



IN PRACTICE

Encounters with the Israeli Health Service: impressions from a support group for people with HIV

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Abstract *The article which follows documents one of the first short-term support groups for HIV-infected people (PWH) in Israel. The group enabled its members to cope in a positive way with issues of life and death and with the daily hardships that accompany their condition, and became an essential supporting factor in their lives. Four main areas of difficulty emerged in the group pertaining to PWH encounters with the health service, of which all may have detrimental effects on compliance with treatment: (a) sensitivity to the patient; (b) ensuring the patient's privacy; (c) consistency in procedures and in providing information; (d) communication between doctor and patient. The importance of recognizing these difficulties and the need for improvement are underscored.*

Introduction

Various studies relate to the importance of support networks for PWH (people with HIV) (e.g. Chidwick & Borrill, 1996; Green, 1993; Leserman *et al.*, 1992). Support groups were found to be helpful in providing education on living with HIV (e.g. Levy *et al.*, 1990), coping with issues of life and death (e.g. Beckett & Rutan, 1990; Getzel, 1991) and in relieving psychological symptoms (e.g. DiPasquale, 1990; Kelly *et al.*, 1993). Referral to a support group was even recommended to primary physicians as part of their office routine (Coodley, 1993). Most research in this field concerned homosexual white men in the USA (Green, 1993) and may not reflect the situation of PWH in Israel.

The number of patients diagnosed as having AIDS in Israel as of March 1997 was 440, of which 67 were female and 373 were male; of these, 93 people are alive in Israel. The number of PWH who have not developed AIDS reached 1527, of which at least 401 were female and 960 male; for 166 PWH gender was not reported (Israel Ministry of Health). The actual number of PWH is probably much higher, but still low in comparison with other countries, both in absolute terms (cf. World Health Organization, 1995) and as compared to the general population aged 15 + (a little over 3 million). Approximately 90% of the PWH aged 15 + in Israel belong to 'well-defined sub-segments of the Israeli population'; they are

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either people from countries with pattern II infection (almost exclusively Ethiopians), people involved in high-risk behaviour (homosexual contact or injecting drug use) or haemophiliacs, though the latter group is very small (Slater, 1993/1994). Whereas almost all PWH diagnosed in Israel are Jews, there is a small number of Palestinians (Maayan *et al.*, 1993). PWH may feel rejected by Israeli society not only because of their HIV status, but also because they belong to a specific social group. In fact, in a study of high-risk men in Israel, it was found that overall psychological distress reached psychopathological levels, regardless of HIV status (Soskolne *et al.*, 1990). It was reported that homosexual men in Israel tend to be involved in a gay sub-culture, their social network consisting mainly of homosexual men and heterosexual women. In this study, 24% of homosexuals felt they could never turn to their friends for support, while 48% felt they could not rely on organizational support (Soskolne & Bentwich, 1992). With the Ethiopian community, different language and concepts of health and disease create linguistic and cultural barriers (cf. Maayan & Handzel, 1993).

Despite the growing numbers, psychosocial assistance for PWH in Israel remains limited and even possibilities of meeting other PWH are extremely restricted. Only a few attempts have been made to create support groups for this population (Hayward, unpublished manuscript) and these have functioned within the framework of the Israel AIDS Task Force. The groups—in common with the group described here—have attempted the complicated task of integrating PWH from different backgrounds, with or without AIDS. Since Israel is a small country, the idea that everyone knows one another prevails. This situation may foster more secretiveness than elsewhere, which may result in reluctance to expose oneself by joining a group. Furthermore, it appears that in Israel the emphasis has been on survival through action, a life-style which makes it difficult to create a psychotherapeutic framework stable enough to allow introspection (Kretsch & Elizur, 1994).

The group

Selection of applicants for group membership

The group was started in 1994 and was at the time the only one in Israel. Applications (nearly 20) came from all over the country, either through referrals by health professionals or directly from individuals, but many were withdrawn even before the initial interview with the facilitator. At the interview, information was given about the group and the issue of privacy was addressed. People in poor physical condition and those suffering from severe psychopathologies, including injecting drug users, were excluded. Some applicants did not have the appropriate motivation to improve their emotional state and coping abilities, but were interested only in meeting other PWH. The applicants who were accepted signed a contract which specified the group's rules.

Group members

Eight people participated (five of them were men); two participants were married, one woman was divorced, and the rest were single. The members' ages ranged from 25 to 40. Two participants were probably infected by unsterile hypodermic needles, while the others contracted the virus through sexual intercourse. All but one of the group members were working or studying; five had a university education. The group was heterogeneous as regards the participants' ethnic backgrounds. Half of the members had either been born in Europe or Africa or lived there for a substantial period and were probably infected there. Five participants belonged to high-risk groups: one had a history of injective drug use, one was of

Ethiopian origin, and three had homosexual contacts. Most participants presented some hiv-related symptoms; some had developed AIDS, but would not admit it. All members displayed some psychological symptoms in response to the disease, especially depressive or anxious conditions, and reported social seclusion to varying degrees since learning of their infection. As for antecedent psychopathologies, one member displayed a personality disorder and another had previously been a drug addict for many years, but had been rehabilitated for 5 years prior to joining the group.

Progress of the group

The group had 30 weekly one-and-a-half hour sessions with the author as facilitator. The venue chosen for the group meetings was secret and unassociated with ill-health. The group started out with six members, while two new members joined and four dropped out before the end for various reasons. The group framework allowed for the exploration of issues such as whom to tell, giving and receiving support and questions of life and death. For some of the members, the sessions were the sole locus for sharing of feelings such as loneliness, rejection, helplessness, despair and fear of exposure and of death. The atmosphere of the group was familial, though at times the intensity of the emotions expressed endangered its continued existence. Much time was spent on giving vent to frustration arising from interaction with the surrounding world, and especially from encounters with the health service.

Encounters with the health service

As observed among the group members, PWH tend to be vulnerable in encounters with the health service and often feel rejected and helpless. PWH who become depressed may be reluctant to comply with medical treatment, as is the case with depressed patients in general (cf. Shearer & Adams, 1993). Moreover, at times, PWH feel anger towards their doctors and mixed feelings about their treatment, as do terminal cancer patients (cf. Yalom & Greaves, 1977). Only one research study related to the interaction between PWH and the health service. It was found that homosexual and bisexual men with AIDS were more likely to report being refused treatment by a doctor or dentist on the basis of a known or suspected HIV-related condition than were homosexual or bisexual men who were seropositive (without AIDS) or seronegative (Kass *et al.*, 1992). The authors also found that more respondents reported refusal of dental than of medical care. Irrespective of the gender or sexual orientation of the participants, the impressions of the Israeli support group accorded with this last finding. It seems that many of the dentists whom the group participants approached refused to treat them, or did so with such caution that the patients were greatly upset.

It has been suggested that it is imperative to maintain a good relationship between doctor and patient, based on trust and understanding, which manifests itself through discussion (Brown *et al.*, 1993). However, in this group, in nearly every session, disturbing experiences of encounters with doctors and medical staff were brought up. Four areas of difficulty arising from encounters with the health service can be outlined: (a) sensitivity towards the patient; (b) safeguarding the patient's right to privacy; (c) consistency in procedures and in providing information; and (d) communication between doctor and patient. Complications in any of these may have detrimental effects on the patient's trust in the health service and willingness to comply with medical treatment. This may be counteracted by exploring and examining related feelings within the group. Following are examples from each area of difficulty.

Sensitivity towards the patient

PWH are not always treated with sufficient sensitivity. During one of the first meetings, Kalman (all the names used in the following examples are fictitious) spoke of this lack of sensitivity which brought him to the brink of suicide. The nurse, after informing him that he was a PWH, told him that he had three options: to go insane, to commit suicide, or to learn to live with the disease. His doctor had drawn a graph representing a forecast of the future progression of his disease—all the way to his death. Even simple procedures may become emotionally loaded. For instance, blood tests may be perceived by the patients as life-or-death tests, since the results serve as a yardstick to measure the distance from death. As was discussed in one of the sessions, personally taking one's blood sample in a test-tube to the laboratory can become very difficult emotionally when the person perceives his or her own blood as lethal and may, for example, imagine dropping the tube. On one occasion, Vicky told of her doctor's insensitivity to her distress after she had learned of a marked decrease in the number of her CD4 receptors.

Safeguarding the patient's privacy

Although workers in the health service are obliged to ensure patients' right to privacy, they may unintentionally err, thereby offending the PWH, who are particularly sensitive to the disclosure of their condition. Vicky told us how upset she was at having to explain to several secretaries in her clinic that she was a PWH in order to get authorization for a prescribed medical procedure. Karen hesitated before entering the hospital, although far from home, for fear that she would be recognized as a PWH. She felt relieved after talking to her new doctor, but as they left his office, he called out to the nurse that Karen would be joining the 'research study'. Karen felt that she had been exposed in front of all the people waiting in the hall and was extremely distressed. This experience continued to bother her until she addressed it in a group session a number of weeks later.

Consistency in procedures and in providing information

PWH are often confronted by the health service's inconsistency, which stems from a lack of clear-cut procedures. Eran was hospitalized, and he later described the humiliating experience of having to put his clothes in a bag labelled 'contaminated' on all sides. On another occasion, he tried to relate with humour to having alternately received regular and disposable cutlery, as though he were suffering from a contagious disease at breakfast, but not during lunch. The medical staff's inconsistency in providing information can induce anxiety. Kalman often spoke of the difficulty of keeping his faith in the health service, and of the confusion and distress that he felt as a result of contradictory information received from different medical sources within the same institution.

Doctor-patient communication

Communication between doctor and patient is of the utmost importance. On a number of occasions group members expressed their dissatisfaction with their doctors, who treated them as ignorant, whereas they believed themselves to be up to date with research developments in the field. The example of Vicky accentuates the (often disregarded) need to discuss the various treatment options. She told us of a meeting with her doctor in which he had informed her, in a patronizing tone, that she must continue taking her medication, even though she had

read of some alarming side-effects. Being unable to communicate her knowledge and frustration, she decided to go against his advice.

Discussion

The support group assisted its members in evaluating and working through the difficulties associated with living with HIV or AIDS, which helped them to cope with them realistically. The members reported that the group had become a meaningful, supportive component in their lives, and that it helped relieve feelings of loneliness, anxiety and depression. It seems that the participants' ability to share their experience of encounters with the health service increased their willingness to comply with their medical treatment.

It is important to emphasize that any inferences from the experience should be made with caution, since its findings relate to one small group of PWH which may not be representative of the entire population of PWH in Israel. However, there is no reason to assume that the experiences of other Israeli PWH differ essentially from those of the members of the group. Furthermore, there was no other group of PWH in Israel to compare with. The relevant professional literature reports on many aspects of support groups, but not on coping within support groups with encounters with the health services. It is therefore difficult to determine whether the encounters of PWH with the Israeli health service are more stressful than comparable encounters in other parts of the world. In addition, if we assume that Israeli encounters are more stressful, it is unclear at this point whether the Israeli health service is less sensitive to the patients' needs, or whether the Israeli PWH experience more rejection, and therefore feel more vulnerable than the equivalent population elsewhere. At any rate, there is no intention to give the impression that these encounters generate only negative experiences, nor that there are no health professionals in Israel who are discreet, sensitive, and empathic; the sole intention is to identify some problematic aspects of these encounters.

It seems that doctors occasionally forget that PWH are forced to cope with the closeness of death, may feel hopeless, and are often in need of support. Where a cure is not available, the doctor can contribute a great deal by displaying a sensitive attitude towards the patient. As for the health service, it is especially important in the case of PWH to make a point of safeguarding privacy and of maintaining consistency in medical procedures and in providing information, so as not to create additional stress in the lives of PWH.

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References

- BECKETT, A. & RUTAN, J.S. (1990). Treating persons with ARC and AIDS in group psychotherapy. *International Journal of Group Psychotherapy*, 40, 19–29.
- BROWN, S.W., NELSON, A.M., BRONKESH, S.J. & WOOD, S.D. (1993). *Patient satisfaction pays*. Gaithersburg, MD: Aspen.
- CHIDWICK, A. & BORRILL, J. (1996). Dealing with a life-threatening diagnosis: the experience of people with the human immunodeficiency virus. *AIDS Care*, 8, 271–284.
- COODLEY, G.O. (1993). A checklist for evaluation of HIV-infected patients. *Postgraduate Medicine*, 93, 101–108.
- DIPASQUALE, J.A. (1990). The psychological effects of support groups on individuals infected by the AIDS virus. *Cancer Nursing*, 13, 278–285.
- GETZEL, G.S. (1991). Survival modes for people with AIDS in groups. *Social Work*, 36, 7–11.
- GREEN, G. (1993). Editorial review: social support and HIV. *AIDS Care*, 5, 87–104.

- HAYWARD, R. (n.d.). Heterogeneous support group for people with HIV and AIDS. Unpublished manuscript.
- ISRAEL MINISTRY OF HEALTH, THE NATIONAL TB & AIDS UNIT (1997). *HIV/AIDS Quarterly Report, No. 1*.
- KASS, N.E., FADEN, R.R., FOX, R. & DUDLEY, J. (1992). Homosexual and bisexual men's perceptions of discrimination in health services. *American Journal of Public Health, 82*, 1277-1279.
- KELLY, J.A., MURPHY, D.A., BAHR, G.R., KALICHMAN, S.C., MORGAN, M.G., STEVENSON, L.Y., KOOB, J.J., BRASFIELD, T.L. & BERNSTEIN, B.M. (1993). Outcome of cognitive-behavioral and support group brief therapies for depressed, HIV-infected persons. *American Journal of Psychiatry, 150*, 1679-1686.
- KRETSCH, R. & ELIZUR, A. (1994). Editorial: practicing psychotherapy in Israel. *Israel Journal of Psychiatry and Related Sciences, 31*, 69-70.
- LESERMAN, J., PERKINS, D.O. & EVANS, D.L. (1992). Coping with the threat of AIDS: the role of social support. *American Journal of Psychiatry, 149*, 1514-1520.
- LEVY, R.S., TENDLER, C., VANDEVANTER, N. & CLEARY, P.D. (1990). A group intervention model for individuals testing positive for HIV antibody. *American Journal of Orthopsychiatry, 60*, 452-459.
- MAAYAN, S. & HANDZEL, Z.T. (1993). Preface: AIDS in Israel—1993. *Israel Journal of Medical Sciences, 29* (Suppl.), 1-2.
- MAAYAN, S., SHINAR, E., AEFANI, M., SOUGHAYER, M., EL KHOUDARY, R., RAHAV, G. & MANNY, N. (1993). HIV/AIDS among Palestinian Arabs. *Israel Journal of Medical Science, 29*, 7-10.
- SHEARER, S.L. & ADAMS, G.K. (1993). Nonpharmacologic aids in the treatment of depression. *American Family Physician, 47*, 435-443.
- SLATER, P.E. (1993/1994). Sutton's law and AIDS prevention in Israel. *Public Health Reviews, 21*, 285-291.
- SOSKOLNE, V. & BENTWICH, Z. (1992). *Response of homosexual and bisexual men to HIV/AIDS in Israel*. Report submitted to the Global Program on AIDS, World Health Organization.
- SOSKOLNE, V., EYAL, A., AVRAMOV, R., BENTWICH, Z., MAAYAN, S. & ENGELHARD, D. (1990) *Psychosocial adjustment of HIV+ and HIV- high risk men: implications for targeted interventions*. Poster presented at the VI International Conference on AIDS in San Francisco.
- WORLD HEALTH ORGANIZATION (1995). *Weekly epidemiological record, 70*, 353-360.
- YALOM, I.D. & GREAVES, C. (1977). Group therapy with the terminally ill. *American Journal of Psychiatry, 134*, 396-400.