A Peer Counselling Program for Persons Testing H.I.V. Antibody Positive

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The World Health Organization estimates that close to ten million people may be currently infected with human immunodeficiency virus (HIV), the leading cause of AIDS. Canadian health officials report that 1,018 Canadians have died as a result of AIDS and officials predict that by 1991 the number of cases of AIDS in Canada will have tripled (Federal Centre for AIDS, 1988). While education, awareness and prevention are still the most likely interventions to reduce the epidemic spread of HIV infection, persons who test HIV positive need assistance, support and counselling services. In addition, the caregivers, families and friends of persons with AIDS need support to cope with the many difficulties they experience caring for their peers and loved ones.

The Vancouver Island AIDS Society has established five types of support programs. In the buddy program, volunteers are matched with individuals testing HIV positive or the loved ones of those who test positive, for ongoing support. In an HIV positive support group, persons who test HIV positive can meet on a weekly basis. A telephone hot line service exists, where volunteers are trained to give information, provide referrals and help with crisis situations. There is a volunteer counsellor program, where volunteers meet with individuals testing HIV positive or their loved ones who request non-professional counselling. Lastly, there is a support group to friends, families and lovers to assist significant others involved with people who test HIV positive.

The Society is now planning a sixth support service, peer counselling. This article will describe the rationale, needs, training and progress of this approach.

Because of the success of the support services provided by the Vancouver Island AIDS Society, the peer program developers wanted to insure that any new programs would fit with existing services and be congruent with the resources and goals of the Society. We also wanted to reach those persons who tested HIV positive who were not using support services offered by AIDS organizations. To assist in achieving these objectives, we conducted a needs survey with members of the Advisory Support Group and persons who had tested HIV positive who were potential peer counsellor candidates. Sixteen of seventeen persons completing the survey believed that a peer counselling program would help meet a need not currently being met. Respondents added comments such as "even after having disclosed to friends, I felt a sigh of relief upon
meeting someone else who was HIV positive. At last I can talk to someone who fully understands.” The majority of respondents also indicated that they knew of persons who had tested positive who were not receiving any kind of support.

The goal for the Society’s peer counselling program is to build on the existing skill and willingness to help of persons who test HIV positive and who wish to help and support others who face a similar test result. The primary reason for starting this program is based on the social experience of persons testing HIV positive, and the impact this has on the existing social support system of the individual. The identification of persons who test HIV positive has a dramatic and sometimes traumatic effect on existing relationships. The moral and social stigma, the disclosure of homosexual activity or intravenous drug use, the great likelihood of contracting AIDS (Acquired Immune Deficiency Syndrome) or ARC (AIDS related complex), and the impact of a life-threatening disease are often too overwhelming for normal social relationships. The support and nurturance expected from existing relationships may be temporarily withdrawn. Families, when finally told, may need time to adjust to news of a relative’s HIV positive test result. Doctors may not be well informed, and reaching out to an agency may seem formal and threatening. And while existing friends may be the most frequent source of support, they may be frightened or confused about how to help.

While there are no specific figures available, it is likely that persons testing HIV positive will seek out others who have had similar experiences. Individuals, often feeling scared or alone, turn to others in similar situations, finding new friends for support. The results of our needs survey revealed that 15 of 17 respondents believed peers are effective helpers in this problem area. Our findings matched the experience of D. M. Joshua, the founder of the Seattle AIDS Support Group, who stated, “the support group is dedicated to the concept that no one more than those actually living with AIDS can fully understand and advocate for our personal support needs than we, ourselves.”

Another purpose for developing a peer counselling program for persons testing positive is to increase the quality of help which is available within their peer group. Peer counselling is not professional counselling or therapy; it is a system to help people further discover and make use of their own natural helping abilities. It is not a replacement for professional services, but an augmentation or extension of services. Persons trained as peer counsellors can relieve some of the pressure on existing services. The peer counsellors are often more accessible than more formally-organized help, and are able to act as trouble shooters, recognizing problems before they reach the crisis stage.

A final reason for developing the peer counselling program stems from the fact that helping others has a therapeutic value for the person doing the helping. A number of studies have shown that acting as a helper can
make people feel better about themselves. Social involvement can contribute to health and well-being. Growald and Luks (1988), after reviewing a number of relevant studies, concluded that "doing good may be good for your immune system as well as your nervous system" (p. 52).

Selection of Peer Counsellors

It is possible to accept all candidates who test positive and are interested in volunteering. However, several factors may limit a candidate’s ability to benefit from the training, and in some cases, the impact of the personal nature of the training may reduce rather than enhance their ability to help others. The program leaders must develop methods to gain accurate information in confidential interviews with each candidate and they must have the interpersonal ability to develop a genuine relationship with each prospective candidate.

Often persons testing HIV antibody positive have experienced much personal rejection. Not passing the pre-training screening may legitimize anger for yet another rejection. A comprehensive selection process can prevent this problem from occurring. Candidates need to be informed that they will be required to engage in self-examination and take some personal risks. If candidates are experiencing denial in their own lives, they may be able to help others, but they may also come to feel that they are always giving without getting anything in return. Trainees may be assisted in examining their denial during the training, and after working through it, they may be better helpers. However, the program leaders must be clear as to whether the training is the appropriate place for such work.

The selection process must also be based on clear and consistent criteria. The program leaders must be aware of issues the candidate is dealing with which might interfere with their helping abilities. In some cases, upon gaining a clear understanding of what is expected of them, the candidates themselves may be the best judges as to whether they are suited for the training at this particular time.

Initially we intended to invite potential peer counsellors to attend the regular training program for the volunteer support workers. However, it became clear that the criteria for selecting persons for the support workers’ training and the peer counselling training were different enough that we experienced two problems. Peer counsellor candidates (persons who tested HIV positive) would likely have worked through a variety of feelings; whereas the volunteer support workers may not have learned how to deal with these same experiences in their own lives (grieving, relationships, expression of anger, etc.). Combining the two groups for training seemed efficient, but it violated our standard of confidentiality, in that it would place the persons testing HIV positive in a situation where their test result might be revealed without their permission.
The Training Program

We asked advisory support persons and a number of persons who had tested HIV positive whether they believed that learning additional communication and problem-solving skills would help them to be better helpers. Sixteen of the seventeen respondents answered yes. Phrases from potential candidates included, "I want to help, but just don't know how to begin;" "for new people who test positive, the peers will have the problems clearer in their mind;" developing new skills will sharpen existing skills;" and "I'll be able to target the problem area more quickly."

We decided to use the manual developed by Carr and Saunders (1979) to begin a pilot group with volunteer support workers. We began our training with an intensive weekend workshop, and the training continued on an every other week basis, meeting for two to three hours each session. We expect to complete the training in twelve weeks. The training has brought up many personal issues for the trainees. Long standing communication techniques previously thought to be effective are being challenged. A few trainees are uncomfortable with this self-examination. As one trainee stated, "If HIV positive, your time is limited so you must look at yourself now!"

The training group has become very cohesive, and this will help peer counsellors to be supportive of each other. The training has provided a safe place for support workers and peer counsellors to express feelings and to do some grieving about AIDS. As those testing HIV positive are experiencing many losses, should they choose to grieve, it may be very intense. Although personal risk-taking is discussed, trainees come expecting to learn to help others, so the intensity of self-examination may catch some people off guard. The facilitators must be vigilant and flexible in determining what is needed and what is appropriate for the group.

The reactions of the support workers to the training has been very favourable. They seem eager to continue to learn from the training exercises. Two comments which reflect the experience of the group are, "I feel full and empty at the same time;" and "it is 99 percent good; the 1 percent is the part of myself I now see and am working on."

Upon completion of the training the peer counsellors will have the option of meeting weekly as members of a "Living Well" support group, where they will be able to continue to develop their helping skills.

The trained peer counsellors will be involved in three capacities. First, they will interact with friends and peers in their own communities offering support and friendship to those with HIV positivity. This may be similar to what they have done in the past, but now they have expanded their helping repertoire. Second, peer counsellors will act as a bridge between those they come in contact with who are HIV positive,
and alternative support and medical resources. Their increased knowledge of resources and their recognition of the process that others are going through will contribute to their ability to get others into appropriate care. Third, peer counsellors can volunteer to meet with persons testing positive who have requested a meeting with someone who has been in a similar situation. Many of these requests are likely to come from the local medical community and other AIDS organizations.

Peer counsellors will likely be the first to know when an individual is in a problem situation, and they can assist in crisis prevention. At the same time, it is likely that individuals who test HIV positive often have this problem interwoven with other issues. These issues may include contemplating suicide, alcoholism and drug addiction. Peer counsellors are not professionals. It is important that they recognize when they are reaching their own limitations and can turn to those with more training.

Confidentiality

The peer counselling program is not structured to solicit clients, but to assist the peer counsellors with their natural helping abilities. In order to respect confidentiality, peer counsellors will not keep a written record of their interactions, but will be encouraged to record their own feelings and thoughts. Also, the meeting and training locations will not be disclosed except to those in the program.

Future Plans

We plan to initiate a complete peer counselling training in early 1989 with the screening of candidates to begin in January of 1989. The support we have received from the Society, the advisory support persons, potential candidates, and the data from the needs survey have strengthened our determination. We hope to maintain some statistical and anecdotal information to help us examine whether we are achieving our goals and to give us ideas for modifications of our service. We also hope to network with other organizations providing similar services, and we encourage people to contact us for future progress reports.

References


About the Author

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