



Illness perceptions and benefit finding among people with HIV/AIDS¹

MARLENA MARIA KOSSAKOWSKA¹, PAWEŁ ZIELAZNY²

1. University of Social Sciences and Humanities (SWPS), Campus in Sopot

2. Health Department, Pomeranian Marshal's Office, Gdańsk

ABSTRACT

Objectives. The aim of this study was to investigate subjective illness perceptions, coping strategies utilized and psychosocial benefits gained from illness in people with HIV and AIDS.

Methods. Participants in the study were 60 patients (30 with HIV and 30 with AIDS) treated at the Pomeranian Center for Infectious Diseases and Tuberculosis in Gdańsk. The following measures were used: the Brief Illness Perception Questionnaire (BIPQ), the Coping Orientations to Problems Experienced (COPE) for patients, an abbreviated version of the Silver Lining Questionnaire (SL-24) and a demographic questionnaire including information on age, sex, education, and stage of the disease.

Results. Illness perceptions were found to be less favorable in AIDS patients than in HIV-infected individuals. Moreover, the two groups differed significantly in terms of two coping strategies: seeking emotional support, as well as focusing on and venting of emotions. Both these coping styles were more likely to be utilized by patients with AIDS than by those with HIV. Psychosocial benefits gained from illness as declared by the respondents turned out to consist mostly in an improvement of their social relations and in their increased personal strengths.

Conclusions. Patients with AIDS typically have less positive illness perceptions and employ less favorable coping strategies than do HIV-infected people, but declared psychosocial benefits of being ill were similar in both groups.

Key words: coping/illness perceptions/HIV/AIDS/psychosocial benefits

HIV infection is a pandemic disease affecting nowadays countries all over the world. According to estimates by UNAIDS, about 36 million of people are infected with HIV or living with AIDS. Each day there are some 14 thousand new cases of HIV infection, in that number about 10 percent are children. The prevalence rate of HIV infection in the 16–24 age group amounts to about 50%. Roughly 8 thousand people die each day of AIDS-related causes².

AIDS (acquired immune deficiency syndrome or acquired immunodeficiency syndrome) is a disease caused by a virus called HIV (human immunodeficiency virus) [1] that attacks the immune system, weakening it slowly but systematically until its total destruction. Human organism becomes then defenseless, completely unresistant to trivial infections. The initial stage of HIV infection is asymptomatic, but despite the absence of any symptoms and signs, the virus

intensely proliferates in lymph glands. A HIV-infected person may feel well and continue their usual way of life for years, unaware of being a source of infection to others. The asymptomatic stage duration ranges on the average from 1.5 to 15 years [2].

AIDS involves various diseases typically affecting people infected with HIV. This stage is characterized by development of treatment-resistant opportunistic infections with microorganisms that normally do not lead to illness or are very well controlled by the immune system. Such infections include, among other ones, pneumonia, mycoses, herpes, toxoplasmosis. Indicator conditions may also include neoplasms (cervical cancer, Kaposi sarcoma), or even dementias. In contemporary medicine HIV/AIDS are considered as chronic diseases, mostly due to the fact that more and more effective antiretroviral drugs are currently available. These drugs suppress HIV plasma viral load

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² The source of data: National Center for AIDS, www.aids.gov.pl of 17th December 2012.

below the level of detection. HIV-infected patients can considerably prolong their lifespan due to the received treatment, but their disease is not curable. Even though they feel reasonably well, the virus exists in their organism and is capable of spreading the infection further [3].

The situation of HIV/AIDS people is not easy. Many patients experience first and foremost negative emotions (anxiety, depression, anger) when informed about the diagnosis. Negative outcomes of coping with the stress of AIDS and HIV infection have been widely discussed both in Polish language and world literature and are commonly known [4]. However, surprisingly enough, people with HIV/AIDS do find some benefits in their difficult experiences and despite their condition report improvements in their quality of life and interpersonal relationships, as well as positive changes in their value systems and priorities. Positive beliefs, such as e.g. an ability to recognize potential meaningfulness in threatening events were found to slow down the development of the disease in HIV-infected people [5], which seems to be a quite spectacular and revolutionary discovery in the world of medicine.

Not only outcomes of coping with the stress of a chronic illness can be positive. Owing, among other things, to promotion of positive psychology ideas, health professionals (medical doctors, psychologists, therapists, nurses) in recent years have tended to more and more often take into account and support the patients' individual resources: their personal strengths, atypical abilities or particular skills that might facilitate the process of adaptation to the challenge of their disease [6, 7, 8]. The focus of this paper is on positive outcomes of coping with AIDS and HIV infection.

Outcomes of coping with the stress of a chronic illness may be related to a variety of biological, psychological and social factors. One such factor is illness perception resulting from cognitive and emotional assessment of the impact of illness on various aspects of the patient's life. The structure of illness perception includes a component of objective knowledge, usually based on information acquired from the medical diagnosis, and a subjective component, i.e. the patient's self-diagnosing or his/her own operationalization of the experienced somatic problems and of their context.

A number of contemporary authors deal with the concept of illness perception in their research. On the grounds of his research conducted for many years Leventhal has produced the Common-Sense Model of self-regulation of health and illness. In this model

illness is seen from the perspective of the patient's understanding and experiencing symptoms of the disease. Such an approach helps patients to ascribe meaning to their illness and to develop their own coping strategies. The patient's perception of illness includes a number of components such as perceived causes, symptoms and consequences of the disease, treatment methods, prognosis, etc. According to Leventhal, people usually develop a cognitive representation of their health problems based on five features: the name and symptoms of the disease, its anticipated duration and consequences, treatment possibilities, and ability to control the disease process [9]. The main function of illness perception is to regulate the patient's behavior towards their illness through the choice of appropriate coping strategies leading to behavioral outcomes – negative and/or positive for their functioning. Among positive outcomes of coping with the stress of a chronic disease there are psychosocial benefits that patients gain from being ill. While it is readily conceivable that such benefits may include e.g. getting constant care and attention from others due to being ill, it is more difficult to demonstrate that the meaning of life can be found owing to (and not despite of) illness. Health professionals quite often report that owing to hospitalization single persons can get their essential needs (not only physiological, but also emotional and social) satisfied more easily and comfortably than it would be possible in their empty homes. In other cases illness can serve to rationalize the patient's failures in life or unattained aspirations, e.g. these concerning their identity. Moreover, illness may help to fulfill the need for acceptance of others, relieve patients of their duties and undertaking new social roles, or replace partnership in social contacts by asymmetric relationships [10]. Even if motives for finding benefits of this type may seem psychologically questionable, from the perspective of positive psychology they should not be dismissed, but rather explored – we should try to determine their nature and find out to what extent and under what circumstances they actually are benefits or rather serve as defense mechanisms [11, 12, 13].

In positive psychology the issue of psychosocial benefits includes the notion of the so-called personal growth construed as the individual's psychological and social development aimed at the attainment of their own purposes and aspirations resulting, above all, in good mental health and wellness, a sense of life satisfaction and fulfillment [5]. As regards people with chronic illness, the notion of personal growth should be specifically understood, not as tantamount to posttrau-

matic growth following disasters or catastrophes, i.e. strong, sudden, short-term stressful stimuli. The stressful impact of illness is a long-term one, with its own, sometimes most variable dynamics that requires the patient's constant readiness to cope with their ailments, particularly when their disease is life-threatening [11].

Personal growth is frequently considered in the literature from the perspective of psychosocial benefit finding or benefit reminding. Various definitions of benefit are proposed in the psychological literature. Benefit seeking may be seen as a coping strategy, as a result of a selective evaluation aimed to minimize effects of stressful events while focusing on their possible gains, it may be regarded also as a process of adaptation to stressful events [13]. Taking into account all these motives for benefit seeking and finding, this construct can be defined as the individual's declared ability to find psychosocial benefits gained from coping with challenge of e.g. trauma, chronic disease, or other stressful situations [12].

It was assumed in this study that due to the awareness of being infected with HIV or living with AIDS, people with both these conditions may declare that they gain psychosocial benefits from their disease, despite the differences in their medical conditions, illness perceptions and strategies of coping with the stress of infection or being ill. Thus, the study is focused on three major problems of: illness perception, coping strategies and psychosocial benefits in HIV/AIDS patients. The following research questions were set forth on the grounds of the above-presented assumption:

1. Does illness perception differentiate between HIV-infected people and AIDS patients?
2. Do HIV-infected persons utilize different strategies of coping with the stress of infection/disease than people living with AIDS?
3. Do HIV-infected and AIDS patients declare they gain psychosocial benefits from being ill?

METHODS

The following dependent variables were investigated in the study: illness perception (e.g. a sense of control over the disease, perceived symptoms); strategies of coping with stress; psychosocial benefits (e.g. personal strengths, modification of life philosophy). The independent variable was the type of illness (two groups: HIV-infected persons vs. patients suffering from AIDS).

Participants in the study were 60 patients: 30 infected with HIV (mean age 40.23, SD = 9.14) and 30 living with AIDS (mean age 45.8, SD = 6.73). In both groups male patients prevailed (73% among the HIV-infected, and 67% of the AIDS group). In both groups predominated people with secondary education (53-60%).

The participants were treated at the Immunodeficiency Outpatient Clinic or at the AIDS Department of the Pomeranian Center for Infectious Diseases and Tuberculosis in Gdańsk. Informed consent was obtained from all the participants, and their privacy and confidentiality were ensured. The examination was individual, and subjects who reported difficulty in responding to the questionnaires used in the study were helped by the examiner.

Three questionnaires were used: the *Brief Illness Perception Questionnaire* (IPQ-B) [14] adapted by Kossakowska [15] served to measure illness perceptions. The tool consisted of 8 items measuring the respondent's assessment of the impact of the disease on their life (originally: IPQ1: consequences), perceived duration of the disease (IPQ2: timeline), a sense of control over their illness (IPQ3: personal control), beliefs about treatment effectiveness (IPQ4: cure control), estimated symptom severity (IPQ5: identity – severity), health worries (IPQ6: concern), a sense of understanding their disease (IPQ7: understanding), and its perceived impact on the respondent's affective state (IPQ8: emotional response).

Strategies of coping with stress were measured using the multidimensional inventory *Coping Orientations to Problems Experienced* (COPE) in the *Illness* version, by Carver, Scheier and Weintraub [16], in the Polish adaptation by Wrześniewski [17]. The items of COPE Inventory are divided into eight coping mechanisms: Problem Focused Coping, Focus on and Venting of Emotions, Denial, Religion, Sense of Humor, Use of Social Support, Alcohol/Drugs Use and Acceptance.

Psychosocial benefits were investigated using the *Silver Lining Questionnaire* (SL-24) [18], translated into Polish and adapted by Kossakowska [15]. This abbreviated version of the SL-38 questionnaire consists of 24 items not excluded by an exploratory factor analysis and supported by a confirmatory factor analysis. The items measured positive aspects of being ill. The following 5 types of psychosocial benefits that may be gained from illness were distinguished in accordance with the original names of the SL-38 subscales: (1) Greater appreciation for life; (2) Improved interpersonal relationships; (3) Changes in life philosophy; (4) Positive influence on others; and (5) Personal inner strengths.

Moreover, sociodemographic data including age, sex, education level, and stage of disease were registered.

RESULTS

To verify the research questions listed above the program SPSS 12.0 PL for Windows was used in the statistical analyses.

Illness perceptions

To verify the hypothesis about intergroup differences concerning illness perceptions ANOVA/MANOVA analyses of variance with repeated measures within the latter factor were conducted using the 2 x 8 factorial design, where 2 was the group (HIV-infected vs. AIDS patients), and 8 illness perceptions (aspects perceived: consequences vs. timeline vs. personal control vs. cure control vs. identity – severity vs. concern vs. understanding vs. emotional response).

Analysis of variance revealed significant main effects of two factors: group [$F(1,58) = 15.61, p < .001$], and illness perception [$F(7,406) = 21.48, p < .001$], as well as a significant of interaction between these two factors [$F(7,406) = 13.80, p < .001$] indicating that illness perception differs the group of HIV-infected people from that of AIDS patients (Fig. 1).

Post hoc analyses were performed using Fisher’s Least Significant Difference (LSD) test. Significant

differences were found in several aspects of illness perceptions, including: consequences (IPQ1) of the disease (respondents with AIDS perceived a definitely greater impact of the disease on their lives than did HIV-infected participants, $p < .001$); ability to control the disease (IPQ3) (perceived as significantly lower by the AIDS group than by HIV-infected participants, $p < .001$); perceived symptom severity (IPQ5) (higher in the AIDS than in the HIV group, $p < .001$); worrying about the disease (IPQ6) (health worries were significantly more pronounced among respondents with AIDS than in the HIV-infected group, $p < .001$); and finally, the effect of illness on the subjects’ emotional state (IPQ8) (patients with AIDS as compared to the HIV group reported considerably more negative effects of their disease on their emotional state, i.e. experienced more sadness and anxiety about their condition, $p < .01$).

Only in 3 aspects of illness perceptions no significant differences were found between HIV-infected subjects and AIDS patients, namely: in the perceived duration of illness (IPQ2) (considered by both groups as long-term and chronic), beliefs about treatment efficacy (IPQ4) (regarded by both groups as moderate), and in understanding the disease (IPQ7) (both groups declared similar levels of understanding their conditions).

Summarizing, patients with AIDS can be said to have a less positive perception of their illness than HIV-infected respondents.

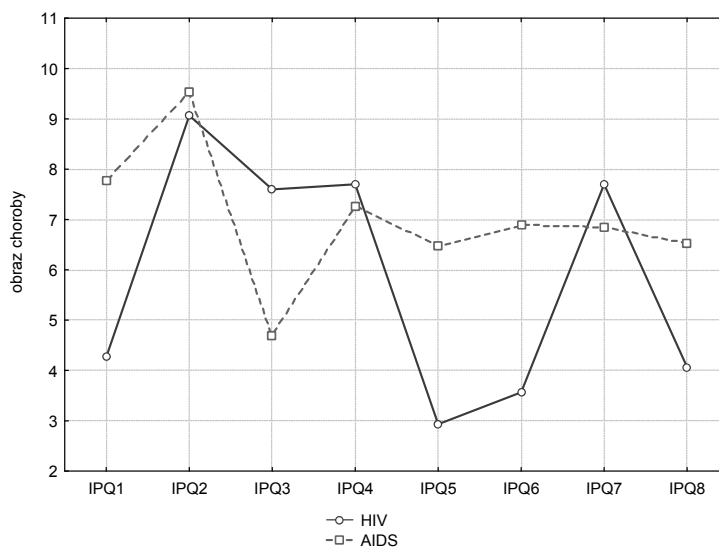


Figure 1. Illness perception in HIV-positive individuals and AIDS patients

Note: IPQ1 – consequences, IPQ2 – timeline, IPQ3 – personal control, IPQ4 – cure control, IPQ5 – identity-severity, IPQ6 – concern, IPQ7 – understanding, IPQ8 – emotional response.

Coping strategies

MANOVA with repeated measures within the latter factor was performed using the 2 x 8 design, where 2 was the group (HIV-infected vs. AIDS patients), and 8 coping strategies (Problem Focused Coping vs. Focus on and Venting of Emotions vs. Denial vs. Religion vs. Sense of Humor vs. Use of Social Support vs. Alcohol/Drugs Use vs. Acceptance). Analysis of variance indicated a significant interaction between both these factors, i.e. group and coping strategies ($F(7,406) = 3.0265, p < .05$). In other words, the level of coping strategies utilized was determined by a joint effect of the group of respondents and type of coping. Main effects turned out to be statistically insignificant ($p > .05$).

Post hoc analyses performed using Fisher's Least Significant Difference (LSD) test revealed significant differences ($p < .05$) between HIV-infected and AIDS patients as regards two coping strategies: Use of Social Support and Focus on and Venting of Emotions. Namely, as compared to HIV-infected individuals, patients with AIDS are more likely to seek emotional support from others and tend to be more focused on their own emotions.

As far as the remaining coping strategies are concerned, no statistically significant intergroup differences were found ($p > .05$). In both these patient groups the following strategies were utilized to a similar extent: Problem Focused Coping, Acceptance, Religion, and Sense of Humor to distance from their problems. They were equally unlikely to deny their condition

and to use alcohol as a way of coping with AIDS and HIV infection (Fig. 2).

Benefit finding from illness

To verify the third research question ANOVA/MANOVA analyses of variance with repeated measures within the latter factor were conducted using the 2 x 5 design, where 2 was the group (HIV-infected vs. AIDS patients), and 5 – the type of psychosocial benefit (greater appreciation for life vs. improved interpersonal relationships vs. changes in life philosophy vs. positive influence on others vs. personal inner strengths). Analysis of variance revealed a significant main effect of benefits [$F(4,216) = 13.516, p < .001$] indicating that irrespective of the group under study the respondents declared they gained most benefits in the form of their improved interpersonal relationships and increased personal strengths, with less pronounced gains on measures of their positive influence on others, appreciation of life and changes in their life philosophy.

Summarizing, both groups of participants can be said to declare similar levels of moderate psychosocial benefits of illness.

DISCUSSION

AIDS patients were found in the study to declare a definitely less positive schema of their illness. This result seems obvious due to objective reasons and is

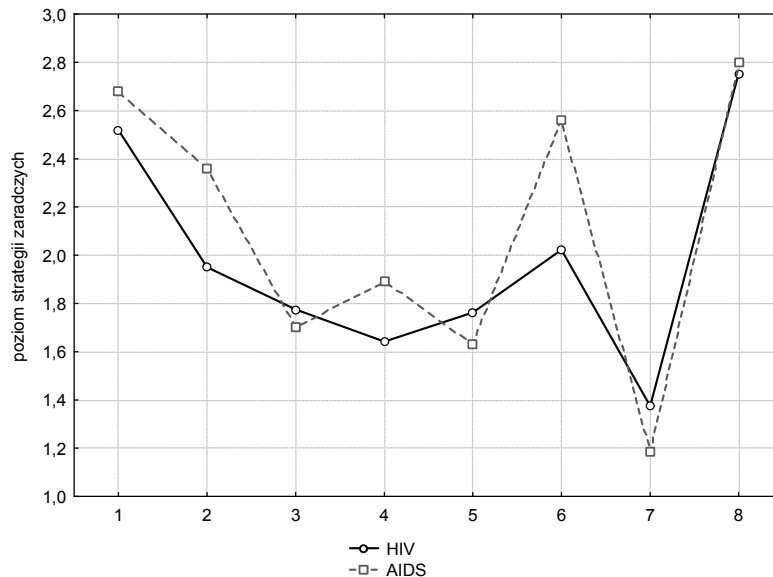


Figure 2. Coping strategies of HIV infected people and AIDS patients

Note: 1 – Problem Focused Coping, 2 – Focus on and Venting of Emotions, 3 – Denial, 4 – Religion, 5 – Sense of Humor, 6 – Use of Social Support, 7 – Alcohol/Drugs Use and 8 – Acceptance.

consistent with the opinion commonly held by experts that the medical condition of patients living with AIDS is more difficult. People suffering from AIDS, i.e. being in the incurable stage of HIV infection, experience, above all, more severe consequences (both physical and emotional) of their condition. They develop many co-morbid opportunistic infections. Since their immunological system is weakened, infections trivial to healthy people may be fatal in their case. Symptoms of AIDS are very evident and troublesome. Thus, consequences of AIDS are most serious. Watching progression of their disease AIDS patients worry more and more about their condition, become pessimistic and not infrequently develop depression. Illness perceptions among people with AIDS are definitely negative.

Negative stereotypes held by the society may be also a factor significantly contributing to the less positive illness perception in AIDS patients. According to common beliefs the infected person has deserved such fate due to their inappropriate or immoral behavior. Thus, people with AIDS not only suffer from their somatic condition with a poor prognosis, but also experience distress resulting from e.g. their loneliness or being misunderstood by their environment. Perceived lack of social support additionally enhances these patients' negative perception of their condition.

However, it seems worthwhile to note the findings that indicate similarities between the two compared patient groups. The most interesting result seems to be that showing similar beliefs about treatment efficacy declared by both these groups. Although medical condition of AIDS patients is objectively more severe, they still hope that treatment will help them. Our AIDS patients' beliefs in treatment efficacy could have been enhanced by their current situation: at the time of investigation they were hospitalized and provided with an intensive treatment due to their symptoms exacerbation. It was demonstrated in an earlier research that hospitalization enhances hospitalized patients' beneficial hope leading to a more favorable perception of their illness [19].

This study shows also that both these groups of patients accept chronicity of their condition. Their responses indicate that they recognize the long-term character of their disease, which constitutes a favorable aspect of illness perception requiring them to behave rationally: thus, they are more likely to cooperate with their doctors and comply with the treatment regimen. Within-group analyses reveal that HIV-infected people perceive their disease as chronic, but controllable and perhaps even curable in a near or distant fu-

ture, while the image of a terminal and uncontrollable illness predominating among AIDS patients is much more pessimistic.

The awareness of the disease chronicity is associated with a strong need for activation of long-term adaptation processes. One of outcomes of the individual's adaptation to illness is the degree of understanding their psychosomatic condition. In this study the degree of understanding their illness was similar in both patient groups. Considering that the clinical pattern due to the stage of illness is different in the two groups, it seems surprising that the level of understanding the disease is similar in HIV-infected patients and those with active AIDS. However, it is difficult to hypothesize in which patient group the level in question should be higher: among those with the more severe condition or in the less affected group. In order to answer this question another series of studies should be performed dealing with determinants of the patients' understanding of their illness.

According to the theoretical assumptions of the Leventhal theory, the illness perception serves a regulatory function manifesting itself in the ways of responding to the situation of illness [9]. Analyses of strategies used by the two groups under study to cope with their diseases shows that the strategy most differentiating between the HIV-infected and AIDS patients was that of "seeking emotional support". As compared to HIV-infected participants, AIDS patients are more likely to seek emotional support of and emotional contact with others. In the course of adapting to their illness HIV-infected persons might have learned that this strategy is not welcome to others, and besides, perhaps these patients do not wish to burden others with their problems. On the other hand, perhaps they have no need for this type of support, frequently still being in good physical and mental health.

A tendency was noted in this study as regards emotion-focused coping: HIV-infected persons as compared to AIDS patients turned out to be less likely to focus on their emotions. Emotion-focused coping is necessary and beneficial when the individual has a low sense of control over stressors. Such individuals when faced with stress have to cope, first and foremost, with their emotions evoked by the stressful event [20].

No statistically significant differences were found as far as the remaining strategies are concerned. AIDS patients do not differ from persons infected with HIV in terms of humor, alcohol abuse, or denial of their illness. It should be noted also that turning to religion is rather infrequently used as a coping strategy by both groups. HIV/AIDS patients declared no ten-

dency to pray or participate in religious practices so as to reduce their illness-related stress. This result seems noteworthy, the more so that it is not typical of patients. For example, patients with sclerosis multiplex (SM) seldom utilize problem-focused coping, but turn to religion instead (especially women) [21]. Spirituality regarded as an outcome of coping with the stress of illness turns out to be also a very important resource and benefit gained from coping with SM [22].

Psychosocial benefits declared by HIV/AIDS patients were rather few and did not differentiate between the two patient groups. An analysis of the type of benefits gained from illness revealed that the patients appreciated most their interpersonal relationships and personality development (growth of personal strengths), while they declared less benefits related to their spiritual development and changes in life philosophy.

The study results may have practical implications for professionals working with HIV/AIDS patients. First and foremost, the findings suggest that therapy focused on expression of emotions should be applied to patients with AIDS to a larger extent than to HIV-infected people. Thus, the development of groups providing emotional support and self-help groups for AIDS patients seems to be particularly indicated in the light of these research findings.

It follows from many studies that the image of illness may indirectly or directly influence treatment outcomes. Studies on determinants and manifestations of a positive illness perception are in progress. Patients with AIDS typically have a not too favorable perception of their disease, but from an objective point of view such an image is justified and realistic. However, every possible effort should be made to encourage the formation of a hopeful image of the disease. Therefore, authors of this study recommend that individual cognitive-behavioral therapy should be provided to AIDS patients who consider their health condition as serious and not giving much hope (i.e. who have a low sense of control over their disease and do not believe in treatment effectiveness). Thus, therapeutic interventions and talks should be targeted particularly at these aspects of illness perception that are unfavorable from the theoretical viewpoint. Rather few studies have demonstrated that such interventions are meaningful and e.g. allow to discharge the patient to home after a shorter period of recovery [23, 24]. Research is in progress into efficacy of therapeutic interventions that are aimed mainly at a positive modification of illness perception. Researchers encourage continuation of studies on these problems and expect

that this research area holds promise for improving patients' quality of life [25].

CONCLUSIONS

1. Illness perception or the subjective image of their disease is more positive among HIV-infected people than in AIDS patients.
2. The group of AIDS patients as compared to the HIV-infected group is more likely to seek emotional support from others.
3. Both studied groups declared gaining psychosocial benefits at a similar level.
4. The research findings have important implications for therapists working with HIV/AIDS patients.

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Address: Marlena Maria Kossakowska, Ph.D., University of Social Sciences and Humanities (SWPS), Campus in Sopot, 16-20 Polna Str., 81-745 Sopot, Poland, e-mail: mkossakowska@swps.edu.pl