Counseling and Preventive Intervention for HIV-Positive Persons and AIDS Patients

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1. Introduction

The HIV-drama is in the subjective experiences of affected people and in their minds, not a tragedy of virus and immuno-suppressors, but a tragedy of psychological agents such as anxiety, loss of one's job or loved ones, a tragedy of aggression and solitude. This tragedy and it's relative mastering have effects on the quality of life, on the illness course, and probably on the immune system. Furthermore, the improvement of the coping with this critical life event has consequences for the primary prevention of the disease. The future health of the HIV-positive's sexual partners depends to a great extent on their successful adjustment to the fact of being infected.

Different adaptive demands emerge over the different stages of the illness. The following paper deals with the questions:

(i) what is known at present about the types of stressors related to HIV-infection? What adaptations are needed, or in other words: what are typical coping tasks of HIV-infected persons? And
(ii) what counseling and crisis intervention models have been applied and evaluated recently to assist the readaptation process.

The survey is concentrated on non-addicted HIV-positive people and AIDS patients.

2. Types of Stressors Related to the HIV-Infection and AIDS over the Course of the Illness

Summarizing the most important stressors which arise during the whole illness path I refer to a diagram of Kindermann I have adapted for this purpose. It illustrates the type of problems, which require adaptation according to the time-axis and it distinguishes between coping tasks and modes of adaptations characteristic of the different periods.
2.1. Pre-test Phase

Problems with AIDS begin with the fear of being infected. Not only members of high risk groups are affected by this fear. The number of people consulting counseling-centers with no reason to fear being
infected – is considerable. Figures for 1987 show that about 13% of the adult population of the German Federal Republic were afraid of being HIV-positive at least at one time. These persons have to deal with the first concern of the diagram which is “Should I undergo the test?” Possible modes of adaptation or response to the decision to avoid a test are represented in the right column of Figure 1.

In recent years test counseling has become of considerable importance. Published reports of experience in this area show that counselors have to determine whether the person asking for advice has an AIDS phobia, whether the person seems to be able to cope with the potentially frightening information, whether help is available from the social network and whether professional help for crises intervention is available, if necessary.

2.2. Test Crisis

The first deep crisis begins when a person wishes to know the result of the test and the results reveals the person as HIV-positive. Most people react with shock, depressed mood and fear according to different studies. Frigo et al. observed in their sample that 48% of the people tested with positive results reacted with depressed and anxious mood. For 10% of them these dysthyemic emotional responses were strong. O'Reilly et al. observed increased conflicts with sexual partners after their becoming aware of being HIV-positive. Hagenberg calls this response pattern the “test crisis”, evoking among some people, who, before the diagnosis, were free of symptoms, sudden unspecified clinical symptoms of AIDS like loss of weight and night sweats. Drug addicts seem to react to the same message in a less intensive way.

2.3. Phase of Adaptation to the Fact of Being HIV-Positive

The period following the test crisis (see Figure 2) requires adaptation in many respects: The infected person has to learn to live cognitively and emotionally with this diagnosis, and with the uncertain future. This inner (intrapersonal) adaptation concerns the self-concept, the reconciliation with the past, the adjustment of goals for the future etc. The outer (interpersonal) adaptation consists of dealing with social problems of different types. They involve fear of public knowledge of the diagnosis including the prospect of loss of work. On the other hand communication of the diagnosis to relevant people is often experienced as helpful. In this context we also have to consider the problem of “coming out” for many gay men if their relatives did not previously know about their sexual identity.
A third problem of this phase is the adaptation of behavior to a new healthy life-style to reduce the risk of health deterioration and protect others from the infection. This coping task is associated in most cases with the change of well established behavior patterns which can be considerably costly in psychological terms. We know today that a high percentage of the persons concerned are unable to change their practice of sexual behavior to limit the transmission of HIV. The study of Calabrese et al. shows that nearly half of the 305 homosexual HIV-positive men who answered a questionnaire on current sexual practices and modification of sexual practices admitted to continuing active and passive intercourse without condoms.

This whole period – number 3 in the diagram – is characterized by high insecurity and the possible beginning of the AIDS-related complex (ARC) or the beginning of the Acquired Immune Deficiency Syndrome. Chuang et al. compared psychosocial distress and well-being across three groups: homosexual and bisexual male patients diagnosed as having asymptomatic HIV-infection (N = 24), AIDS-related complex (N = 22), or AIDS (N = 19). “Patients with an asymptomatic HIV-infection and an AIDS-related complex showed significantly greater levels of depressive symptoms, more disturbance, and trait-anxiety than did patients with AIDS” without being mentally disturbed in the pathological sense.

These findings are in accordance with those of Moulton, Tross and Holland, and Temoshok and Mandel. The increased incidence of distress may be caused by the fact that their situation is characterized by ambiguity of their health condition, or by the fear of an unclear future concerning the course of the infection. They “suffer from a lack of certainty and predictability” and by patients with ARC the “symptoms serve as a constant reminder of their condition and its prognosis while simultaneously compromising social and occupational functioning.” The number of available support services for persons with ARC does not correspond to this well confirmed result that this group has to cope with a particularly difficult situation.

Some of the people concerned are not able to meet the inner, outer and behavioral demands inherent in this critical life event. But an increased incidence of distress does not mean that these people have more mental disorders in a psychopathological sense. In periods of critical life events people usually need social support from their relatives and friends or professional help, consisting of psychological counseling or crisis intervention. The Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) considers the attempt at readaptation as an “adjustment disorder”, only if people fail to meet the demands of the new situation after a certain time, and if they react with “impairment in occupational (including school) functioning or in usual social activities or relationship with others” or with “symptoms that are in excess of a
normal and expectable reaction to the stressor'\textsuperscript{26}. Most HIV-positives continue to work during this phase, continue their social life over many years, but do so under conditions with a higher degree of difficulty, and with more risk of crises. Being unable to master such a difficult coping task does not mean that a person has a mental disorder
but that he or she needs professional or non-professional help to cope with the exceptional circumstances and to prevent the development of mental disorders and to stop the risk-behavior. The published results on the rates of mental disorders by HIV-positives before stage IV B are quite confusing. From the point of view of available studies there is some doubt as to whether the rate of AIDS patients meeting mental disorder criteria is higher than the rates of other people with chronic illnesses. According to Selwyn's study the percentage of those with asymptomatic HIV infection meeting DSM-III criteria for an adjustment disorder with anxiety, depression or both is 39%, and of those with an AIDS-related complex 78%. In Williams' et al. study 6.5% of 110 HIV-positive subjects met full criteria for a current mood disorder (DSM-III-R), and 2.5% of HIV-negative subjects. In a study of Perry et al. one week before HIV serological notification on 207 physically asymptomatic subjects at risk for AIDS DSM-III-R psychiatric diagnosis were obtained. The rate of current Axis-I disorders was in total 26.1%, depressive illness 12.6%, anxiety disorders 7.2%. The rates are comparable to reported community samples. The 35 subjects found to be seropositive were comparable in their disorder rates to the 172 seronegative subjects. They did not have more disorders. According to this study, which may suffer from a certain selection bias (high educational status of the sample, high motivation for participation) people at risk from AIDS do not represent a population with higher rates of psychopathology.

Blaney et al. published a longitudinal study. 50 asymptomatic newly diagnosed HIV-seropositive gay male with either chronic lymphadenopathy or T4 cells count below 700 were compared with normative data and a small control sample (N = 13) of seronegative gay males. The majority of seropositive participants scored below the norms for patient groups. (Individuals with antiviral medication or immunomodulators were excluded.) This study again shows that many of the concerned people do cope with success.

It can be concluded for this period of the illness path that this period is characterized by a series of mentally demanding coping tasks. Many of the concerned persons are not able to meet the demands of this period – especially the need to change their health and sexual behavior. This conclusion does not mean that these persons meet criteria for mental disorders. The rates of disorders seem to be unclear.

2.4. AIDS Diagnosis Crisis

A new type of problem arises, when the period of insecurity is followed by the certainty of symptoms of the AIDS-related complex or of AIDS in the stage IV-A or IV-B. When the diagnosis of the full symptomatol-
ogy of AIDS becomes clear, the AIDS patient has to cope with a similar crisis as the one he or she had to cope with when the positive result of the test was communicated. Both crises are usually intensive and with strong emotional responses. The revelation of the diagnosis often occurs step by step, announced by the ARC. The "diagnosis of AIDS is an especially stressful event for AIDS patients and has been identified as a critical but often neglected time for psychosocial intervention". People with AIDS react, according to the study of Cohen and Weisman, often different psychic disorders such as major depression, reactive depression, borderline problems, bereavement etc. Nichols describes the different psychological stages most patients go through after the diagnosis of AIDS, beginning with an initial crisis, which evokes strong stress responses during a period of two to six weeks.

2.5. Phase After AIDS Diagnosis Until Death

The crisis is followed by the transitional state as a period of distress, high emotional vulnerability, and changes in self-esteem. The patient has to learn to accept the diagnosis. He or she has to deal with some specific coping tasks such as the maintenance of control over life as long as possible and active cooperation with the physician. Social isolation seems to be a problem for many of them. Social support and individual counseling are needed for the necessary re-orientation towards the last period of life. The deficiency state, the last phase, allows many patients to accept their situation, to live the remaining time more consciously and to prepare themselves for death. This coping success is often interrupted by crises and conflicts. According to Selwyn's study, the percentage of people with AIDS meeting DSM-III criteria for adjustment disorder with anxiety, depression or both is about 56%. These results are not confirmed by the study of Chuang et al. The percentage of AIDS patients with mood disturbances reported in different publications varies to such an extent that it is not possible to draw clear conclusions. The percentage of failure in mastering this final development may be analogous to the percentage of other people with similar fatal diseases.

What is the impact of neuropsychological impairment? Psychological problems and psychopathological states can be influenced by organic mental disorders caused by HIV – in particular in later stages –, such as AIDS Dementia Complex (ADC), infections of the central nervous system, and CNS cancer. The impact of neuropsychological impairment is much less clear in pre-AIDS stages. Perry concludes in his recent review on this question that it is not yet clear how often clinically significant neuropsychological impairment occurs before physical manifestation of HIV infection. If it occurs, "it is well documented that the early mental changes may be subtle". Perry concludes that even if
there may be neuropsychological impairment, medical treatments have to be completed by psychoeducational and psychosocial support.

Summarizing the first part it can be concluded that different types of adaptive demands emerge over the difference stages of the illness. From the psychological point of view these stages can be labelled as

1) pre-test problems,
2) test-crisis,
3) inner and outer adaptation to the fact of being HIV-positive including changes in risk and health behavior,
4) crisis after the diagnosis of AIDS, and
5) inner and outer adaptation to the demands of the treatment and facing the reality of death.

These psychological stages are not identical with the CDC stages. The psychological stages are organized according to the specific coping tasks during the course of the infection and illness. People experiencing this critical life event are often overwhelmed by the demands of the problems inherent to the course of the illness, depending on their own vulnerability and coping competence and on the social support available to the subject. This is not equivalent to the state of mental disorders. We don't have clear evidence at present that the rate of mental disorders is higher among HIV-positives from stage I to IV A than among other groups meeting critical life events. In the latest stages neuropsychological impairments can often be observed.

The main problems beyond the goals of inner adaptation to the threatening reality are the problems of changes in risk and health behavior. This second type of problem concern the primary prevention of the spread of the disease. What are responses from the psychosocial part of our care systems? The considerations of the next part of the paper focus on counseling and intervention programs in this field.

3. What Professional Psycho-Social Counseling is Offered to People with HIV or AIDS?

Counseling services including psychotherapy, behavior training etc. can be systematized according to the time axis of the psychological stages of the illness path.

3.1. Counseling in the Context of Pre-Test Problems, of AIDS Fears and Phobias and the Test Crisis

Telephone counseling, especially established for information on HIV and AIDS, can be considered as an example of knowledge- or informa-
tion-oriented counseling. A continuously scientific evaluation of such a counseling service is provided by the AIDS Telephone Counseling of the German Federal Center for Health Education (BZGA). They counted during the first quarter of 1988 23,070 calls. The number of calls per month was decreasing during the last two years in favor of a more intensive focus on counseling concerning individual problems in the context of AIDS and HIV. At the present the number of calls varies between 2000 and 3000 per month. The subject of the calls according to the content analysis of the evaluation team was as follows (see Figure 3):

- 54% of questions were about AIDS,
- 34% about the test,
- 29% about infection in everyday situations,
- 26% about infection by sexual intercourse.

Figure 3 shows the frequencies (36).

![Figure 3. Percentual distribution of the contents of 23,070 telephone calls to the German Federal Center for Health Education Cologne (first quarter 1988).]
The mode of help was classified in 55% of cases as counseling, in 43% as information giving, in 4% as requests for information documents, in 1% as crisis intervention (see Figure 4).

A second example from Europe focussing on test counseling is the Anonymous AIDS Advice Center of the Public Health Office of the City of Munich. Since 1983 the Center has offered advice and counseling for persons seeking information concerning HIV and AIDS. During certain months there were more than 1000 individual counseling sessions; in 1984/85 they counted about 200 individual counseling meetings per month.

- People do receive information on infection risk, giving them a better appreciation of their own situation;
- people can be tested, if they wish to be tested and if contra-indication is not given; and
- people can get psychological support, when the test result is positive.

The whole procedure works anonymously. From 1985 (June) to 1986 (June) 5316 persons were tested; in the total 4.6% were seropositive. The different group-specific percentages are represented on Figure 5. In 1990 the number of consultations varies between 400 and 600 per month. Between 70 and 80 clients wish to be tested. About 1 to 2% of them prove to be seropositive.

Figure 4. Percentual distribution of type of help offered in 23,070 telephone calls to the German Federal Center for Health Education Cologne (first quarter 1988).
5316 PERSONS WERE TESTED OF WHICH
246 WERE WESTERN-BLOT-POSITIVE

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Görgens et al. (1987)

Figure 5. AIDS Counseling of the Munich Health Department (Ref. 37).

Other counseling procedure for people with fear of AIDS or with AIDS phobia are described by Jäger\textsuperscript{13} and Bruhn\textsuperscript{2}. Krieger\textsuperscript{38} outlines a step by step counseling approach as a framework for dealing with anxiety about AIDS.

3.2. Counseling and Preventive Intervention Approaches for HIV-Positive People: Stage of Adaptation to the Fact of Being HIV-Positive

Most of the intervention approaches can be characterized as psychoanalytic and cognitive behavior approaches, as relaxation techniques and as coping oriented interventions\textsuperscript{39}. It may be that psychoanalytic and cognitive behavior therapy approaches are more appropriate for problems of inner adaptation, relaxation techniques for palliation competences and behavior and cognitive therapy more for changes in health and sexual behavior. All of them are intended to improve coping abilities in the difficult task inherent in the situation of being HIV positive. If they are able to do so is a subject of future evaluation research. At the moment only a few published studies are available on this question.

Experiences with psychoanalytic groups (n = 1) and single short psychotherapy (n = 8) with HIV-positive patients are reported by Hinrichs\textsuperscript{40}.
Most of his patients were depressive. The contents of the therapy sessions, treatment processes and problems are described. The report lacks a control group and quantitative measures for change parameters. Reports on experiences with psychotherapy for HIV-positive persons are collected in a volume edited by Dunde\textsuperscript{41}. It contains reports on different German institutions without scientific evaluation. They are, like the report of Hinrichs\textsuperscript{40}, of heuristic value. Barrows and Halgin\textsuperscript{42} discuss specific issues pertaining to psychotherapy with gay men to prevent transmission of the disease. They suggest how therapists can help gay patients (a) to develop a positive gay identity, (b) to reevaluate their social life and to discover non-sex-oriented fraternal groups and activities, (c) to learn safe sex techniques and new styles of intimacy, (d) to understand the HIV antibody test and its implications and (e) to develop strategies for coping with the loss of loved ones. Kermani\textsuperscript{43} reports the improvement of psychological criteria for 50 HIV-positive individuals, in 14 patients suffering from AIDS and 14 patients with ARC (AIDS-related complex) of PGL (persistent generalized lymphadenopathy) – all treated by autogenic training and group psychotherapy. All took part in a 7 week course. The measurement of the psychological changes consisted of questionnaire data from pre-, post- and follow-up measurement. The author reports a significant improvement for quality of life and positive attitudes towards the future. The follow-up data show in the ensuing months the maintenance of progress in the majority of groups even if they developed further complications. The study lacks a control group and a sophisticated data analysis.

Whereas the above mentioned reports are concerned more with attitude change and inner adaptation, the studies of Coates et al.\textsuperscript{44}, Kelly et al.\textsuperscript{45} and Perrez et al.\textsuperscript{46} analyse possibilities of health behavior change including sexual behavior. When persons have a long-standing history of risk activities, when the immediate effects of the risk behavior are reinforcing and the negative consequences long-delayed it is clear from a psychological point of view that behavior change is not attainable without serious training and assistance\textsuperscript{45}. The following programs take into account these conditions.

Coates et al.\textsuperscript{44} published a report on a stress management training on sexual behavior and immune functioning in 64 HIV-positive gay men. The training consisted of 8 two-hour sessions over 8 weeks containing systematic relaxation, health habit change, and stress management. Subjects were randomized to the treatment and control group. With exception of a significant reduction of the number of sexual partners there were no post-test differences in the reported measures of immune number of function. Unfortunately the authors don't report the pre-post scores of the other behavioral criteria. It is possible that the negative immune outcomes are due to the fact that the psychological intervention was not strong enough.
The project of Kelly et al.\textsuperscript{45} took place in an American metropolitan area of 400,000 residents. Gay community organizations helped to recruit the subjects. The study entry criteria for 104 men (average age 31 years) were: being over 21 years of age, being homosexual, being engaged in high-risk sexual practices, and having no symptoms of AIDS or other HIV illnesses. The \textit{assessment} consisted of multiple measures including behavioral self-monitoring records of high-risk activities occurring over a 4-month period. All subjects had been assessed pre, post and the treatment group was assessed additionally in follow-up. The \textit{subjects} were randomly divided into the experimental (intervention) group (n = 51) and the waiting control group (n = 53). The \textit{intervention} consisted of 12 weekly group training sessions (75–90 minutes) led by two clinical psychologists and two project assistants who worked in three groups. The program contained: information on AIDS-risk education, training in behavioral self-management, assertive and relationship skills training, and social support development. \textbf{Results:} Much evidence was found of a decrease in unprotected anal intercourse (see Figure 6) and an increase in condom use (see Figure 7). A more precise analysis indicated that, in each case subjects lowered risk behavior and did not change from post-training to follow-up in these risk areas.

![Graph 6](image1)

\textbf{Figure 6.} Frequency of unprotected anal intercourse.

![Graph 7](image2)

\textbf{Figure 7.} Frequency of condom use.

\textit{Kelly et al. (1989)
Other practices did not show change (e.g. number of sex partners). The authors emphasize that similar intervention procedures can be used on an individual training basis.

This was realized in a counseling and health behavior training project of Perrez, Hüslar, Schmid and Ewert46 with similar results, HIV-positive homosexual people seeking medical help at a university hospital were offered psychological assessment and individual counseling. 24 subjects decided to take part in the counseling program. They were reassessed three times at 4-month periods. The (re-)assessment included questionnaires on coping tendencies and other psychological features relevant for the groups and self-observation. The counseling program was intended to improve general coping competencies by behavioral training and client-centered counseling sessions. The specific treatment goals were: to treat anxiety by improvement of palliative competence (relaxation), to improve ability to cope in an active and instrumental way in controllable situations, and to improve health behavior (sexual, nutritional). Every participant could attend between 25 and 30 sessions. The treatment group (N = 17) had higher values in all pre-measures of negative psychological indicators in comparison to the control group (N = 15). This was a predictable effect of the strategy for recruitment. The group differences had to be controlled by statistical procedures such as analysis of covariance with repeated measurements.

All in all, the study shows that it is easier to change cognitive than behavioral coping competencies of motivated HIV-positives by a counseling program which contains elements of behavior training.

3.3. Counseling in the Context of the Crisis After the Diagnosis of AIDS and of AIDS Patients

In the following an outline of some counseling services for AIDS patients that have been established and evaluated in part over the last few years is given.

The most comprehensive service model providing different types of help is certainly the well known Shanti Project in San Francisco. It tries to respond to different needs of AIDS patients through the different stages from falling sick to dying. It includes psychotherapy, individual counseling and consultation. The experiences of this huge project are reported in different publications8, 47, 48.

Another psychosocial intervention model was developed by the social work department of the Memorial Sloane-Kettering Cancer Center. It may serve here as an example for a hospital service31. A social worker accompanies the patient from his first visit to the hospital until the end of his treatment. The social worker prepares the patient for life in the hospital, informs him of the possibilities of individual counseling,
of psychotherapy, of community resources such as gay service organizations, social security, public assistance, legal services etc. and invites the patient to the weekly support group at the center. The same social worker helps the patients to solve practical problems. In addition to immediate crisis intervention and individual counseling, the program provides: support groups for patients, lovers and families, patient education, instruction in relaxation and other behavioral techniques, and liaison with community resources.

Similar services are described for hospitals in London\textsuperscript{49}. Since 1983 Jäger\textsuperscript{13} has developed in Munich a service for psychosocial support of AIDS patients and HIV-positives integrating social support in single or group counseling, medical help, and coordinating the medical and psychological resources of the clinic and the resources of the private physicians, patients and social institutions of the city. A network of medical and psychosocial treatment "satellites" working outside the clinic in the city is integrated in the service.

I could not find well designed evaluation studies concerning the effects of counseling for AIDS patients.

Special counseling opportunities for the lovers of AIDS victims have been organized. Descriptions of problems were given by Klein and Fletcher\textsuperscript{50} and Geis et al.\textsuperscript{51}.

4. Conclusions

The different counseling and preventive interventions programs discussed in this paper can be classified first according to their goals. As goals three important intentions can be distinguished: Knowledge-oriented counseling that support people dealing with decision problems and problems of information lack; attitude and palliation-oriented counseling to facilitate inner adaptation, and skill-oriented trainings to change health and sexual behavior. The attitude and palliation oriented goals such as the goal of health-behavior change are important for secondary prevention to prevent a psychologically determined deterioration of the immune competence. Whereas the change of sexual behavior is indispensable for many of the people concerned to prevent the spread of the disease. That is a task of primary prevention.

There is no coherence concerning the different empirical findings. This lack applies to the rates for disturbed people in the different psychological stages of the illness path and it applies to neurological diseases related to the different CDC stages. It applies also to the effects of intervention programs and counseling. It can be pointed out that the analysis of the published literature about HIV and AIDS counseling reveals a richness of concepts, approaches, and narrative reports on individual experiences with HIV and AIDS counseling. This richness
contrasts with a paucity of controlled studies to date. There is no lack of ideas and concepts but a lack of well designed and controlled evaluation studies.

A first source of incoherence is the weakness of research designs; a second the use of different criteria for describing the stages of HIV and AIDS development. A further reason for the incoherence of the results is the fact that the different studies use different assessment instruments and different sampling methods. Furthermore, the social and cultural context influences in a powerful way the situation of the populations concerned so that psychosocial results from San Francisco cannot be compared with results from London or Zürich. Many of the reports are based on individual experience without scientific evaluation. Only a few studies have been carried out to evaluate the impact of educational methods on behavior in relation to the change of high risk behavior. This statement is true in general for sexually transmitted disease education, and it is true in particular for AIDS risk behavior.

Nevertheless, we can summarize some consequences for the area of counseling: We have to offer and to evaluate preventive counseling and crisis intervention for those who are not able to cope with some parts of the mentally demanding illness path in the sense of their inner adaptation. For the subgroups meeting criteria for mental disorders facilities for psychotherapy are needed. Counseling, crisis intervention and psychotherapy help to control fear and depression.

To control the spread of the disease other psychological techniques are needed. The change of sexual and health behavior habits cannot be achieved without intensive training.

For this purpose programs like those in preparation by the Swiss Federal Office of Public Health will have to be promoted and evaluated. This program is intending to provide a health behavior training for all HIV-positives in Switzerland, who are in medical care.

The training program consisting of 8 weekly group training session includes: the training of relaxation skills, the training of coping with stress skills, and the training of changes in health behavior (sexual behaviors and others). The evaluation of the pilot phase is just running.

Summarizing my comments from the point of view of a future research agenda I would draw attention to three points:

(i) For the purpose of secondary prevention and the primary prevention of the spread of the disease we need counseling and training programs, which meet the demands of the different types of adaptation problems.

(ii) The implementation of such programs presupposes well designed evaluations of the programs. The evaluation research is just at the beginning in this area. However, we have excellent research models from other counseling fields.
(iii) The counseling and training models that I discussed in my paper are models from western societies. Counseling and behavior change models for people of developing countries have to be developed taking into account the specific cultural conditions.

References


