Distress, coping and quality of life in patients who underwent a Bone Marrow Transplantation

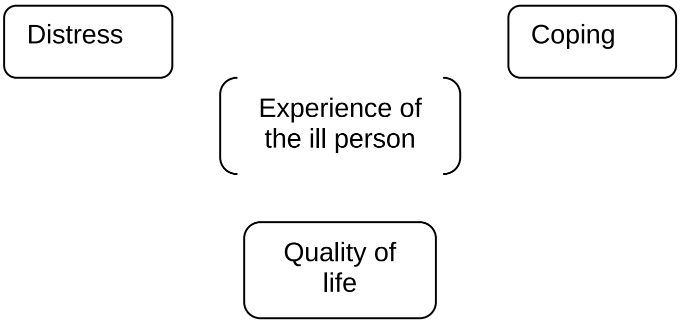
by Ezio Menoni[*], Alessandro Ridolfi[**]

> *I live, I live fully*
> *And it is worthwhile to live my life now, today, right now;*
> *And if I knew that I have to die tomorrow I would say:*
> *I am very sorry, but it was good the way it was.*
> *(E. Hillesum, “Journal 1941 – 1943”)*

Introduction

Bone Marrow Transplantation (BMT) is a therapeutic procedure aimed at curing various forms of malignant haematological forms. It has been progressively applied to other forms of oncological pathologies as well (Bone Marrow Donors Worldwide, 2004). BMT is a very effective therapeutic intervention, but for the patient it is at the same time a very extreme (sometimes even dangerous) one. BMT may have some irreversible consequences on various levels, i. e. biological, psychological and social level. It may involve, for example, loss of fertility or capacity to work, and so on (Lee *et al.*, 2005; Schulz-Kindermann, Hennings, Ramm, Zander & Hasenbring, 2002; van Aghtoven, Vellenga, Fibbe, Kingma, & Uyl-de-Groot, 2001; Jacobsen *et al.*, 1998; Wettergreen, Langius, Björkholm & Björvell, 1997).

Fig.1 – The experience of illness.



The ill person is forced to face an experience that produces a feeling of crisis, whose main manifestations affect his/her personal identity and perception of integrity, since the series of stressful and destabilizing events involved by the illness may deeply endanger one’s self-sense. Therefore a coping process becomes necessary. Seriousness of the diagnosis, strictness of the therapeutic protocol and specific psychological reactions of the ill person are the main objects to which such process is related.

All the recent research works are mainly oriented to psychological distress activated by the effects of the onco-haematological illness and BMT therapy, as well as to the quality of life.

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Along the care path of onco-haematological illnesses, the experience of BMT produces a series of changes that require a set in motion of the patient’s coping resources. The main characteristics by which the illness affects a person (on a physical and psychological level) are unified in the notion of *distress* (Heinonen *et al.*, 2005; Beanlands *et al.*, 2003; Trask *et al.*, 2002). The specific modalities of response to illness, in other words the characterization of the coping process, are studied as further coping reactions, and each one of them seems to be inscribed in a context of personal history and meanings belonging to the ill person (Kirsh, Mcgrew, Dugan & Passik, 2004; Watson *et al.*, 2004; Johnson Vickberg *et al.*, 2001). The modalities of response of the ill persons are so articulated that for each person it is possible to understand how such experience affects his/her personal perception of the quality of life (Redaelli, Stephens, Brandt, Botteman & Pashos, 2004; Schulz-Kindermann *et al.*, 2002; Heinonen *et al.*, 2001; Chiodi *et al.*, 2000).

Even though most of the literature is focused on the patient, there exists also a relational perspective, involving his/her relatives and the care personnel (Futtermann, Wellisch, Zighelboim, Luna-Raines & Weiner, 1996; Zabora, Smith, Baker, Wingard & Curbow, 1992; Singer, Donnelly &Messerschmidt, 1990; Patenaude & Rappeport, 1984).

The present work develops by focusing on the most recent research works dealing with the triad “distress, coping and quality of life (QOL)” in relation to the ill person (see picture 1).

Criteria of research

The works that we analyzed within this review originate from an on-line research in the “Medline” and “PsycInfo” databases, updated to the first quarter of 2007. Altogether we carried out five sessions of research, using the following key words, associated in various ways: “distress”, “bone marrow transplantation”, “coping”, “quality of life”, “psychotherapy”. In this research we collected about 400 abstracts and selected almost 100 among the most important recent works. Likewise, we started some more specific sessions of research in the “Medline” database (with the following key words: “post traumatic stress disorder”, “fatigue”), to deepen some specific aspects of the experience of illness in relation to the frameworks of distress, coping and QOL.

Clinical research

The research on the psychological aspects within the onco-haematological field has recently grown to a great extent. Many studies are dedicated to recognizing specific factors related to distress (Lee *et al.*, 2005; Futtermann, Wellisch, Bond & Carr, 1991), coping (Schulz-Kindermann *et al.*, 2002; Molassiotis, 1999) and QOL (Dow, Ferrel, Haberman & Eaton, 1999; McQuellon *et al.*, 1994).

A whole series of research is dedicated to studying the relationships between the factors of “cost” and “modulation” inherent to the ill person’s experience of the care. Such works, which make use of instruments that are partly borrowed from the clinical research in the oncological field, study the effects of BMT in physical and psychological terms (Dimeo *et al.*, 2004; Sherman, Simonton, Latif, Spohn, Tricot, 2004; McQuellon & Andrykowsky, 2000; Neitzert *et al.*, 1998).

Such research works are mainly aimed at understanding the consequences of therapy, the nature of distress processes and the variable factors (i. e. character of the ill person, chronological evolution of the way a certain symptom is perceived, or - more in general - of the health condition, information supplied by the care personnel, etc.). The purpose of such studies is defining the factors that determine the distress processes, with the intention of preventing and treating illness (Kettmann & Altmaier, 2008; Wellisch & Wolcott, 1994; Hengenveld, Houtman & Zwaan, 1988). Further studies are dedicated to the psychopathological consequences of the illness (Khan, Irfan, Shamsi & Hussain, 2007; Lee & Santacroce, 2006). Some specific ‘lookout points’ along the chronological continuum of the experience of illness have been identified in the last few years. Such points in general coincide with especially meaningful moments, which are true critical points, in which reactions of distress tend to manifest with greater frequency and importance (McQuellon & Andrykowsky, 2000; Zittoun, Achard & Ruszniewski, 1999; Hengeweld *et al.*, 1988). Such data have been recently re-confirmed: Lee et al. (2005) recognize a series of critical moments, along the care path, the most important of which are: diagnosis, beginning of treatment, hospitalization before, during and after transplantation, isolation period, dismissal, possible relapse, etc.

The studies on coping highlight the relationship between the experience of illness, effectiveness of the coping strategies and therapeutic factors of support, which help to get by with the illness (Schulz-Kindermann *et al.*, 2002; Molassiotis, Van den Akker, Milligan, Goldman & Boughton, 1996). Another series of studies draws the attention onto the interaction processes between distress and coping (Holzner, *et al.*, 2001; Hjermstad & Kaasa, 1995). It is remarkable that, in the field of studies on QOL, research often makes use of instruments that are widely shared by the researchers, as well as of plans that are mostly pre-experimental or almost experimental.

Besides the above mentioned subjects, there are also works, although they are less in number, which deal with interventions of counseling or psychotherapy (such as, for example, techniques of cognitive control of anxiety, hypnosis etc.). Such interventions aim at improving the patient’s way of dealing with illness and counteracting the side-effects of BMT, both on a physical and psychological level (Classen, Hermanson & Spiegel, 1998; De Luca, 1998; Eslinger, 1998; Ezzone, Baker, Rosselet & Terepka, 1998; Spiegel, 1995).

Just a few more works try to describe, with a phenomenological perspective, the complexity of the life-experience of people who face an onco-haematological illness (Cohen, Ley, Tarzian, 2001; Cohen & Ley, 2000; Tarzian, Iwata & Cohen, 1999; Gaskill, Henderson & Fraser, 1997).

Studies on psychological distress

Various researchers (Paterson, Trask, Scwartz & Deaner, 2001; Holland, 1997) suggest that the concept of distress should be studied in a deeper way. Contemporary literature defines distress as an extremely complex condition, which is determined by a series of variable factors: characteristics of the illness, character of the ill person, time of observation, social relationships (e. g. with one’s relatives or with the care personnel), etc. Some studies belonging to this literature (Trask *et al.*, 2002; Coyne, Benazon, Gaba, Calzone & Weber, 2000) outline certain traits, which present some less evident psychopathological features than the nosographical sketches proposed by DSM IV. As far as the quality of coping processes and social representation is concerned, such traits are more representative of the real condition of illness than the nosographical sketches. A recent study by Lee et al. (2005) recognizes the early signs of distress, for the purpose of understanding their predictive meaning in terms of psychopathological risk, in the care path that follows transplantation. As far as the prevention of distress is concerned, the results of various researches agree with each other on the importance of the elements concerning patients’ character, chronological evolution of the clinical-therapeutic course (Fife *et al.*, 2000) and psychotherapy as well as counseling interventions. On the other hand, certain degrees of disagreement are present, in relation to some specific characteristics of personality or key moments within the therapeutic journey.

Among the research works dealing with such issues, the one by Mc Quellon & Andrykowski (2000) recommends an analysis of the psychological complications following staminal cells transplantation. On the basis of a previous work by Twillman, Manetto, Wellisch, & Wolcott (1993), they classify patients according to the risk of psychological complications.

They identify three main stages, along the care path:

- in the pre-transplantation phase a state of existential anxiety and depression, mainly related to the fear of dying, is present;
- in the hospitalization period the patient may meet an experience of stress, due to isolation;

- in the post BMT phase, the patient may experience fear in relation to the loss of support from the care personnel. He/she may also experience a crisis of compliance in the relationship with the care personnel as well as, in the end, a deep distress in case he/she undergoes an experience of permanent loss (such as loss of fertility).

Jacobsen et al. (1998) show how much the perceived gravity of the situation can expose the ill person to the risk of developing the symptoms of a post-traumatic stress disturbance. This is above all true in relation to the potential psycho-pathogenic charge of BMT and to other variable factors, among which, for example, are age and seriousness of the illness.

Other studies (Schulz – Kindermann *et al.*, 2002; Wettergreen *et al.*, 1997) confirm how the problems that are most often present in people who underwent a BMT should be referred to:

- decrease of social abilities
- feeling of fatigue
- emotional distress (mostly linked to anxiety and depression)
- sexual problems.

In a research work on the psychosocial impact of BMT, Neitzert et al. (1998) highlight how psychological and physiological processes facilitate each other to protract one's perception of being ill. According to many researchers (Gaston-Johansson, Lachica, Fall-Dickson & Kennedy, 2004; Akaho *et al.*, 2003; Bellm, Epstein, Rose-Ped, Martin, & Fuchs, 2000; Molassiotis & Morris, 1999) the follow-up phase, even years after the BMT, shows that a considerable part of the subjects experiences a feeling of tiredness and fatigue, which may be combined with other disturbances. In a qualitative research, Heinonen et al. (2005) explored the mental maps of a number of patients in relation to their illness experience. The efferent issue fields related to illness and BMT turn out to be especially relevant, both in terms of personal meanings and subjective perception of the events connected to illness and BMT.

Various studies explore the life of patients in isolation, mainly as far as the distress experience is concerned (Cohen *et al.*, 2001; Cohen & Ley, 2000; Tarzian *et al.*, 1999; Cohen, Headley & Sherwood, 2000; Gaskill *et al.,* 1997). They all use some essentially analogous research patterns, which refer to certain hermeneutic-phenomenological paradigms. Their conclusions show how many occasions of contact and sharing the ill persons offer, in order to be able to receive help. These occasions start from the elements that are normally present in the caring context. The results of such works show how much the delicate balance existing between fear and hope, and in some cases between fear and faith, may offer the care personnel numerous starting points for interventions of psychological caring.

A remarkable series of studies shows a significant increase of the risk of a psychopathological maladjustment, mainly in relation to depressive, anxious and mixed syndromes (Akaho *et al.*, 2003; Illescas- Rico, Amaya-Ayala, Jimenez-Lopez, Caballero-Mendez & Gonzales-Llaven, 2002; Zittoun *et al.,* 1999). In recent years, researchers have been showing a growing interest in referring the patients' psychological disturbances to a PTSD clinical pattern.

In fact many works show a particular incidence of syndromes that can be related to PTSD (Widows, Jacobsen, Booth-Jones, & Fields, 2005; Mundy *et al.*, 2000; Widows, Paul, Jacobsen & Fields, 2000; Mc Grath, 1999).

Among the works dealing with the possible psychopathological implications of oncological illnesses, in relation to the development of PTSD, McGrath (1999) and Holland (1997) emphasize the fact that patients often avoid speaking about their condition, do not look for a psychological support and end up locking themselves in a particularly painful isolation.

Andrykowski et al. (1999) analyze the most emotionally significant issues related to BMT. In a research work carried out on 110 subjects, they have been taking into account differences of sex, age and chronological evolution. The results of this research confirm the existence, in the first year after transplantation, of a chronological evolution. Fear of a relapse (present in the 95% of the subjects), worry for a condition of decreased energy (present in the 91% of the subjects), hope to become normal again (79%) turn out to be the most significant issues in that period. According to the authors, the difference of sex can be described as a better acceptance, in women, of their own condition of necessity and weakness, as well as a greater capacity of communication and disclosure.

In synthesis, an outline of the contemporary research shows that the issues raised several years ago by Holland (1997) are still open:

- To which extent is distress normal?
- How can one recognize an abnormal level of distress?
- How can one guarantee a sufficient recognition of the ill person's distress from the care personnel?
- How can one ensure an adequate therapeutic response?

With this respect many authors agree that under the present conditions research has, to a certain extent, drawn conclusions of a provisional character (Grulke *et al.*, 2005; Akaho *et al.*, 2003; Neitzert *et al.*, 1998).

Studies on coping with illness

The notion of coping has already been, for some time, an essential subject in the field of psycho-oncological research. According to Lazarus (1993) a possible definition of coping is the cognitive and behavioral effort of handling the psychological stress when this exceeds a certain level. The reaction to illness, which is related to the stressors and personal characteristics, allows one to handle the illness related crisis as a transition period towards a later condition of adjustment or maladjustment (Molassiotis, 1997). A critical analysis of the related literature shows how important it is researching in this field, both with the aim of discovering the adequate approaches to the ill person, which may effectively support her/him (Wellisch & Wolcott, 1994), and of clarifying the role of the coping processes which are activated within the context of BMT. Many works are focused on the value of the different coping styles, as far as adjustment and survival are concerned (Grulke *et al.*, 2005; Tschuschke *et al.*, 2001; Murphy, Jenkins & Whittaker, 1996; Andrykowski, Brady & Henslee-Downey, 1994; Colon, Callies, Popkin & McGlave, 1991). Despite a great level of agreement among researchers, up to now the roles of the different coping styles and their effects have not been defined in a univocal way.

Hoodin, Kalbfleisch, Thrornton, & Ratanatarathorn (2004) and Hoodin & Weber (2003) identify, in their works, some determining psycho-social factors capable of affecting the patients' survival after a BMT.

Schulz-Kindermann et al. (2002) and Heim, Valach & Schaffner (1997), having analyzed the stages of illness and its chronological evolution, divide the coping strategies into *positive* vs. *negative* ones. The *positive* ones are those in which illness is accepted and social support is searched, with the purpose of exerting some control over the illness. On the other hand, the *negative* ones involve some fatalistic attitudes, feelings of guilt and resignation.

In a perspective study, carried out on 213 patients affected by multiple myeloma, Sherman et al. (2004) discuss the implications of BMT and confirm the need of a careful screening of the candidates, to meet their needs of being looked after and treated before, during and after the illness.

The level of adjustment to illness is a key-factor that must be taken into account before transplantation: in fact many works focus on the pre-transplantation phase, which is often connected to a relevant condition of stress (Siston *et al.*, 2001; Keogh, O'Riordan, McNamara, Duggan, & McCann 1998). During this phase the ill person often experiences anxiety and fear of death, and worries about her/his imminent involvement in an extremely hard kind of therapy. In their research, Beanlands et al. (2003) analyze the notion of self and its evolution, in relation to the intrusiveness of the illness and the emotional overload caused by the perception of oneself as helpless and hopeless. This piece of work highlights the decisive role of the intrusiveness of the illness, which determines a strong change in one's self-perception and creates a new representation of oneself as a BMT ill person.

Researches that focus on the personal positive evolution following a BMT are not missing. A study by McGrath (2004) focuses on positive adjustment to illness. The author stresses the fundamental role of the ill person's capacity of re-elaborating in positive terms the events of his/her life, and the fact that this may also happen within a spiritual dimension. Clinical experience shows how some patients activate a resilience process, which makes them more aware of the meaning of life, more capable of enjoying pleasures and feeling lucky for the unexpected period of life that is now available to them, which they would not have hoped for.

Studies on the Quality of Life

The term QOL appears for the first time in the research indexes in 1977, with 28 quotations; in the next few years its quotations have been multiplying exponentially (Schmidt, 1994). More recent studies (McQuellon *et al.*, 1998) also confirm this tendency to study the relationship between BMT and QOL. According to the World Health Organization, QOL is defined as "the subjective perception that an individual has of his/her position in life, within the context of culture and values in which she/he lives, and in relation to her/his purposes, expectations and cares".

According to some authors (Apolone, Ballatori, Mosconi, Roila, 1997) who share this perspective, QOL is a wide-range notion, which may be modified, in a complex way, by one's perception of one's health in a bio-psycho-social sense, by one's level of independence, social relationships and interaction with one's own specific surroundings.

In a recent study (Heinonen *et al.*, 2001a) female and male people are compared in relation to their perception of QOL after a BMT. The researchers analyze the general categories of physical, functional and social well-being, and point out some meaningful differences, related to more specific dimensions. Women are more worried than men about the quality of their sleep, are less satisfied of their sexual life and complain about their level of emotional well-being. Men seem to be not so satisfied by the level of social support they receive, especially from their family, and tend to draw a greater benefit from the support they get from the care personnel.

A cross-sectional research (Sutherland *et al.*, 1997) on 231 subjects who survived their illness, compared with a reference group, studies the effects of time after BMT. The two sub-groups of patients (of which the first one underwent transplantation more than three years before and the other one less then three years before) diverge in relation to their self-evaluation in different fields. The further the illness event and its implications are, the better QOL is considered to be, under various aspects. It is especially interesting that, after the third year post-transplantation, the patients' adjustment and perception of health condition improve to a great extent and under some aspects (in relation to the variable factors of vitality, mental health, social ability) they even become better than in the reference group. According to the authors, such a result, different from what one could have expected, gives space to more than one hypothesis, the main of which are:

- Long-time survivors change their point of view about their own personal situation;
- They experience a revaluation at the level of their existence;
- A predisposition, based on some personal characteristics (liveliness, positive feelings, etc.) as well as on a strong social support, is present in all of them.

Such factors seem to play an important role in the survival processes, in qualitative and quantitative terms.

A recent research (Kiss, Abdolell, Jamal, Minden, Lipton & Messner, 2002) on a group of 89 patients confirms the result found in Sutherland et al. (1997). Long-time survivors seem to have a good QOL, above all in relation to the recovery of roles and social relationships that existed before the illness, even though the recovery of their physical capacities seems to be partial.

Kopp et al. (1998) studied the effect that the variable factor of time has on the level of QOL perceived by the patients who underwent a BMT. Their observations point out that the psychological consequences of illness are only indirectly dependent on its clinical course. The researchers conclude by suggesting that the care given to the patients should also be protracted after their dismissal from hospital. Adjusting to returning home and to a new life-style requires a considerable amount of psychological support, which should be given by qualified personnel. This is especially true regarding the patients who had already manifested some significant psychological and emotional distress during the pre-transplantation stage and during the treatment.

Fatigue, associated with other symptoms that affect the Health Related Quality of Life (HRQOL) is the main focus of the perspective study carried out by Hjermstad et al. (2004) on a group of 248 patients. The perception of fatigue and tendency to get tired, experienced by the patients after transplantation, emerge in such research as a fundamental issue, among other variable factors.

A series of works is focused on the methodological aspects (experimental plans and instruments) of the research on QOL. Holzner et al. (2001) highlight how in general the results of research are affected by the instruments and experimental plans used by researchers. The authors warn us against interpreting the data, which emerge from the various researches, without considering what kind of measurement instruments have been used. A large part of the researchers agree about the opportunity of taking into account the intrinsic limits of the instruments that are mostly used in the onco-haematological research. The FACT-BMT scale is one of the most common instruments for evaluating the impact of BMT on QOL. Its psychometric characteristics are found in the works by McQuellon et al. (1997); Cella (1994); Cella et al. (1993).

Mc Quellon et al. (1998) studied the chronological course of three variable factors: distress, QOL and concern about the experience and consequences of the illness.

Even though there is a growing consensus on the improving of QOL in post-BMT subjects, a particularly important matter is the chronological evolution of recovery and how this recovery should be supported. The subjects who survived over two years reach a good QOL level, which can be compared, to a certain extent, with that of people who never became ill.

Conclusions indicate that the perceived QOL can be graphically described by means of a parabolic function, where improvement starts from the dismissal period and extends over the years. The graph of the experience of distress varies according to a linear function, decreasing with time. The one describing the concern about many illness-related problems varies in the same way, but it gets worse with time.

McGrath (1999b) analyzes a series of processes related to coping and QOL in subjects affected by acute and chronic leukemia. The patients who find themselves in the first clinical condition turn out to be deeply focused on giving a meaning to their experience, according to a *here and now* modality. Those who find themselves in the second clinical condition mainly express questions related to their QOL, according to a perspective related to time and projects, involving satisfaction about their own health and proactive capacities (or concern about the decrease of such factors).

In a work on the issues that define the concept of QOL in relation to 687 long-time survivors, Down et al. (1999) make a qualitative analysis of the answers given by patients to a series of questions. These questions deal with the subjective meaning of QOL, the aspects that subjectively determine a variation of this meaning (in a better and /or in a worse sense) and the modalities through which the experience of illness causes such variations. The authors divide the answers into eleven general categories, through which they define the perception of QOL. The results of this research point out that the improvement of QOL is fostered by a series of support factors, the main of which are:

- acquisition of a sense of control over the illness, with a relative recovery of the perception of one's capacity of being independent, also in relation to social support and family care;
- recovery of one's capacity of viewing a renewed life purpose and assimilating the experience of illness into the whole of one's existence, by integrating one's immediate needs with deeper and more meaningful ones;
- acceptance of the changes that take place along one's life-journey through past, present and future. Such acceptance can be shaped as a kind of balance between security and fear combined with the awareness of the possible death, especially in relation to the experiences of loss in a psychological sense;
- acquisition of the capacity of adjusting to the series of long-lasting physical symptoms that one may experience.

Conclusions

The peculiarity of the BMT therapeutic protocol is a central element in the process aiming at overcoming illness. The frameworks of distress, coping and QOL, which turn out to be complex and to have more than one significant dimension, are considered to be the most relevant ones in a large part of the literature on clinical research. It is possible to notice a certain degree of homogeneity in the research methods, often based on an “experimental” approach, which is, more precisely, a pre-experimental or an almost experimental one. This approach makes an extensive use of instruments aimed at collecting data. Such instruments cover a whole range, which extends from questionnaires to self-assessment scales and to more or less structured interviews. Many studies are of a retrospective kind, a minority are of a perspective type and much more rare, and for now *in nuce*, are the ones focusing on the psychological support and psychotherapy interventions.

The analysis we made of the collected material, which is related to a wide survey of recent literature, allowed us to come to a series of conclusions that we briefly summarize:

- the QOL of the ill person deteriorates in a significant way, starting from the diagnosis time and for a period of time (of a variable length) after transplantation;
- the ill person experiences a condition of crisis and psycho-physical distress: this condition of crisis (of identity and personal integrity) requires some processes of change and adjustment;
- there is not just one adequate coping mode. Many different modalities of coping have been identified, which may configure themselves within the adjustment processes (e.g. the attribution of sense and meaning to the illness). There is evidence of the fact that one’s capacity of asking for assistance, as well as the presence of an adequate social support, are help factors that may oppose feelings of helplessness and hopelessness;
- as far as the difference of sex is concerned, it turns out that women have a better capacity of communicating and accepting their condition of suffering, even though there are no substantial differences in the processes of crisis and adjustment;
- in general, people who overcome their illness return to a satisfactory level of QOL, even though some consequences of the therapy, such as fatigue and loss of fertility, may persist;
- interventions of counseling and psychological support, especially if they were timely, show a good level of effectiveness in helping to overcome distress and allowing a personal elaboration of the meaningful life-experiences related to the illness and therapy period.

Recapitulating, a new perspective emerges more and more clearly from all the recent literature. Such perspective is centered on the ill person and focuses on his/her needs of care and psychological well-being.

Therefore the results of the studies on psychological distress, coping and QOL converge into an investigation of the risk factors and individual and psycho-social resources. Such results set up a particularly meaningful field of studies, aimed at identifying the aspects which prevent psychopathological risk, as well as protecting the psychological well-being of the ill person.

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