlines and job requirements, refer to Sunderland and Shelp (1990).

Agency Statistics

Presently, there are 60 AIDS care teams representing 70 churches and synagogues in the Houston metropolitan statistical area (HMSA). Serving on these care teams are 1,200 active volunteers. These volunteers provide care and support services to an average daily census of approximately 215 clients. This census is roughly 6% of the 3,732 documented number of people living with AIDS in the HMSA (Houston AIDS Surveillance Update, 1993).

As of December, 1993, the Care Team program had provided non-judgmental care and support services to 1,310 men, women, and children affected by HIV/AIDS since January, 1986. The Houston AIDS Surveillance Update (1993) reports that a total of 9,567 people have been diagnosed with AIDS in the HMSA. The 1,310 clients served by care teams represent 14% of the total number of AIDS patients diagnosed in Houston.

In 1988, FIRM began documenting the number of hours donated by volunteers. To date, volunteers have provided over 350,000 hours of service. Darling and Stavole (1992) report that the average hourly value assessed for time donated by volunteers to nonprofit organizations is \$10.91 per hour. Based upon this figure, care team volunteers have documented services valued in excess of \$3.81 million. In 1992 alone, the number of volunteer hours exceeded 110,000, representing a value greater than \$1.2 million. In order to continue providing this level of client care, the program must maintain a rigorous approach in its commitment to the support and well-being of

each of the 1,200 volunteers.

Volunteer Support

It is during the monthly care-team meetings that the preponderance of volunteer support is provided. Though staff-labor intensive, the psychosocial support of all volunteers is regarded as an administrative priority crucial to the integrity and survival of the program.

Over the past several years, the range and content of the volunteer support component has gradually evolved to incorporate the changing demographics of people infected with HIV and those who volunteer their services to assist them.

One illustration of the modification of the care team model occurred when there was a rise in the number of women and children requesting services. These women and children were predominantly black or Hispanic, a contrast from the white, homosexual male population volunteers traditionally served. Instead of providing support to only one person in the household, volunteers were now faced with the challenge of working within the complex dynamics of an entire family unit. Often times, these families were suffering from poverty, lack of adequate health care, or drug addiction. Add to this burden the emotional impact of the impending death of an infant and perhaps one, if not both, parents, and the situation has the potential to become overwhelming for volunteers. Consequently, the care team model was augmented in its structure, volunteer support, and minority volunteer recruitment in order to account for these difficulties (DuBose and Shelp, 1990).

What has been achieved by program efforts over the years is simply one approach toward combating burnout and the volunteer attrition which typically ensues. The psychosocial approach utilizes the following three elements of volunteer support: education, social and psychological. An examination of

the specific goals and tasks required to accomplish these goals is presented below.

Educational Support

The goal of the first component, educational support, is to provide a comprehensive foundation of the knowledge and skills necessary to allow volunteers the opportunity to be successful and effective in their role as care givers. The educational tasks of the volunteer coordinator begin with the introductory orientation and continue throughout the volunteer experience. Volunteer coordinators are required to keep abreast of all pertinent issues within the study of HIV/AIDS. Another task of the coordinator is providing continuing education and training as new information is learned regarding such topics as medical discoveries, therapy innovations, disease symptomology, etiology and epidemiology, infection control procedures, etc.

As an adjunct to continuing education, specific skill modules are provided by consulting medical and mental health professionals. These modules include, but are not limited to, nursing and hospice care for pediatric and adults, boundary setting and other drug related issues for working with the chemically dependent personality. The Volunteer Coordinator facilitates monthly meetings for all Team Leaders which consist of seminars on suicide, case management, grief, cultural diversity and client advocacy. Finally, Connections, a quarterly agency publication, is mailed to everyone which affords another opportunity to disseminate information about important events, agency news, AIDS information, and special recognition.

Cross cultural or minority issues must also be addressed. Volunteers and clients may come from very different religious and ethnic backgrounds. The coordinator must be knowledgeable about and sensitive to these

issues so that volunteers have every advantage for providing the best possible care in a manner acceptable to the client. Sometimes this may require a special educational session which helps to illuminate potential differences such as family structure, socio-economics, cultural values and an occasional reticence in the acceptance of help. Hopefully, this conversation enlightens volunteers toward a better understanding of the living arrangements and conditions of their clients. What may at first seem like an unwillingness to accept a volunteer's offer of assistance may in fact be simply a matter of ethnic or cultural difference. These differences may require an interim period of trust building before services can be accepted.

Because of the diverse scope of material presented over the course of the volunteer experience, a variety of learning modes have been utilized. This varied approach to teaching is much more conducive to reaching a broader range of volunteers who may not always acclimate to the standard lecture style of learning.

Social Support

The goal of the second component, social support, is to foster a safe volunteer environment where team building, fellowship and nurturance can transpire. The tasks of the coordinator consist of regular team meeting attendance, facilitation of team building, team and volunteer recognition through anniversary parties and social events, assisting the team in its visibility within the congregation through bulletin articles and recruitment and setting an example of open, safe communication skills that can be learned by all members.

Many teams choose to meet in individual homes rather than at the church or synagogue. This grants the occasion to share meals or refreshments with one another. This

meeting environment serves a dual purpose; first, as a primarily social event for fun and fellowship and, second, as a tool for team building and mutual nurturance.

Team leaders facilitate the team meetings. However the volunteer coordinators must maintain an objective, resourceful presence should they need to intervene with comments and suggestions, guidance, or conflict resolution. By using effective communication techniques, volunteers swiftly learn how to interact and discuss topics and situations that are sometimes volatile. Two such examples are learning to react appropriately as a team to the behavior of active drug users, and reaching consensus about team guidelines to be upheld by everyone. Due to the concept of team care, it is extremely important that the team acts as a cohesive unit. Independent volunteers who undermine the decisions of the team by keeping secrets or not respecting team boundaries must be confronted, so that these types of issues are resolved.

A second type of social event, the anniversary party/ is subsidized by FIRM. Parties are given annually to each care team to celebrate a year of service. This event permits teams to reflect and celebrate the many things that they have accomplished as well as plan for the upcoming year. The party is also a chance for the agency to publicly recognize the individual and collective achievements of the team.

A third type of social support is spiritual support through the annual Service of Hope and Remembrance. This interfaith worship service is conducted by volunteer clergy of many denominations and permits care teams, staff, clients, and the general public an opportunity to come together and pray for hope and healing, reaffirm a commitment to serve those affected by HIV/AIDS and to grieve as we remember clients, friends and family who have died.

Also, care teams plan many different

outings and social events with their clients. These entertaining events include birthday parties, dinner, movies, picnics, walks, theater and concerts. If the clients are not physically able to participate, then appropriate events are planned that allow volunteers and clients a chance to socialize in a way that is sensitive to the clients' limitations.

Psychological Support

The final and perhaps most important component is psychological support. The goal of this component is to empower volunteers to confront and process their emotions, fears, concerns, frustrations, and grief so that stress, burnout and attrition can be minimized. The major task for the volunteer coordinator consists of paying careful attention when volunteers process their personal concerns or feelings during the team meetings. These personal disclosures are intimate windows into how effectively a particular volunteer is coping with his/her experience. This type of emotional sharing should always be encouraged, unless it becomes dysfunctional for the team. Should this occur, it is appropriate to suggest counseling to the individual.

It is also critical to spend time discussing the current health and condition of each client assigned to the team as well as how the volunteers assigned to that client are handling their duties and emotions. Other tasks of the coordinator include supervision and input, personal recognition of volunteers, and suggesting "time-out" when a volunteer is overwhelmed by grief or fatigue.

The manner in which the psychological stressors are addressed is essential to the successful amelioration of their symptoms. Volunteers must be given the chance to reveal their honest and sometimes very personal feelings about a particular issue or problem. This must be done in an

environment which is both safe and welcomed by all members. Coordinators can help assure this safe environment by respecting the feelings of everyone, regardless of personal agreement or disagreement. By constantly stressing the importance of sharing emotions and then respectfully exploring those emotions, the coordinator sets an example which can be quickly emulated by others.

Pre-existing beliefs, attitudes, or moral judgments about the behaviors which transmit HIV must be confronted candidly from the very beginning. FIRM's philosophy of care is compassionate, nonproselytizing, and nonjudgmental. If pre-existing attitudes are addressed at the initial training, or during the first team meeting, it may weed out those volunteers who cannot accept this philosophy of care. Since volunteers are recruited from the religious community, it is meaningful to remind those who want to volunteer that they have a religiously grounded moral obligation to care for the sick and dependent regardless of the affliction or the means by which the illness developed (Shelp and Sunderland, 1992).

It is imperative to not only challenge the prior beliefs or myths about AIDS, but the volunteer coordinator must also be sensitive to the individual religious beliefs and traditions of each denominational care team. Volunteer coordinators must be flexible and willing to learn from and accept the uniqueness of each team and the manner in which it operates. This may not always be easy. It is essential to view the relationship with volunteers as a reciprocal learning experience.

Volunteers are confronted by countless issues which arise over the course of working with someone with AIDS or other chronic diseases. Some of these issues include fear of contagion, personal confrontation with death and dying, over identification with clients,

assuming control of things outside of their control, unrealistic expectations of accomplishments, prejudice or lack of familial support caused by the stigma of working with someone with AIDS, learning how to set and respect boundaries and placing proper emphasis on self-care to avoid burnout. Inevitably, many, if not all, of these issues will surface. It takes skillful coordinators working closely with their volunteers to manage each problem as it arises. One approach to volunteer management is knowing that not every problem can be effectively resolved, but the stress underlying the problem can be alleviated through proper processing of emotions.

Perhaps the most stressful part of the AIDS volunteer experience is coping with the grief and loss of all those served and loved. Some type of team ritual or memorial service after a client dies seems to be very cathartic. This ritual can simply be an evening of sharing memories by candlelight, a formal memorial service given by the team's pastor or rabbi, the making of an AIDS quilt, or the planting of a tree. Attention to grief during regular team meetings is vital. It may also be meaningful to remember a team's many losses over the course of its work, for example, sharing memories about deceased clients on the anniversary of their deaths, or on other special holidays. If a volunteer's grief goes unresolved, the volunteer will probably soon become overwhelmed by his/her anguish or depression and be unable to continue volunteering productively. The loss of volunteers must be averted to assure the successful continuity of the program.

Discussion

Macks and Abrams (1992) assert that burnout is not only costly to the individual, but also to the organization and the population served. The first step in

implementing appropriate and effective mechanisms of volunteer support is acknowledging the crucial role of self-care for both staff and volunteers. Further, each agency must be committed to offering psychosocial support that is acceptable and welcomed by its volunteers. The stress of working with AIDS or other chronic, debilitating diseases will always be present. However, the effects of these stressors can be reduced.

The author believes that a multidisciplinary approach to volunteer support is crucial to maintaining a healthy pool of active volunteers. A seven-year analysis of the volunteer roster, beginning in 1986 when the agency first began recruiting volunteers, has shown that the average duration of volunteers in active service is approximately two years (643 days). A significant factor in the longevity of volunteers' commitment is the intensive support extended to everyone; however, there are some limitations. Findings are based on volunteer records, anecdotal evidence learned at team meetings and through personal conversations and other data available during the seven-year history of the care team project. There is a need for a scientific investigation with an a priori hypothesis. Unfortunately, this type of investigation is extremely costly, both in dollars and in staff time. To help overcome this obstacle, a demographic survey of volunteers will be implemented and is expected to be followed by an annual volunteer satisfaction assessment. These evaluation tools will allow a determination of what changes may be needed in order to enhance volunteer support. Until then, the data will continue to rely on correlational findings based upon the trends in volunteer data.

The three components of psychosocial support described above can be modified to suit virtually any type of volunteer

environment and are appropriate tools to enhance a variety of settings. In fact, FIRM's care team approach has proven so successful that in 1993 the model was adapted to include the care of people suffering from additional diseases, such as Alzheimer's and other dementia-related disorders.

To adapt the illustrated psychosocial model of volunteer support for author organization's use, here are several suggestions which may help in facilitating this process.

- Encourage collaboration dialogue between staff and volunteers to determine the types of volunteer support that is most beneficial.
- Institute an "open door" policy for volunteers with the volunteer coordinator.
- Incorporate a strong education and training program that utilizes varied modes of learning throughout the volunteer experience.
- Offer *safe* support meetings that 1) foster the processing of volunteer emotions (especially grief and burnout), 2) provide problem resolution, 3) create a forum for suggestions or improvements that can be conveyed to the staff, and 4) provide socialization and nurturance. It maybe useful to conduct special meetings of volunteers related by job responsibility or geographic location in order to promote team building.
- Provide volunteer recognition in a manner that is acceptable to the volunteers. Ask them what is important or appreciated.
- Periodically evaluate volunteer support using all data at disposal. Do not hesitate to revise or discontinue what does not work and retain or enhance what does.

These are only a few ways to get started toward developing an individualized

approach to volunteer support. Exactly how a psychosocial approach can accommodate a program depends upon creativity, organizational structure and a commitment to healthy, satisfied volunteers.

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