REVIEW PAPER

Social Dimension and Work with the families of AIDS Patients and Carriers

Stefanos Koffas, PhD
Frederick University, Department of Social Work, Nicosia – Cyprus

Abstract

The family constitutes a small social group. Each problem and each experience of one of its members touches the others in the group. Namely, there is a form of constant interaction among the members, which is intensified by internal and external factors. For situations that the family members classify as low in importance, temporary and controlled, their resolution process as well as any cost is manageable. Therefore, reactions are, most of the time, quite limited. What happens though with serious multi-factor impact situations, especially non reversible ones, such as illnesses? What is the reaction of the family members in cases of terminal illnesses, which are also related to the sensitive issue of a person's sexuality? Every professional in health, welfare and rehabilitation services will face these questions and situations in his direct or indirect involvement with the members of the patient's family, in his effort to properly accomplish his task.

Key Words: AIDS Patients**,** HIV Carriers, Families, Social Dimension

The family's first reaction to the diagnosis

"When a family is informed that one of its members suffers from AIDS all its prejudices arise through panic, defeatism and impasse. The web of prejudice surrounding this negatively charged term derives from the public's incomplete or poor information and inadequate knowledge about the causes of the illness. Hence, the announcement of the diagnosis to the family gives rise to feelings of chaos and profound disorganisation, both psychological and practical. This is true whether for the father who often bears not only the financial responsibility for the family, but, in his traditional role, imbues the members with confidence and security, or the mother, who may bear her share of financial responsibility, but is also the person that provides equilibrium to the family through her affection, warmth, love and rich sentiment. If the diagnosis concerns a child the situation is even harder. The parents feel guilty about the illness, inadequate in their role and are consumed by feelings of despair and crushing despondency" (Greek Cancer Society, 1991: 87-88).

So what happens when a family is informed that one of its members is ill with AIDS? Does a crisis erupt and if so, how is it dealt with? Should it be discussed among its members, but also with professionals or is it a secret that causes shame and should remain within the confines of the household or even between certain members? Which defence-reaction-support-protection mechanisms should it develop towards, but not only, the sick member? What should it know and which actions-behaviours should it avoid? Which are the behaviours that provide assistance-support- relief? These are questions which, at least initially, lead those involved to despair and impasse since they do not know how they will handle them. Even more so they cause erratic or even violent reactions, but also changes in the behaviour and reactions of the family members; if not dealt with, they will not be able to use their strength to effectively help and support the patient along his difficult path of the unequal battle with the illness.

The contribution of people such as the medical staff is necessary; but also of helping professions, such as social workers, with specialised scientific knowledge in cases of terminal illnesses, crisis situations and handling of negative behaviours, but more so of systematic approach in the intervention process, whether for treatment or support purposes (Koutsogiannidou, 2001).

Family behaviour patterns and professional help

In order to properly help the patient's family along

the difficult path of living with the illness, we should be aware of all the possible reactions the family may exhibit, immediately after the diagnosis of the illness. The reactions depend on many factors, but are mainly related to the particularities of each family, the religious and philosophical perceptions it maintains on matters concerning life and death, the broader human and social values and the extent to which it adheres to them, the relationships and the importance it attaches to the outlook of their social milieu etc. By taking all these interrelated factors into consideration the reactions that may occur are the following:

1. Abandonment of the agency or the AIDS patient by his family.

"After the diagnosis of the illness the family frequently abandons the member that has been infected with AIDS, especially if it is one of its children. The reasons that lead the family to this action vary. The family either considering that the member-patient is solely responsible for his illness –especially when he is homosexual, has free sexual relations–,or fearing social isolation and outcry, or the strict principles and values it adopts is led to[adopt] this behaviour, causing what ensues even harder for the patient. Relationships among members in families with this behaviour could not be described as particularly good or satisfactory even before one of its members contracted AIDS, while the father's behaviour is more negative and rejective than that of the mother and the siblings of the patient. The patient has now to deal with, besides the "shock" of the diagnosis, the loss of family care. Emotionally, this loss is especially detrimental for the patient" (Greek Cancer Society, 1991: 89). None of his familiar persons are near him; the valuable emotional support is lacking. Quite often livelihood issues also arise since the patient is now alone and without financial support.

In the case of abandonment, the health professional tries to approach the family and explain that the member-patient is not solely responsible for his illness and, at the present stage, needs their emotional and financial support. Experience so far has unfortunately shown that the health professional's effort does not yield positive results or at least not immediately. It has been observed that relationships among the other members deteriorate; feelings of personal guilt, disputes and intense rows often arise, especially in an effort to prevent some of the members from offering help. The professional addresses the patient first, since he is the person in immediate need and works with him in view of his emotional support, which at this given time is essential; he continues to offer his services throughout the stages that the illness's development progresses (Koffas, 1994: 215). Pre-specified procedures, such as benefits, special hospitalization cards for chronic illnesses, psychological support through existing social welfare programmes, are also activated for the support of the individuals. Meanwhile, if and whether possible, the professional tries to mediate among the family members with a double objective; on the one hand to reinstate a relatively balanced state among the other members and on the other to possibly bring about reconciliation with the rejected member (Konstantinides, 2004: 53).

2. The family may become hyperactive.

"Immediately after the first 'shock' of the diagnosis and the initial awkwardness a spike of activity by the relatives may follow, which instead of supporting the patient tends to 'obliterate' him, namely completely substitute him as an individual. The relatives inundate the patient's room with overwhelming care and a multitude of benefits which bewilder the patient. He begins to feel strained towards his kin, even before he realises what is happening to him. Surely this emotional outburst is impulsive, and dwindles or dissipates when the patient needs or seeks it" (Greek Cancer Society, 1991: 89). In the worst case scenario the family will even proceed with the virtual obliteration of the patient-member, if this is deemed essential for 'its normal continuation', in an effort to overcome the impact of the pressure of the social milieu.

The health professional who will diagnose this type of reaction should direct the family to abate its energy, so that the patient will feel more comfortable and normal, and neither party will become physically and emotionally exhausted. Depending on the reaction and the behaviour exhibited by the patient, namely receptive-awkward or, conversely, denial, his relatives should understand that they are indeed valuable and he needs them by his side, but at the same time this should happen in the same way it was happening until now, that is discreetly and not in an obtrusive manner (Koffas, 1994: 216).

The provision of care and any form of support should be supplied, as much as possible, in

measure, 'normally', that is with empathy, by respecting the patient's need to think, reason, act and decide autonomously, recompose and mobilise defence mechanisms, similar to any normal person. It is desirable that the family avoids any exaggeration and leads a normal life as much as possible. It is also essential to clarify to the family that care will need to be offered for a long time, hence they should be prudent and not deplete it during the first stage, because the patient will need it in the following stages; but also the members themselves should not become exhausted by the initial phase of their extreme efforts. In the case of the artificial virtual obliteration of its member from public life, it is necessary for the professional to apply techniques to combat feelings of shame or apology towards individuals in their social milieu. It is quite a painful process; first of all it presupposes the members' will to participate in the so-called process of emotional self-control and self-realisation. Past experiences and defence mechanisms deriving from guilt, which individuals use experientially and unconsciously to a great extent, should be detected, analysed, realised as being negative and replaced by others which emphasise reinforcement, self-control, initiative, determination, but also an overall more positive life attitude towards personal issues, while ignoring the impulsive but at the same time often indiscreet meddling of third parties.

3. Overprotectiveness may be another possible reaction of the family.

"Through it the family marginalises the patient. It does not allow him to participate in activities within his powers and abilities. He loses his energy and he is forced to adopt the passive role of receptor and of whatever is generously offered to him. He abandons activities, roles, duties, entertainment, obligations. He loses his identity. This behaviour, besides motives of love, may encompass 'pathological conditions'. It is possible that the relatives are manifesting a guilt complex, a need to confirm their presence and their personality, vindication and self-fulfillment through the unconscious repression of the patient" (Greek Cancer Society, 1991: 90).

The health professional's work with this family type should help the patient maintain his self-confidence in his personal life, and his functionality in the execution of all his usual activities; at the same time he should direct the relatives to get involved in other activities in order to allow them to decompress from their personal obligation to offer help, to attain emotional balance and self-confirmation. It should be clarified to the family members that the focus of their activities should not aim to replace the patient himself, but rather to normalise their relationship beyond any guilt feelings of obligation (Koffas, 1994: 217). The professional's efforts should focus on making clear to the family that their relative is still alive and consequently he is able to respond to most challenges and cover his needs by himself. By depriving him of the possibility to function autonomously and manage his life, the motive to continue trying and living is severed. The lack or the artificial lack of self-reliance leads to withdrawal and waning. The patient's family should unquestionably take care not to doubt their relative's ability and capability to keep being active and assuming responsibilities. They should realise that the role they ought to assume is ancillary and supplementary to the patient's efforts and only when he consents, but it should never deprive or substitute.

4. "The family's self-subjection to personal hardship at any cost, *when the patient does not need it, transcends the boundaries of overprotectiveness, becoming almost self-punishment. An indicative example of this are the endless sleepless night and days, sitting on a chair by the patient's bedside, when the patient has no such need. The causes for this kind of behaviour may be extreme love which is manifested through personal cost and exaggeration. However, there is a possibility that latent feelings of guilt for a past poor relationship or behaviour may exist and hence submit themselves to some form of hardship and redemption. The reaction of self-punishment may also be indicative of emotional immaturity"* (Greek Cancer Society, 1991: 90). In such a case, any concealed or even overt feelings of personal guilt ought to be dealt with within the scope of a personal internal endeavour to investigate their causes, to self-control thoughts, behaviours and actions, and not within the scope of a self-subjected effort to redemption or exoneration, mitigation or reimbursement of existing or fictitious responsibilities. When the inordinate offer of care towards the ill family member is based on unconscious reciprocation in order to attain

redemption, it can only accrue pain and emotional misery. In cases of self-subjection the discharge process requires individualized treatment by detecting the personal factors/causes which lead to the manifestation of such obsessive-compulsive behaviours and displays of feelings of self-rejection. A deeper personal analysis of the life and an overview of the personal experiences that these individuals have had becomes the onset for recovering self-control and balanced emotional expression. In this case the professional approach aims to reteach the individual self-esteem, optimism which the individual has suppressed to the unconscious and to restore positive thinking. Through such psychosocial rehabilitation the family members' tendencies to self-punishment and exaggerated reactions of self-subjection can be dealt with, a fact which will eventually lead to change their behaviour towards the ill member.

5. Anger or rage may be another possible reaction of the family when they hear of the diagnosis.

"At a difficult point in life, anger as a feeling may be described as perfectly normal and decisive of the tension following the diagnosis. The anger directed at the illness can be described as an expression of frustration which may provide relief to both the patient and his relatives. However if the anger of the relatives gets directed at the patient the problem is intensified. In this case, the patient is blamed as being solely responsible for the condition of his health and consequently for all the problems that result from it. Even more so when there are unpleasant social side effects caused by the social milieu due to sensitive personal matters, especially of sexual life and conduct" (Greek Cancer Society, 1991: 89,90).

The health professional's role consists of the effort to channel the anger correctly. It is natural, that many in the first stage of anger will react quite negatively and forcefully. It is a normal reaction and should be viewed positively, in the sense that it is being used as a means of release by the angry individual, even if it is not considered a warranted reaction. Next usually follows the phase of guilt for the improper behaviour, which, by suitable help by the professionals, will usually lead to redemption. The relatives should gradually understand that the situation is now given and efforts should be directed to supportive behaviours towards the patient and cooperation with the medical, nursing and welfare staff in order to deal with the problems. It should also be understood that the mental equilibrium and tranquility of the patient are necessary prerequisites in order to cope properly and effectively with the difficult fact of the illness. In the end, even with the existence of elements of anger, it will be the relatives who, to a certain extent, will bear the consequences of caring for the patient. They will also have to deal with their personal wearing out due to psychological pressure and feelings of ambivalence. The health professional should discern these situations and bear them in mind when developing the intervention plan with the patient's relatives (Papadatou D., Anagnostopoulou F., 1999).

"Everything that has been so far mentioned is not airtight, as there is nothing 'absolute' or 'airtight' in human behaviour. The aforementioned types of family reaction might be come across as cited or two different reaction types might coexist or even be combined. In such a case the situation becomes more complex and requires careful consideration and handling" (Greek Cancer Society, 1991: 90).

The professional's role is important in order to maintain equilibrium between the two parties: the patient and the family. The patient's family defines its vital space, despite the probability of any tension. The patient needs increased communication and emotional support on a genuine basis from the family members. When despite the goodwill of relatives for substantive support they are lost for words, a tender look remains as a token of love and holding the patient's hand passes the message: 'you are not alone, we will fight together'. This is the work that the professional should pledge through his job (Pantazakas/Mentis, 2003).

The course towards the end

"It is a fact that as the illness progresses and brings about changes in the psychological make-up of the patient, important rearrangements take place in the family's structure and the psyche of the patients as they head towards death. The entire family is in crisis and the characteristics that have been described are:

a. Depression
b. Perplexity and constant occupation with the patient
c. Thoughts and stress

d. *Planning the family's course in relation to the illness's course and after the death of the patient"* (Greek Cancer Society, 1991: 93).

A family whose member is ill and is at the terminal stage of the illness has been through many distressing emotional and structural changes and reaches this stage tired and exhausted. After a long, hard course full of frustrated hopes, fears and failures, endurance, particularly mental, is limited. Especially since the end is now in sight.

"The imminent death mobilizes en masse stress, fear, uncertainty and depression in the family members. Often very practical and routine problems of financial or organisational nature become the obvious targets for the imminent stress of losing someone so close. In cases of terminal stage AIDS patients the family often hears from the doctors that the situation is hopeless and the patient's life is short. Even in these cases, even when the patient is unable to fight and prevent death, he can enjoy however many days or months he has left in a positive way. However, when the family resigns and simply waits for the patient to die, how can [the patient] hope for himself when they don't hope for him?" (Mamai, 1994: 30).

"The aim is to help both the dying AIDS patient and his family so they may feel that the patient still has something to give to the family; even from such a dependent position he has something worthwhile to offer. He is an individual who is still alive and able to think, who through the present experience might be a source of wisdom and critical thinking for others. Being able to offer something important to the others, allows the patient to accept the protection and care and to feel less abandoned and lost.

It is vital and necessary that the family vents out. The health professional's job is particularly difficult and complex. He is available to all the members, who must be able to feel that they have someone to whom they can express their concerns, fears, guilt and grief, hence vent out in order to be able to stand by the patient's side with greater courage and strength" (Mamai, 1994: 49).

The health professional is required to be knowledgeable of the aforementioned stages and situations and to proceed methodically, discreetly, patiently and very carefully. Each family member should be able to see the problem similar to how the patient is experiencing it, through his position as a patient. Therefore, special handling is required in order to elicit from the family members mainly the emotion, so that their feelings become known, to listen to the views of the other members, their complaints, their expectations and demands, the agonies and fears, the questions for the unknown, and maybe their guilt (Athanasopoulou, 1995). By voicing feelings through this behaviourist approach, their thus far unconscious identification is achieved, their processing becomes conscious, which often leads to some form of venting out and relief or even to the onset of new more honest relationships among the members.

In the terminal stage, shortly before the end, the professional's attitude *"towards the family takes on the form of support to enable them to accept the reality of their relative's life ending, without burdening him with their own needs. [They have] to accept that he has the right to leave peacefully. [They need] to find within them why they want to extend his life. Is it their own or the patient's need? Mostly what surfaces is a need of their own and references to the patient are rare. When something like this is achieved the relatives are released from their stress and agony. They are helped, as much as possible, to stop transferring their own feelings to the patient and so he is left as free as possible to taste his final moments.*

Hence, gradually the family members are helped to accept the reality and familiarise with the illness and death. From the moment on that the definite course towards death is prescribed, all individuals have the right to choose how to die and at this point the family is paramount. The notion of separation is not easy. The contrast that emerges through the different 'wants' of the patient towards the family and vice versa extremely complicate the process of accepting the right of someone to die according to his wishes and it is not just physical death we refer to, but also social and even mental" (Mamai, 1994: 50).

Death and the acceptance of mourning

"The patient's death is an event which marks the onset of important, critical and transitional stages in the life-cycle of a family. During this time the family is undoubtedly threatened by a crisis. Its reason, and often its cause, is found in the death, causing havoc and upsetting the balance of the entire family, with psychological, social and physiological disorders

appearing as a result. Whether the death will constitute a crisis, depends on the prior structure and operation of the family and on how roles were allocated. In a family where conflicts and inflexibility in communication existed, death is a 'dangerous opportunity', a 'challenge' since it prompts the family members to adopt new methods of coping which may contribute either to the more mature and effective functioning of the family as a whole or to its dysfunction or even its break-up. The family is undoubtedly undergoing a transitional period, through intense stress. (…) Usually, during this period of emotional tension, the family, being vulnerable, is more receptive and inclined to external interventions. Therefore, the professional's timely intervention may have important effects on the family's long-term adjustment to the new conditions in life. His intervention, which should be dynamic, therapeutic and of limited duration, will aim to:

a. *Reduce the stress that the members experience during the transitional period of the crisis.*
b. *Mobilise the family system to organise its strengths and support sources it has available in order to respond to the demands that were created during the crisis.*
c. *Help the family find a new equilibrium that will contribute to its satisfactory functioning.*

When the crisis is caused by the death of a child or a parent the family is never restored to the same pre-crisis equilibrium. What is achieved through suitable therapeutic intervention are the redefinition of the role and the identity of the members within the scope of a new reality" (Lagou & Papadopoulou, 1991: 165). With the death of a member the pre-existing family and the way in which its members had experienced it dies.

"With the death of a loved one the remaining family members grieve not only for the loss of a loved one, but also of the family itself, the way in which they had experienced it for so long. The grieving process might be long-term. It is influenced by personal, social and cultural factors and bears different consequences for each family member. When all the members are facing the death of a loved one, yet each one grieves for the loss of a different relationship they had with that individual. The professional should be very well aware of this and help the members understand and accept that their grief can never be the same. The professional should help them comprehend that there is no right or wrong way to express their grief, but rather different ways of expressing it and that each one of them will accept and adjust to the new circumstances in a different way.

During this stage the professional is the family's supporter, who offers understanding and acceptance of the pain and mental collapse, initially by mainly listening to the members and gradually directing them to set goals for the life that goes on. He should encourage the family members to externalise the feelings of guilt that overwhelm them and help them, through therapeutic sessions, to overcome the sense of void that the death caused, before it becomes an integral part of their everyday life. (…) In order to be able to work with the family after the death, he ought to have worked with it prior to [the death]. When the family members have adjusted to the mourning, as per the therapist's judgment, they set future goals, they look ahead. When the wounds heal and the family emerges from the crisis, then the cooperative/therapeutic relationship between professional and family is complete" (Lagou & Papadopoulou, 1991: 168).

Afterword

Working with the patient's family through all the stages of the illness's development, right to its prescribed ending is painful; it is accompanied by intense feelings and requires special handling. Health unit staff, who as professionals are called upon to intervene both professionally and ethically should exhibit the necessary compassion. According to M. Charalambous *"every profession acquires its identity through the visible deeds it performs, responding to some needs or demands of society. These exclusive deeds suggest a sum of valid knowledge, values and convictions, ethics and special techniques –which every profession encompasses– and shape the outcome of its objective goals. The entailed deeds are executed by members of the profession and to a certain degree bear the seal of the individual qualities and behaviour of the professionals"* (Charalambous, 1991). What is expected, beyond plain duty, is empathy in how human pain functions and is dealt with and the suitable *"handling of various problems which are related to the person himself, his family*

and society in general" (Trianti, 1997: 15).

Refferences

Athansopoulou M., (1995). Counseling to seropositive individuals. Presentation during the 4th Panhellenic Psychology Conference, Athens School of Philosophy, Athens, Greece

Charalambous M., (1991). The position of Social Work in today's world. What can it offer in the treatment of current problems, presentation at the I.A.K.E. conference, Athens (19 April 1991)

Greek Cancer Society, Association of Social Workers of Greece, Commission of the European Communities, (1991), "Europe against cancer", Psychosocial dimension of cancer, Athens, Greek Cancer Society Publications, Athens, Greece

Greek Cancer Society, Commission of the European Communities, (1991), "Europe against cancer", Continuing nursing care for the cancer patient, Athens, Greek Cancer Society Publications, Athens, Greece

Koffas S., (1994), Social knowledge and perceptions of AIDS and the role of the Social Worker in its handling, Thesis, TEI of Athens, Department of Social Work, Athens, Greece

Konstantinides M., (2004), AIDS and social exclusion. Social work and seropositivity, Kinoniki Ergasia Journal, 73: 51-62

Koutsogiannidou S., (2001), Biopsychological approaches at the first aid medical department, Proseedings of Hellenic emergency nursing care seminar, Thessaloniki, 5-7

Lagou S., Papadopoulou M., (1991), Social work with cases of death. Journal Eklogi, 90: 161-172

Mamai A., (1994). The terminal stage of the disease of cancer and its dimensions in Greek reality, Athens, Thesis, TEI of Athens, Department of Social Work, Athens, Greece

Mpotsi X., (2001), Addressing the epidemic of AIDS: the state and the civil society, HIV/AIDS basic knowledge, Zagoraios Publications, Athens, Greece

Pantazakas P./ Mentis M., (2002), Social Service in Health sector. The challenge of modernization the national health system and the role of social worker, Koinoniki ergasia Journal, 66: 97-112

Pantazakas P., & Mentis M., (2003), The role of social worker at the first aid medical department, intervention in case of crisis, Journal of Social Work, 70: 71-80

Papadatou D., Anagnostopoulou F., (1999), Psychology in the field of Health, Ellinika Grammata Publications, Athens, Greece

Papagianidou M., (2010), Goodbye AIDS! Did it ever exist?, Oksi Publications, Athens, Greece

Papaioannou K., (1998), Sociomedical work, Kinoniki Ergasia Journal, 9-10: 7-13

Sherr L., Family-based approach & structural approach at AIDS 2010, XVIII International AIDS Conference, Vienna, Austria

Tomlinson M: MSM and legal barriers to familybased care. XVIII International AIDS Conference, Vienna, Austria

Trianti V., (1997), Social intervention for seropositive individuals, Annual Report K.E.E.A., Athens, Greece