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Is there a need for regular psychotherapeutic intervention before, during and after bone marrow transplantation?

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abstract

In the past 2o years Bone Marrow Transplantation (BMT) has emerged as the treatment of choice for a series of well identified hematalogical diseases such as acute or chronic leucemia, but it is highly demanding for the patient as well as in physical and in psychological respects. On the other hand only recently BMT has been established as a subject of psycho-somatic research. There is little systematic knowledge about the experiences of the patients confronted with the diseases and the treatment.

In a prospective observational study we are investigating the long term adaption of patients after BMT in order to increase the knowledge about the experiences of the patients, their fears and conflicts which are hypothesized to be reactivated in connection with the somatic impact of this intensive and life threatening medical intervention.

This paper reviews the role of psychological interventions over the course of the treatment integrating ours and other collegues approaches and experiences.

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In the past 2o years Bone Marrow Transplantation (BMT) has emerged as the treatment of choice for a series of well identified hematalogical diseases such as acute or chronic leucemia, but it is highly demanding for the patient as well as in physical and in psychological respects.
In contrast to the great progress transplantation medicine has achieved research on psychosocial adaption to the underlying disease and to the intensive somatic treatments there is only scarce knowledge available. Generally it is assumed that BMT due to its specific initial conditions and its specific course in addition to the well known somatic complications also imposes a series on psychosocial stresses on the patient that are specific for the three phases before, during and after BMT (Brown & Kelly 1976; Lesko & Hawkins 1983).
The course of a BMT as it is habitual in most centers for transplanation today is shown in figure 1.

Our observational study conforms with the evolving course by placing the points of observation into that frame.
The patients initially are interviewed before the actual transplantation when all decisions are made (T1). At that time the patients already have passed through a longer series of stressful events; for methodological reasons it is impossible to actually observe these as the patients are coming from all over Germany to the transplantation procedure to Ulm. The semi-standardized interview at that time only retrospectively gets hold of the patient´s experiences. The patient has gone through a quite intensive informed consent procedure provided by one of the physicians and is about to enter the procedures of chemical conditioning and total body radiation.
The infusion of bone marrow itself - the real transplantation, lasts fairly short and some patients consider it as uneventful whereas other euphorically react to it as the moment of a second birth. It may be moment of hope for a total cure from the life threating disease. The then following time of isolation isdominated by waiting for the take of the transplant with hopes and fears changing continously. The events like somatic complications and pain increased by restriction of social contact make for a considerable amount of stress during that second phase. As

many patients are quite far from their homes the isolation from intimate relationships become quite a burden. In terms of patient cooperativeness the treatment in these phase needs a hiugh degree of working alliance between patient and the team. The end of this phase often is experienced as ambivalent: relief having come so far is counter-acted by a reasonable fear of loss of protection. Infection now becomes a real problem.

So the patient entering phase 3 of the treatment program is now confronted with bodily restrictions have have been imposed (like sterility on all patients) and with the task of taking up his real life assigments again. Anticipating the return to personal and professional life is emerging in the patient´s feelings when the second interview of our study protocol is taking place.

The time after discharge from the hospital is often experienced as quite difficult.The patients are asked to take up normal life again yet they are still under the impact of quite severe restrictions caused by increased danger of infection, by tight out patient routine control and- not too infrequent - readmission to the hospital when serious complications occur. Especially the fear of succumbing to a remittance of the initial disease is quite striong within the first months after BMT.

The following table 1 systematically comprises the stages and the events and strains that we have sketchily outlined so far.

TABLE 1: STAGES OF COURSE OF DISEASE AND TREATMENT OF PATIENTS BEFORE, DURING AND AFTER BMT

stages	**events and strains**
onset of the disease/ diagnosis	fears and phantasies, fear of death, anticipation of pain, changed self-concept, changed body image,

treatment of the primary disease	side effects of the chemotherapy, possible progression of the disease, social and professional changes, searching for a donor, dependence on the well-being of the donor, possible conflicts with the donor
decision-process to accept BMT	informed consent, ambivalence, hope of possible cure
waiting list	uncertainty, fear of relaps, sometimes admission before very long, anticipation of complications
informed consent	confrontation with complications, the life-threatening situation is made topical
preparation for BMT	diagnosis, radiation treatment planing (RTP), placement of a Hickman catheder, decontamination, entering the reverse-isolation room and constricting patients freedom of movement, fears and phantasies concerning the radiation effects, "point of no return"
infusion of the transplant	hopes and fears, worry about the donor
aplasia and waiting for the take, reverse isolation	complications with physical strains, hopes and fears
discharge from isolation/further treatment in hospital	relief vs. lost protection, hope and worry about the future, commonly difficulties with the appetite
discharge from hospital	dependence-autonomy-conflict, adaptation to handicaps and the life outside of hospital

the 100 critical days after BMT	convalescense, complications, fears of relaps, close-meshed clinical visits, difficulty or inability to reenter normal activities
3 month to 1 year after BMT	complications, fears of relaps and prolonged effects, turning concern from "living as patient" to "living as a survivor", planing the future
survival after BMT	fears of secundary injuries, rehabilitation (social and professional)

Empirical studies on the psychological impact of BMT on patients from the various phases of treatment have been reported by Futtermann & Wellisch 1990; Lesko et al 1989 and focusing exclusively but in a prospective design on the time during the in patient treatment phase by Neuser 1989. The various studies report about a clinically relevant level of psychiatric symptomatology in about 8 - 15 % of patients; these levels are not different from those in other severe somatic diseases. While these psychiatric complications can be dealt with by usual liaison interventions and would not require a specific psychological program tailormade for BMT patients we would like to discuss the relevance of phase specific interventions that ultimately could lead to an improved psychological program component.
In these matters one has to be careful to distinguish what we as psychotherapists think these patients would need and what we are able to objectively identify as helpful interventions. Involved are complicated issues of psychosomatic intervention theory that are part and parcel of any therapeutic action even if they are the silent background of one´s daily routine. The critical question resides in the issue of labour division between somatic and psychologic doctor "yes or no". Should we have another expert in the BMT team or would we prefer a psychological holding environment for the team to stay as close as possible with the patient. Are we able to identify those patients that would need more than the holistic intervention and can we demonstrate that this more in

psychotherapeutic care provides a more in well adapted survival and life qualities ?
Our careful approach to bridge the gulf of not knowing consists on careful qualitative and quantitative evaluations of the patients at different times during their passage.

Results of our studies and their impact

The sample of the ongoing study:has been collected from 1991 until end of 1992 at the bone marrow transplantation unit of the Department of Internal Medicine (Prof. Dr. Heimpel) University of Ulm.

TABLE 2: SEX, AGE, DIAGNOSES

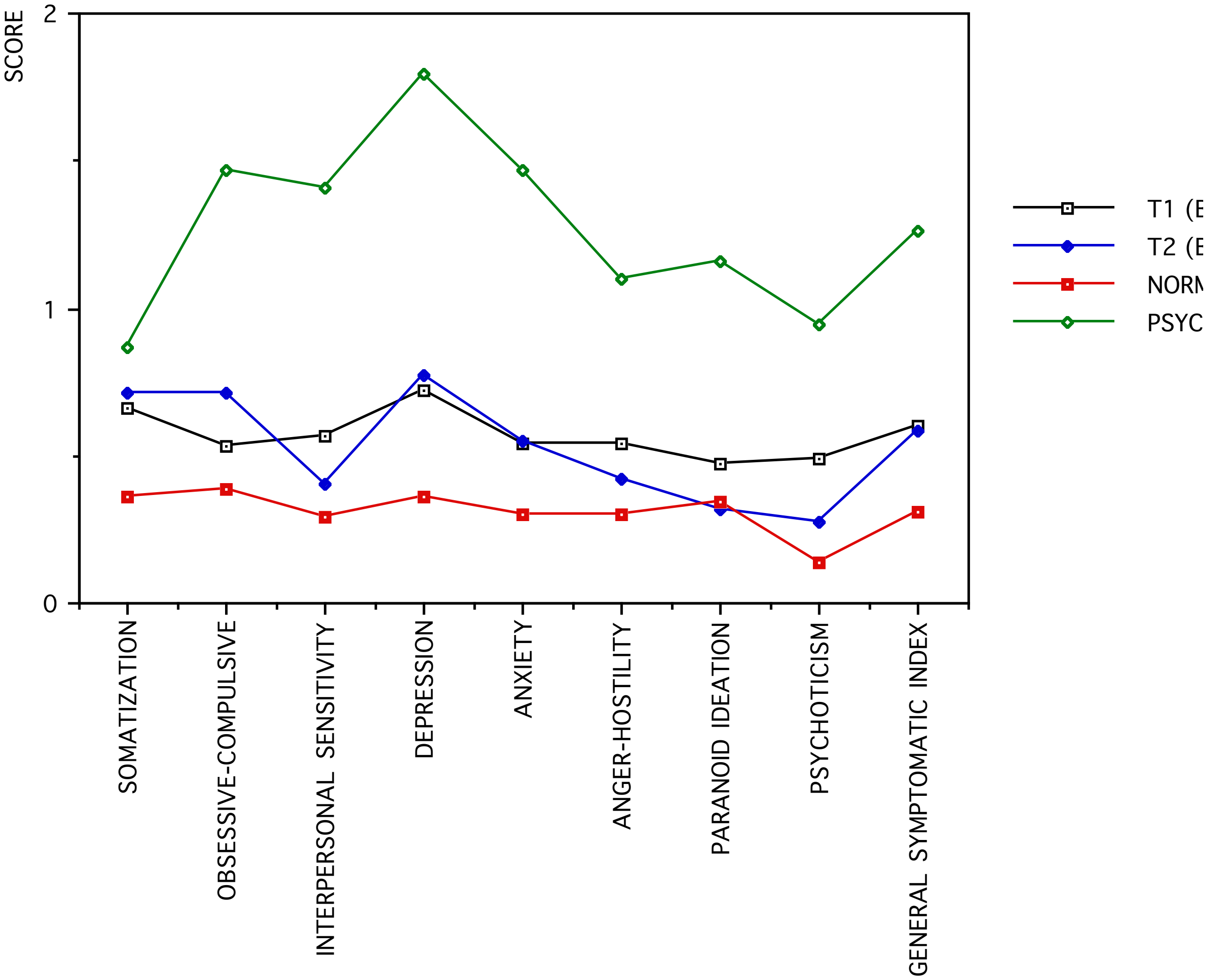
SEX		
	MALE	24
	FEMALE	11
AGE		
	MEAN	34
	RANGE	16 - 55
DIAGNOSES		
	AML	17
	CML	14
	ALL	4

a. Psychiatric morbidity

With the SCL-90 (Derogatis 1977; Derogatis et al. 1973) we evaluated the presence of psychiatric impairment at t1 and t2. Figure 2 including a normal and psychiatric population demonstrates that our patients at both times of study are in all scales only slightly divergent from a normal population.

It may be that the long procedural way from first diagnosis to the decision for BMT actively filters out more psychiatric disturbed patients:

FIGURE 2: SCL-90-R SCORES (MEAN-VALUES)



b. Informed consent

One main result from our retrospective study on 34 patients and from the ongoing prospective study of 35 patients pertains to the overall importance of the procedure of achieving informed consent as a powerful agent of establishing what psychotherapists call "working alliance". This is in agreement with thre findings of Lesko et al (1989) and Singer et al (1990) though we tend to interpret the importance of this bargaining transaction more in terms of a psychotherapeutic interaction.

Though repeatedly empirical studies have demonstrated how poor and how selective the memory of the contents of "informed consent" is these findings do not invalidate the transactional nature of the process between doctor and patient of achieving a shared understanding of what is ahead of both. The concept of informed concent may be looked at as a monitoring device running over the whole course of the BMT intervention and providing the patient´s necessary cooperativeness. Mechanisms of denial, idealization and omnipotence take away from conscience the real substantial dangers (Aeschelmann et al. 1992); however they do not impair the relational impact of the experience having been well informed.

c. Defense mechanisms

Using an adapted version of the Perry instrument for classifying defense mechanisms (Perry 1988, 1990) as present in the semi structured interview we find a broad spectrum of mechanisms, especially of those that have been identified as probably favourable for successful coping (Heim 1988). Figure 3 demonstrates that at both times of observation those mechanisms dominate that are likely to protect the ego from affective experiences like obsessional, denials and narcissistic dms´.

d. Coping mechanism

Coping was analyzed by an instrument we have developed ourselves based on a selective reading of available instruments (Burgmeier et al. 1992). The fighting activities are most prominent at both time points whereas the deferring activity is more dominant durin the phase of isolation (Figure 4)

e. Social support

Besides the helping alliance to the staff - nurses and doctors our qualitative evaluations of the interviews underscore the social and emotional support by close, familar persons - relatives or friends. Anothe quite important factors seems to be the possbility to create the feeling of familiarity within the transplantation unit - my home is my castle feeling - a contextual variable that seldom is explicit. Another source of support is the identificatory contact with other patients that have been through and survived.

From our interviews we would conclude that there are some risk patients that heavily deny side effects and complications before the bmt procedure has even begun. Some other show such high levels of anxiety which turnds out to be a impedimen t during the second phase of isloation. To identify these patients the kind of interview which is now part of our research observation would be a useful routine procedure.

Interventions during the second phase could be targetted very directly to strong, regular side effects of the somatic treatments without accessing the psychological domain; it has been suggested that behavioral interventions for pain reduction (BMT group Tübingen) or musictherapy interventions for improvement of subjective sense of well being (BMT group Hamburg) are indicated. These recommendations are at a phase of testing out. The Ulm BMT group feels in consonance with the psychosomatic orientation of von Uexküll that as little as possible intervention from outside should be applied during this second phase; however regular contact of a psychotherapist with the staff may provide a basic holding function.

Our impression from the second series of interviews is that the patients underscore the close contact to family members as well as good relations to the staff more than any other expert intervention. This finding would feed into our central concept of a working alliance which should be experienced as helpful (Luborsky 1976).

The third phase of the treatment process tends to encounter more specific psychotherapeutic intervention points as the clash between patient role and re-awakening normal role expectancies may rouse specific neurotic difficulties. Life planning has to be adopted to the new situation and new life concepts have to be developed. Seldom ist a total restitito ad integrum achievanble within the fiorst months after BMT. Especially the cases with a severe GvHD require increased social support which often involves family interventions as well.

Concluding we summarize our findings based on the qualitative extraction of the tape recorded interviews with the patients b efore, during and after BMT that the key element in the psychosocial co-treatment of these patients resides in the social network formed by the staff. The labour division among doctors and nursing staff in itself is complicated enough; too often patients´difficulties echo in complications among the staff - so we would like to recommend routine consultation of the staff as the measure with high priority. However, the recipe of a

Balint group is illusory; to difficult the very job of coaching the patients through a life threatening treatment. So psychosomatic consulation to the BMT team has to be available when needed, to be present unobtrusively.

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