SPECIAL PAPER

Social dimension and work with the individual - AIDS patient or carrier

Stefanos Koffas Ph.D, SW
Lecturer, Department of Social Work,   Frederick University, Nicosia , Cyprus

Abstract
"It is already internationally accepted that a disease is not an exclusively biological phenomenon but has a social basis as well. Therefore the health question cannot be solved through care services alone, but through the harmonious coexistence of the individual and his ecological and social environment. The existence of Health Services is a fundamental agent of social organisation and quality of life. The social determination of health which does not deny the biological part of the person, but rather correlates it to the social conditions" (Greek Cancer Society, 1991: 73) is the dimension that rehabilitation sciences, such as Nursing and Social Work, take into account. Hence, social causality should be examined as a determining factor in shaping health. The disciplines participating in the provision of care, rehabilitation and welfare services have vast fields of intervention, which are mostly implemented in the natural space, family, work and social; they always take into account the extent of the framework of the possible needs and causality factors, of problems pertaining to the individual or the community (Agrafiotis, 1993).

Key Words: AIDS, Intervention, Psychical support, social care

Coresponding author: Stefanos Koffas, Frederick University,Nicosia – Cyprus, koffas@gmx.de

Stages of the AIDS disease

Within the operational framework of a wider interdisciplinary team, which works with AIDS patients and carriers, systematic work with the AIDS patient-carrier at all stages of the disease is absolutely essential. These stages include the "familiarisation" phase with the given health condition and the phase of the psychological processing of emotions.

According to Kubler-Ross (1987) familiarisation is distinguished by five adjustment stages, which have been found to be descriptive of patients who find out they suffer from AIDS.

a. **Denial and isolation**

The patient denies accepting the truth that is being disclosed to him and withdraws. It is usually accompanied by a series of appointments and repeated medical and clinical tests, based on the secret hope of proving the diagnosis wrong or finding a specialist to restore his health. It is quite a distressing situation which creates many problems to the patient's behaviour and his relationship with his immediate and wider social environment, but also with health professionals, since at this stage he does not accept their offer for help and is usually in denial.

b. **Anger and envy**

The proverbial question "why me" is accompanied by intense anger and envy of the healthy people around him. These are clearly negative feelings which do not only burden the patient himself with his overall aggressive behaviour, but also all those around him. Quite often this anger is addressed to health professionals, since they are the people he is more closely in contact with, who should be prepared to deal appropriately with such manifestations of emotion.

c. **Some sort of bargaining of the problem**

This is a first attempt by the patient to adapt,

during which, though, he denies to face reality and tries to lighten the problem. It regards an attempt to seek alternative solutions, an intense search of religious support, but also a turn towards, often questionable methods beyond the admissions of medical science. When he finally realises the situation and the extent of the problem, after of course unsuccessful efforts, he shifts to the next stage.

d. Depression

It concerns the acute form of negative reaction, which states resignation and is quite dangerous due, perhaps, to the extreme self-destructive reactions of the patient. Health workers, whether nurses or social workers, being aware of the symptoms and the distinctive signs of emerging depression should certainly take the initiative to intervene, in cooperation with the doctor and psychologist of the interdisciplinary team.

e. In the end **Acceptance** sets in through the defence mechanisms (denial, displacement, projection) which will either lead to adjusting to the disease or the patient will continue to exhibit behavioural problems towards himself and his environment (Greek Cancer Society, 1991: 54).
According to specialised scientists who work with AIDS patients, the second phase that the patient goes through includes, basically, three psychological stages.

First stage – Judgment

"The first reactions after the announcement of the devastating news are very similar to the reactions following the diagnosis of other fatal illnesses, such as cancer. They are characterised by interchanging periods of denial of reality and intense stress. The patients are dominated by mingled emotions of anger, sadness, depression and despair over the ill fortune of being the victims of a terrible disease. The emotions which govern the patients, at this initial stage, are interpreted as a reaction to adjusting to a cruel reality. In the case of AIDS, though, the reactions stemming from the stigma of the disease and the fear of looming social isolation are also added; 'I'd like to infect the entire world and annihilate humanity', was a patient's confession. Hence, their initial reaction may be so intensely negative that they are consumed by emotions of indifference and anger about society and to revert to high risk activities, such as uncontrolled or multiple sexual encounters or excessive use of drugs. Their emotional charge is so severe that self-destruction tendencies often develop (Annual Pediatrics Therapeutic Briefing, 1988: 76).
At this stage the health professional's objective is to facilitate the patient in expressing his emotions and fears and to listen to him carefully. In order to achieve this, the development and maintenance of good interpersonal climate and mutual trust is essential. Many times, the AIDS patient does not dare to discuss the particular subject with people close to him, since it involves very particular personal issues, predominantly of his sexual life. Perhaps he does not even have anyone to talk to about all the things that terrify him, the unknown that scares him and the uncertain future which is closing in and is creating immense feelings of insecurity. He will never hurt his own people by expressing emotions, as he does not even know yet whether they will understand him, but, also, he has not learnt to share such issues with them (Papadatou, 1995).

The Social Worker or the Nurse is usually "the scientist who is able and has a duty to listen to him, while stressing that it is his unalienable right to discuss whatever feelings he has and proving to him that this is the main reason he is standing by him. He is not a judge, but a listener and a counselor. His ability to listen and understand helps the patient believe that no emotion is reprehensible, because no emotion is wrong. Therefore, the patient is empowered to express any of his emotions" (Mamai, 1994: 40). The health professional, with his genuine interest and his presence, might provide a meaning and a message about the patient's worth, even in the condition he is in, through simple, warm human contact. It is an element which is often overlooked (Pantazakas and Mentis, 2003).

Second stage – Transitional adjustment stage

"During this stage denial starts to abate. Emotions of anger and stress ensue. Patients display confusion, prostration, personality disintegration and symptoms of isolation, guilt and despair. They profoundly feel that they are being marginalised even by their own family. Displays of stress might take on the form of panic, while patients treat everyone around them with suspicion" (Kouskoutis, 1988: 89).
The exhaustion of the individual is utterly more intense, since his condition now enters the sphere of consciousness. Hence, the "psychological problems of the patients become more serious and complex at this time, because they now pertain to

their conscious effort to alter their behaviour, to assess their capabilities and to control their actions.   They realise that their personal independence and their very own existence are undermined by the invisible and insidious activity of the virus.   Their only remaining option is medical care, even with its limited ability to control the disease.   The lack of effective treatment, the continuous battering of a hostile and nervous society in conjunction with their withering body, results in their ever deteriorating self-confidence. After all these, they are obliged to accept the new structures, the new values and the new behaviour patterns that society imposes on them.   They review their relationship with themselves, as well as with their families and wider social environment.

The process and the duration of the patients' adjustment depend on their education and the maturity of their personality, but also on their previous way of life. Homosexuals, who almost never regret their sexual choices, find it easier to compromise with their new reality. Bisexuals usually have many feelings of guilt over their previous life and find it harder to adjust. The biggest problems are faced by drug addicts who, while being socially isolated, are at the same time facing a fatal disease which requires behavioural self-control and a substance addiction which requires immediate removal" (Annual Pediatrics Therapeutic Briefing, 1988: 77).

At this stage, patients need to be supported in their new everyday life conditions with its new givens, in an environment that has altered, mostly in its behaviour, probably in regard to its attitudes and values too, in order to approach their situation by taking under consideration these new facts. It is an extremely sensitive process which is permeated by the effort to regain a sense of trust, especially in regard to human relationships; the patient considers them, at least as having been betrayed or full of suspicion or related to feeling pity or sorry for him and his condition. The starting point of the process of regaining trust towards human relationships begins through the professional relationship. In order for the patient to finally manage to see himself in a positive manner, he should be viewed in the same positive manner by the professional.   At this point the attitude of the Social Worker or the Nurse is decisive. He is now certain about the difficult reality of how the patient's life will develop; his intention is not to make the patient forget or smile, but to help him externalise whatever

feelings he might be having, to extricate the denial and pressure and to discuss the reality. The professional's main care "is to not get carried away by his emotions and present a fake, cheerful and joyful image for the patient; the latter having experienced anguish and deterioration on a daily basis, discerns the lie and loses his trust. Solace has no place here. What is needed is head on confrontation with thoughts and facts" (Mamai, 1994: 47).

The professional guides the patient to handle himself the feelings that overwhelm him in regard to himself and those around him, the doctor, the nursing staff, his family and friends. Therefore, he always approaches patients with the objective being their free expression, the development and encouragement of open communication between the patient and the other health professionals, in order to discuss and get answers on the questions concerning the patient both on the medical and everyday personal fronts.   That is because the greatest need expressed by patients at this stage is information.   However, the patient, through previous conversations with health professionals, should have felt that he can trust them and he should have experienced their understanding for his current situation. The support of the patient's dignity by the professional is the foundation of genuine and candid communication.   It is his obligation to find out the patient's sore spots and the way he perceives his situation. He ought to respect his feelings and thoughts and help him to find and use his own sources of strength (Breach, 1988).

During this endeavour, which is hardly easy, the professional should on many occasions be prepared to accept the patient's anger, even when it is directed towards him, as an expression of his anguish and to not become distant, rejective or even vindictive. The social worker or the carer, particularly during the effort of supportive intervention, should reinforce the patient's self-esteem by praising self-care and by reflecting positive appraisals whether with or without words, through his actions and behaviour.

Finally, at this stage the professional undertakes, according to his specialty, alone if he is a social worker or as a member of the interdisciplinary team if he belongs to a different specialty, to handle the practical issues that emerge for the patient and his family, such as financial, employment problems, enrolment of children in day-care etc. The individuals are provided with

information about state benefit entitlements and efforts are made for their arrangement. They are efforts which supplement the attempt to provide mental relief to the patient, since they offer some comfort by providing solutions to additional issues that worry him.

Stage three – Acceptance of the disease

"At this stage, patients develop a new, stable personality. They now accept the behavioural limitations imposed by their disease and handle their situation with realism. They make efforts to lead more productive lives and discover new sources of joy. They develop feelings of courage, and affection for the others and pay greater attention to the quality rather than the duration of their life. They no longer consider themselves victims and find satisfaction when involved in altruistic activities. They take particularly good care of their health and are consistent with the doctors' directions and guidelines. The acceptance of the disease is of course representative of some sort of defence, but at the same time it denotes the loss of their health and independence. The ability of the human nature to exhibit such sources of inner strength, under these circumstances, is remarkable" (Annual Pediatrics Therapeutic Briefing, 1988: 78).

At this stage the professional's presence, by the patient, and his autonomous discipline, render his role pivotal, his responsibility fundamental and his contribution to the rehabilitation programme valuable. The possibility of the patient's psychosocial rehabilitation presupposes the active participation of the patient himself, his family and the representatives of the various disciplines. It is, usually, a long-term process which requires the coordination of the efforts of all those involved, always bearing in mind what is best for the patient's health (Sifakaki, 1995).

Rehabilitation is definitely "an inalienable dimension of the integral individualised care of a patient, in order for him to regain the maximum physical and psychological balance and return to the effort of life, with the greatest possible physical-mental-spiritual, social and professional functionality and performance. The rehabilitation objective for an individual with AIDS is to improve his quality of life, by maximising productivity and minimising his dependency, irrespective of his expected survival rate. Every person with AIDS needs opportunities to deal with what is happening to him at his own pace and manner, in order to live a quality life,

according to his own definition, given that the term is subjective and clearly personalised. For some it might mean return to employment while for others taking over again the maternal or paternal role, to the extent that this is possible (Greek Cancer Society, 1991: 9).

Furthermore, the effectiveness of psychosocial rehabilitation "is reinforced when the patient is hospitalised at special services for patients, in organised palliative care programmes which integrate the continuation of care at home with special teams, which can improve the patient's quality of life and fulfill his wish to spend the last moments of life where he first came to life" (Greek Cancer Society, 1991: 16).

Over time the facts certainly change as the terminal stage patient, who has been through a lot and still is, feels that the more his health condition deteriorates the more helpless, scared and desperate he becomes. As "the end" is looming, he senses it, he expects it but he is also scared of it. Death is something unknown, something unfamiliar and it is in the nature of the human being to fear the unknown, to fear death. It is this fear that causes the feeling of loneliness and failure, but also of the responsibility towards those dependent on him, such as his family. He feels intense loneliness, the victim of a disease that those around him do not even dare to pronounce and whose connection with the expression of sexuality, a subject so misunderstood, causes various aggravating reactions and comments. Many times, though, he does not think about passing away, but that he did not have the chance to complete the things he started and that he is leaving behind something unfinished and half done. That he is duty-bound towards people, like his parents, his family, his children and he is tortured by the fact that he was not able to fulfill his obligations, either through his ignorance or carelessness. Quite often he feels that he has betrayed them. He also senses the pity and the sorrow of the others and feels incapable to react, since everyone has enveloped him in an overprotective cocoon which usually suffocates him and detracts from him all the roles and all the possibilities to feel even a little bit useful (Mpotsi, 2001).

On the contrary, he feels that he is becoming a burden. "A burden to his family, a burden to his relatives and friends, even a burden to the hospital, which he cannot see it able to provide any solution or treatment for the condition he is

in.   Hence, he sees that the things that used to interest him or still do have one by one stopped being with him. His strength has completely left him and he cannot function as he used to. He realises, on his own, that he is withering. Even for the simplest everyday things he needs the assistance of others. He loses weight, his colour and his mobility are minimised. His strength is lost day by day and the situation is now beyond his control" (Mamai 1994: 26).   These are emotions that he probably had not experienced before, which are unfamiliar and difficult to deal with.

And at this final stage he discovers that even the course towards death is a dynamic psychosocial process which he will have to go through. It is at this point that the health professional's role is introduced, to offer the patient and his family support on the psychosocial interchange of emotions, the acceptance of death and grieving. In simple terms, the professional is called upon to offer support to all these people, to stand by as necessary to the patient and the members of his family, to handle bereavement and the sense of hollow in those left behind. The difficulty for the professional is to always be able to give, taking care not to deplete his mental reserves by dragging himself in the self-entrapment of depression, but by distinguishing where, how and what to give (Papadatou/Anagnostopoulos, 1999).

That is why the professional, especially in such health units, should work on himself, his own feelings on death and really accept it, before working with terminal stage patients. The same is certainly true for the other members-professionals of the interdisciplinary team. Let us not forget that he, too, is a person brought up in a specific society, has finite limits, follows principles, but at the same time is affected by social occurrences, which have already shaped a certain stereotype about the meaning of AIDS. Thus, a personality structured under such circumstances has, on the one hand, to work hard on itself, its fears and insecurities in regard to the notion of death and, on the other, on the complex, bilateral transactions of the patient and his family.

Each case that evolves in the professional's presence has the ability to bring up issues related to himself, his innermost doubts, his secret fear, the sense of powerlessness or even despair. If he has not worked on his own feelings first, he will fail as a professional, since he will not be able to offer the support needed and requested by so

many people. In order to get close to a person on the verge of death and actually being able to offer to him takes spiritual, mental, moral maturity and a lot of courage. Replenishment sources as well as means of releasing tension are essential to the professional to avoid burnout.

At this final stage, the minimum that the professional can do is to maintain a consistent attitude towards the patient and his family. It is a great relief to a patient, on the path to his final stage in life, to know that someone is with him. The professional's presence alone offers support, a sense of certainty and security both to the patient and his family, that they are not alone at these grave and difficult moments. He might just sit with him for quite some time and barely talk. During this time even silence can be something extremely special to offer to the patient.   The health professional does not guide the individual into accepting and reconciling with the fact that he is dying. He is not helping the individual to die, but to live until he dies. At this point he is not working on the problem, rather with the individual that has the problem. He maintains a candid communication with him without hiding facts and without imposing on him information about his condition.   He respects the way the individual chooses to deal with his death (Lagou, Papadopoulou, 1991: 170).

At this final stage of life, the health professional should on many occasions and as necessary let the individual guide him and be ready to respond to his needs by encouraging an open discussion. He should be willing to listen to his thoughts and fears, without offering advice or solutions, but to offer emotional support through his interest and understanding. The focus is on the present, on all the possibilities and abilities that the individual may use immediately, without encouraging him to make plans for an uncertain distant future. Hence, the individual is facilitated in accomplishing his short-term goals, the arrangement of pending issues and the development of a deeply emotional and fundamental contact with his loved ones (Lagou, Papadopoulou, 1991: 170).

The nurse's or social worker's most significant offer to the individual is based on the acceptance of his condition and his reconciliation with the idea of dying.   The professional's acceptance helps the person accept his self and death. It is based on the support and the discreet presence near him until the final moment. It is expressed

through actions, the assurance that they will not abandon him and the recognition that he is much more than just a body that is withering and changing daily, a distinct personality that exists as such until the final moment.

The health professional helps the individual to live as painlessly as possible during his stay in hospital until the time of a peaceful, dignified death, still feeling part of his family while being free to die his own death. The support towards the dying patient should be based on the respect of his particularity as well as on his right to choose "how he wants to die", e.g. at home instead of in hospital, with these relatives and not alone, etc., when, of course, this is possible by the specific conditions of the disease.

During this final stage the professional "should be able to assess the situation within which the parting process is taking place and encourage the conditions which facilitate its completion. The way in which the professional will work with the dying patient and his family also depends on the role that the dying patient and his family members had before the death, as well as on the role that each member is to take in the new emerging family pattern" (Lagou, Papadopoulou, 1991: 170).

Every AIDS patient deserves the best care to remain able to be himself for as long as possible. The measure of humanitarian care that each professional is duty-bound to provide depends on the beliefs, the values and the emotions of all those, of us, who participate in his care. Love, as long as it exists, has access everywhere, especially at such difficult times.

Afterword

Considering the course of chronic illnesses and especially those with a predetermined ending, we conclude that certain constant attributes join illnesses together throughout the centuries. "Aeons apart while epidemics of times past and collective forms of reaction to them are today absurdly current. A fear which is easily derailed into a therapeutic apartheid and cruel suppression joins all epidemics together. In order to restore social order and as countermeasures against the divine wrath the obligatory denouncement of the patients, their exclusion and special health bulletins take hold. From plague, to syphilis, to cholera, to leprosy, to the most recent disease of AIDS, fear is constantly engraved at the heart of the epidemic" (Tsalikoglou, 1994).

These reactions are directly correlated with the institutions, the mores and the structure of society and depend on the extent and the quality of the information of the various social groups. This sequence of societal institutions and structures assert the complexity of AIDS as a phenomenon and enforce its investigation as a multiple challenge. "Thus at the theoretical level AIDS may be characterised as a hybrid, since it belongs to the category of standard infections and to the category of civilisation diseases. At the social practice level, AIDS charges social ties and renders them more fragile and at the same time it is connected to differentiated ways of life. In regard to the cultural background it is connected to rules that define the limits and the notions of individual and collective actions. The limits appertain to what is tolerated, normal, acceptable, private and public" (Agrafiotis, 1987: 177).

At a personal level the various reactions are the outcome of the psychological parameters that constitute the personality of each individual. The investigation of the changes in the behaviour of the carriers and the patients, because of AIDS, is a significant step for the attempt to deal with the risk of developing discriminatory trends against specific social groups which are already marginalised in the wider social perception. These trends can easily flow over even to individuals who do not belong to the specific groups that exhibit "dangerous" behaviours. In any case though, they are not consistent with the work of health professionals who are required to offer at all stages of the disease without prejudice or social obsessions.

Hence, by assessing the positions of individuals, based on bibliographical data, we are obliged to note primarily the confusion between diffuse fear which accompanies this disease, more so because of its correlation with the abused meaning and stereotypes of sexuality, the feeling of infection risk, but also many professionals' awkwardness to react due to social comments (Papastamou, 1989). This confusion, as the prime factor of the fear which is all encompassing, constitutes one of the most fundamental investigation objects of the disciplines who deal with AIDS. Within the scope of this effort, the sciences that deal with the psychosocial aspects of the issue have fairly contributed, with the development of data and observations, which helped both to understand the spread of the HIV virus and the intervention methods. Thus, the need for being interdisciplinary became apparent through four

fundamental facts. "First, AIDS is foremost a social problem; second, AIDS demands the complex compound mobilisation of forces (social, cognitive, psychological, financial) in its management; third, the AIDS epidemic has proven the vast significance of the role of the media in the shaping of the social discourse on the epidemic and fourth, the emergence of new groups which are implicated in the spread of the virus" (such as families and orphans, the wives of drug addicts) (Agrafiotis, 1993: 88).

AIDS, a definitive factor in human relations today, should be dealt with, especially by the members of the health sector, as a serious social-medical phenomenon. Timely information and briefing, the correct adoption of measures by the citizens-state, the avoidance of racist policies are paramount in the interventions of the health professionals, so as not to allow the breakdown of human relations and, certainly, the professional attitude and offer to those suffering, on all fronts and with all involved, whether directly as patients or indirectly as individuals of the family and the social environment.

It is certain that science will eventually prevail, as has been the case on so many occasions in the past, the virus will be defeated; until then the offer to the patient should be professionally provided, as correctly and integrally as possible, by addressing through interdisciplinary means all facets of the disease.

By adopting the World Health Organisation message "let's share the challenge", health professionals can contribute to the challenge – challenge cause, challenge effect – of the alienation of the moral, political, medical, social act brought on by the disease by offering their services at each phase and at all intervention stages of the disease.

As health sector professionals, focused on offering for the well-being of the human being, we are not allowed to let the disease's social "profile" take on larger proportions than themedical "profile", neither to allow the Acquired Immunodeficiency Syndrome to correspond to the Social Deficiency Syndrome (Tzortzi-Tzannone, 1991).

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