

The Organization of a Counselling Service for the Families of Patients Undergoing Bone Marrow Transplant*

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Abstract. *The organisation of our Counselling Service for the relatives of patients undergoing bone marrow transplant is structured in various phases. During the first phase, contact is established with the relatives. The therapist introduces himself to the relatives when the patient is hospitalized and enters the sterile ward. The second phase consists in an illustration of the objectives and purpose of the Service. During this phase, two weekly interviews lasting approximately one hour are proposed, plus assessment tests (CFI, Camberwell Family Interview - and MMPI - Minnesota Multiphasic Personality Inventory). A third phase, which is often contextual to the presentation of the Service, consists in the recognition of the needs and suffering of the given relative. Here, the therapist acts as a receptacle for the anxieties and fear of death brought to him by the subject, thus empathetically accepting these states of mind and legitimizing them. Moreover, our model of intervention envisages the formation of support groups for the relatives of patients suffering from blood cancers. A further phase concerns the exchange of information between the two therapists helping, respectively, the relative and the patient, and also with medical and nursing staff. To further the same aims, for a number of years now, our Service has been organising intervention groups for nursing staff working at CTMO. The final phase is counselling, which takes place twice a week. There are two fundamental areas of intervention that must be taken into account for families of subjects suffering from blood cancers: providing information and offering support. From our experience, it emerges that the relatives need to obtain information on organic aspects of the illness and the transplant.*

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One is never adequately prepared for adjusting to an illness that reduces one's life expectancy. Moreover, unlike other chronic organic illnesses, cancer affects not only the patient, but the whole family and all its members. As in every illness, the diagnosis of a tumour requires a series of "adjustments" that involve the whole family nucleus, which often finds itself obliged to confront a whole series of both strictly medical and psychological problems which it is unprepared to deal with. Consequently, over the last few years, there has been a tendency to give greater importance to the role of a relative caring for a cancer patient, which has become increasingly less "secondary" compared with that of the patient.

The psychological effects of a blood cancer and the treatment that patient undergoes (chemotherapy, radiotherapy and bone marrow transplant) are very stressful events, not only for the patient, but also for his relatives. The resulting crisis is often deep-seated and severe: the whole family is involved in the process of coping with the illness. Often, in these circumstances, the burden of the diagnosis and the illness is borne as much by the relatives as by the patient and, as a result, the family's cohesion and solidarity increase. Positive family relationships can help the subject adjust to the situation, but sometimes, when these relationships have always been problematic, the relative is unable to tolerate the additional stress introduced by the illness.

In most cases, the family relationships provide the patient with the support he needs and, indeed, usually become closer and more intense than they were prior to the diagnosis. However, some relatives may find that relationships are not so harmonious. Often a relative that has to deal with the fear of death reacts with the mechanism of denial, in order to distance and suppress the problem. This intensifies the patient's sense of isolation and loneliness by reducing communication. It has been shown by various authors (1) that, when there is a decrease in communication, the patient's depression, feelings of loneliness and discouragement increase proportionally. If communication within the family has been open and abundant in the past, it will probably

remain so even in the event of a terminal illness. Instead, in families where communication has been obscured by lies, evasion and half-truths, these maladaptive modes of communication are destined to be perpetuated, unchanged, even when a member of the family is dying. The barriers erected to prevent genuine, spontaneous communication derive from the constant attempts of both patient and relatives to avoid letting the rest of the family realise how much they know, thus hoping to protect others from additional suffering. However, it is important to help those concerned to understand that the truth, sincere answers to questions, co-operation and sharing between patients, families and physicians is the most functional way of coping with the illness (2). Moreover, the patients themselves may also raise "barriers" against their relatives in order to protect them and save them from having to face the distress associated with cancer and the numerous treatments. For example, patients may try to appear happy and carefree in order to avoid causing their loved ones emotional stress and to prevent relatives suffering for their sake.

Other types of barriers may be raised because of the reactions that patients perceive in their relatives. Cancer creates two kinds of conflictual reaction in relatives: feelings of fear and aversion towards the tumour on the one hand, and the conviction that they have to appear optimistic on the other (3). The conflict between these two reactions may create an ambivalent behaviour towards the patient and anxiety in relations with him. As a consequence, the relatives may even avoid the patient physically speaking or, at least, avoid any open communication about the illness. These discrepancies in the behaviour adopted towards the patient, which are usually manifested within a positive verbal context and not a negative one, may induce him to feel rejected and abandoned by those he loves. The patient may also respond to this ambiguous or negative feedback with a lower sense of self-respect and strong psychological distress (4).

In order to break this type of interpersonal relationship, the subject may exaggerate the negative aspects of the situation or he may, on the other hand, hide them in order to be more "acceptable". This way of coping usually proves to be counter-productive because it does not permit free expression of the real feelings (5). In some cases, the patients are "victimised" by their relatives and this becomes dysfunctional because, rather than providing the patient with adequate support, those around him isolate him, reject him, or even blame him for the presence of the tumour (6, 7).

Our understanding of the importance of emotional interactions in the families of patients with cancer has led us to evaluate the characteristics of the family environment and the model of interaction between the blood cancer victim and his relatives. Our experimental design also provides for an assessment of the influence of the family emotional make-up on emotional responses and on the patient's adjustment to

the illness, with particular attention to the identification of a possible correlation between the emotional responses of relatives and depression in the patients.

Assessment of relatives

For five years, the Family Therapy Unit of the Ospedale Maggiore in Milan has been using focus psychotherapy for patients suffering from forms of cancer (lymphoma, leukaemia, myelodysplasia, multiple myeloma) hospitalized in the Marcora ward of the aforesaid hospital prior to autologous or heterogeneic bone marrow transplant. The service is structured in such a way that, at the time of hospitalization, both the patients and relatives are contacted by two different therapists. If the family agrees, the therapy sessions are held twice a week and last about one hour. The family emotional climate is also assessed, by means of the Camberwell Family Interview (CFI), which is used to evaluate Expressed Emotion.

The CFI is a semi-structured, audio-taped interview, originally used to evaluate the affective style of the families of schizophrenic patients. Subsequently, it has also been used in other kinds of psychiatric illnesses and for acute and chronic organic illnesses (6). The specifically adapted form of the CFI used for assessing cancer patients includes questions on the history of the illness, symptoms, therapy and side effects, changes in role and function that have taken place in the family, and the emotional impact of the illness on family life. Family Expressed Emotion is assessed by a researcher trained in the technique, who awards points on five specific scales: Emotional Overinvolvement, Criticism, Hostility, Warmth and Positive Remarks. Each of these scales has a different threshold level. When scores on even one of the first three aforementioned scales exceed the threshold level, the relative under assessment is given a high Expressed Emotion rating. Since a family is defined as high in Expressed Emotion when even one of its members has a high Expressed Emotion status, (8). For purposes of data analysis, a "key relative" is selected for each family, in other words, the co-resident relative with the highest level of emotional components. Each relative is also asked to complete the Minnesota Multiphasic Personality Inventory (MMPI) (9) to determine the personality profile.

From our experience it emerges that patients respond to profoundly stressing situations, such as a transplant, by mobilising defence mechanisms, for instance denial. This leads them to play the role of a "strong" person, who does not give in to adversity, but overcomes it, as they seek to maintain the role they had prior to the illness. When faced with this "heroic" attitude, where the illness is denied, relatives generally respond by modifying their behaviour towards the subject, whom they tend to regard as "ill" and therefore in need of particular attention. Relatives thus tend to change their life rhythms, their social relations and work activities, effacing themselves in caring for the other and in his needs,

although they still collude in denying the presence of the tumour.

An extremely ambivalent situation is therefore created, where three different factors come into play. On the one hand, we have a denial of the illness by the patient, who tries not to change his own role; on the other, the denial of the illness also by the relative who, however, behaves in such a way that this is still a constant presence in family life. Relatives tend to diminish the role of the subject, allowing him solely to be a sick person. The patient is also deprived of his role (paradoxically, both the role of a patient, because it is not recognised, but denied by the relative, and that of a person, as he is actually only considered a sick being) and only "tacitly" considered ill. He thus has difficulties in keeping up his "courageous" and "heroic" act which he needs to put on in order to try to adjust to the cancer. In this game of "reciprocal triangulation", the relational message proves highly dysfunctional, allowing neither the patient nor the relative to cope with the illness properly. Families that, while denying the illness, adopt behaviours that make the patient effectively feel like a sick person, and which turn their way of life upside down to accommodate the needs of the cancer patient, automatically render these defences less valid and more fragile.

The communication block within these families, which play the "I know you know I know" game, where nothing connected with the illness is openly verbalised but, as we have seen, only communicated through action, does not allow empathetic experiences to be conveyed, so these risk being dominated by aspects of emotional overinvolvement. This behaviour by relatives is reflected in a poor illness course. Indeed, when only action bears the meaning of a relationship, a poor illness course seems to be the only tool the patient has to vindicate the role that both the relatives and patients themselves tend to deny. Faced with the impossibility of openly verbalizing their fears and cries for help, the patients can only "amplify" their illness, and as in an - albeit unspoken - "self-fulfilling prophecy", their anxieties and their fear of death which cannot be voiced are expressed by an objective worsening of the clinical course.

The deterioration in the medical condition, in turn, amplifies the relatives' dysfunctional emotional response and therefore perpetuates high levels of emotional overinvolvement (EOI) and high EE. It also amplifies pathological communication within the family, in a vicious circle that can be broken only by breaking through the dysfunctional relational mechanisms, allowing both patient and relative to express their real emotions and to openly communicate their feelings as regards the illness.

Focus psychotherapy in the family

Organisation of the Service. Our organisation of the Counselling Service for the relatives of patients undergoing bone marrow transplant is structured in various phases:

During the first phase, contact is established with the relatives. The therapist introduces himself to the relatives when the patient is hospitalized and enters the sterile ward. At the same time, another therapist belonging to the team introduces himself to the patient with a view to possibly working with him (patient-directed focus psychotherapy). This approach has the two-fold aim of emphasising the importance of the needs of the relative, not as set against of the subject who is ill, but in terms of a therapeutic continuum that implies the participation of all members of the family. Moreover, the warmth of the sessions allows the therapist to gather the first impressions of the relatives and to establish, where possible, a good therapeutic alliance.

The second phase consists in an illustration of the objectives and purpose of the Service. During this phase, we feel it important to stress the fact that psychological assistance is offered to the relatives of all patients hospitalized, in order to avoid any relative feeling guilty or incapable of coping with the situation. It is, moreover, clarified that relatives (although they generally feel that their suffering and distress is "secondary" to that of their sick loved one), are still going through an extremely difficult period, full of fears and anxieties. We feel it important to emphasize this point, as it often proves difficult to hold sessions in the therapist's office because the families find it extremely hard to tear themselves away from the glass partition of the sterile ward and "abandon" the patient, if only for an hour. It is as if taking care of themselves were tantamount to "diminishing" the importance of the patient's suffering.

So during this phase, two weekly interviews lasting approximately one hour are proposed, plus assessment tests (CFI and MMPI). A third phase, which is often contextual to the presentation of the service, consists in the recognition of the needs and suffering of the given relative. Here, the therapist acts as a receptacle for the anxieties and fear of death brought to him by the subject, thus empathetically accepting these states of mind and legitimising them. At this point, the therapist can understand the meaning that the subject attributes to the illness and how it is experienced. This is what the therapeutic work is based on.

Our model of intervention envisaged the formation of support groups for the relatives of patients suffering from blood cancers. However, this project met with a number of difficulties, both psychological and practical. Firstly, the relatives put up considerable resistance to these group sessions, although they did define them, formally, as "very useful". From our experience, it has emerged that this rejection was due to two kinds of reasons. The first was that although the group allowed the sharing of similar states of mind, on the other it still "scared" people because each member thus became a "mirror of the other". Moreover, knowing that one group member might discontinue his attendance because the relative concerned had died, or that he/she might bring accounts of death, was unbearable for most of those involved. Precisely because denial (both of the

illness and, with even greater justification, of death) proved to be the most frequently used mechanism, any element disturbing the psychological balance was categorically rejected. The second reason was purely organisational: many families lived outside Milan and found it difficult to participate in the meetings, especially after hospitalization, when the regular and frequent clinical check-ups required by the patient involved numerous, wearisome journeys.

A further phase concerns the exchange of information between the two therapists helping, respectively, the relative and the patient, and also with medical and nursing staff. This exchange of information, where those involved are also updated as to how each person involved (patient, relatives physicians and nursing staff) experiences the same situation, seems to be of great help in focusing the therapeutic objective.

To further the same aims, for a number of years now, our service has been organising intervention groups for nursing staff working at CTMO. In addition to therapeutic work dealing with the experience of death, ways of interacting with the patient and group dynamics, another aspect emerging is interaction with the relatives of subjects in hospital.

The final phase is counselling, which takes place, as mentioned above, twice a week.

Family counselling. There are two fundamental areas of intervention that must be taken into account for families of subjects suffering from cancer: a) providing information, b) offering support.

a) In most cases, the spouses of patients complain that they do not receive enough information about the illness of their loved one. From our experience, it emerges that the relatives need to obtain information on organic aspects of the illness and the transplant. This is especially important because the relative must be able to assess the gravity of the situation and have sufficient information to help him distinguish "normal" fluctuations in the course of the illness from an objective deterioration of the patient's clinical condition. In addition to obtaining information on the characteristics of the illness, family members should be informed about and learn to recognise the emotional aspects connected with it. The therapist can help the relatives to understand that feeling tired or anxious when the patients are in hospital is perfectly normal and does not indicate a lack of sympathy. It is implicit that, in this phase where information is requested, the psychiatrist and the medical staff should work together synergetically. While the former deals with specific topics, such as sexuality or the patient's ability to cope during hospitalization, explaining that certain of the patient's reactions and of the relative himself may be "normal" ways of adjusting to the illness, the latter covers more general aspects of the illness, including required procedures and side effects connected with the transplant.

b) Providing support is the second main focus of intervention for relatives. The aim of this is two-fold: on the one hand,

relatives are directly helped to cope with the illness and all its consequences and, on the other, the relative's capacity to take up a supportive role with the patient is reinforced. When supportive intervention is planned, it is important to take various factors into consideration. First and foremost, the kind of intervention must be appropriate to the particular requirements of the relative. Those who use the mechanism of denial as a strategy to limit the emotional distress aroused by the cancer in their partner are less likely to agree to a support program that obliges them to undertake self-analysis and to verbalize their fears regarding the illness. In this case, the therapist must confine himself to supporting the relative in his "support" of the patient, without interfering with the defences: speaking about the patient is already one way of lightening the relative's emotional burden. On the other hand, with relatives willing to work on their own emotions, but who find it difficult to express them to the patient, the aim of the intervention is to help to maintain the effectiveness of support systems for the patient, to promote communication of the emotions and to facilitate the functioning of the relationship. However, it is important that the therapist's intervention should not concentrate too strictly on relatives' cancer-related problems; it should also offer them an opportunity to use the session to speak of other stress factors in their lives. The focus of the intervention therefore needs to be flexible, so as to allow the relatives to unburden themselves both as regards problems directly concerning the tumour, and on more strictly personal problems. In his work, the therapist encourages relatives to discuss their reactions to the illness of the cancer patient and the reactions of the patient himself. During this phase, the operator offers support and encouragement, reinforcing positive adjustment responses and helping relatives to identify the problem. The relative is invited to identify and reflect on what he considers to be the most pressing problems, in order to then help him focus on his reassessment of the problem, on an increasing use of formal and informal support and on changes in coping responses.

It can thus be asserted that the aim of focus psychotherapy is to create a space in which the various aspects of the illness can be discussed and in which there is a sharing of personal feelings and problems. Moreover - and this is an extremely important point - it allows people not to feel isolated, but understood and sympathised with. One of the therapist's most important functions is to bring out the subject's needs, and this should be done at the beginning of each session, in order to promote sharing of his expectations and needs.

Conclusion

From the above, it appears evident that a blood cancer is not an "individual" illness, but one which involves the whole family system, which is reorganised and changed to accommodate the illness. It moreover emerges that stress

levels are similar for both patients and relatives, the latter often finding themselves faced with problems they are unprepared for. It is therefore necessary to help both parties to cope with the illness, first and foremost, by offering the medical information they need to properly assess the situation and, secondly, to allow them to adjust to the illness, to react and communicate effectively about the "cancer problem" in a climate where not only feelings and fears can be shared, but also their hopes.

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