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Emotional and relational state of the cancer patient's family: what interventions?

الوضعية الإنفعالية و العلائقية لأسرة مريض السرطان : أي تدخلات ؟

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Abstract:

Cancer is a serious physical disease. It is a borderline situation not only for the patient, but also for his or her family, in that it tests not only who he or she is as a person, but also the entire interactional balance of the emotional and social context from which he or she comes. In order to truly understand cancer as a lived experience, it is essential that everyone involved takes into account the family's relationship to the event that is each patient's diagnosis of a tumour.

We contribute to this effort by reviewing the scientific literature on the emotional and familial dimensions of cancer. We propose a model of the "psychologist-patient-family" relationship that focuses not only on knowledge, but also on the emotional response to adaptation to the disease. The therapeutic implications of this model are also considered. Interpretation and discussion of this model conclude the results of this paper.

***Key words** : Cancer ;Psycho-oncology ; Family; Emotional.*

ملخص :

السرطان مرض جسدي خطير، فهو يشكل وضعية حدية لدى المريض و لكن أيضا لأسرته. فالأمر لا يؤثر عليه فقط كشخص مريض بل يصيب كل التوازن المابين علائقي للسياق الانفعالي و الاجتماعي الذي ينتمي اليه. و حتى يكون الفهم الحقيقي للسرطان كمرض معاش، يكون لزاما على جميع المتدخلين في مجال السرطانات أخذ العلاقات الأسرية على محمل الجد إزاء هذا الحدث و الذي يكون لكل مريض مرتبط بتشخيص المرض الخبيث.

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ستكون مساهمتنا في هذا المجهود التدخلي معتمدة على تحليل الأدبيات العلمية حول البعد الإنفعالي و العائلي للسرطان .سنقترح نموذجا للعلاقة :"نفساني ـ مريض ـ أسرة" يستهدف ليس فقط المظاهر المعرفية و لكن أكثر من ذلك الاستجابات الانفعالية بالنسبة للتكيف مع المرض آخذين بعين الاعتبار التدخلات العلاجية لهذا النموذج. تفسيرات و مناقشة هذا النموذج تلخص نتائج هذه المساهمة .

الكلمات المفتاحية: السرطان؛ علم النفس السرطاني؛ الأسرة؛ الانفعال.

Introduction

Cancer is a pathology that deeply involves the patient's life. The family members are undoubtedly the people who participate in this drama. The suffering of the patient, the need for ongoing treatment and constant medical supervision, the functional limitations that can reach an extreme degree, often have a dynamic effect on the family members and on the system of relationships. In order to truly understand cancer as a lived disease, it is essential that all those involved take into account the family's relationship to the event that is the diagnosis of a malignant tumor for any patient.

Psycho-oncology today constitutes a body of knowledge that is developing exponentially and is as much concerned with understanding the difficulties experienced by patients and their families as with interventions that promote psychological adaptation (Dauchy, Doleault, Marx, Kimmel, & Pellicier, 2005).

Interest in the family dimensions of cancer has developed in psycho-oncology firstly because of the need to integrate relatives into the management of patients in the advanced stages of the disease, and more recently because of the prevalence of cancer currently affecting one family in four in Western countries. This article highlights the process of family adaptation to the reality of cancer, and proposes some actions focused on the resolution of specific problems related to particular moments of the disease.

1. The time of diagnosis in the family

The diagnosis of a tumor is a traumatic event. It can even become a terrifying event in the patient's perception. Cancer is analogous to a natural disaster which confronts the individual with a total upheaval of his or her world and forces him or her to reorganize his or her own way of perceiving and confronting it. (Taylor,1987) to synthesize very usefully the two fundamental individual reactions to the event that is cancer.

On the one hand there is indeed the perception of oneself and the world, which undergoes in these patients a strong negative change. Bulman explained this understandable discouragement by the fact that certain basic principles necessary to live and act, such as confidence in the stability of our world, of the reality of our person, are shaken at the root and replaced by doubt and anxiety.

On the other hand, however, there is the indisputable fact that most patients' ability to cope with difficulties appears to be sufficient not only to overcome the disorganization but also to reap the psychological benefits. (Taylor,1987) observes that many of his patients had discovered new values in their lives, a better way of setting priorities and also a greater ability to interact with and understand others. The author suggests that the ability of patients to cope with cancer is related to anxiety about the disease (prognosis, pain, degree of disability) as well as the ability to establish a form of cognitive control (Bandura, 1977) over the self and related events. This control, however, depends on the structure of the personality as well as on the interaction with one's world and with the whole family world.

First, the diagnosis of cancer precipitates the family into an acute emotional crisis (Wellisch, 1981, Lichman, 1984, Lichman et al, 1984, Weader, 2000). This crisis is primarily triggered by the threat of losing a loved one and the challenge to the patient's and family's fantasies of immortality (Cohen & Mckay, 1988).This situation induces feelings of fear, alienation, vulnerability, helplessness and guilt. Fear of experiencing, directly or indirectly, the side effects of treatment and the anticipation of pain, as well as uncertainty *("will the treatment lead to a cure?"), the search for meaning ("why him/her?", "why now?")*, the feeling of failure, of being stigmatized, and practical problems are other preoccupations of this period (Delvaux, 2006).

For Peris & Miklowitz (2015), the announcement of serious illnesses such as cancer to the patient and his or her loved ones ushers in a period of acute stress in which a flood of sometimes contradictory emotions is mixed together; feelings of anxiety and frustration, guilt and loss of control, anger and despair.

According to Sophie Beugnot & Linda Roy (2010), it is a time of crisis that triggers a reflection on the issues related to differentiation and that opens the possibility of a reorganization of the links, thus allowing to move away from intergenerational repetitions. And in the same sense, for Véronique Feuilleron (2011, p179), the cancerous disease exerts deep upheavals on the family

dynamics, both emotionally and functionally, it is a real shock wave that impacts and disrupts the family rhythms, the roles of each, the parental personality traits, the financial balance and many other aspects. And in the same sense, the study of (Wong, et al., 2020), carried out on 98 members close to cancer patients, showed that 78.1% of the relatives suffered from health problems and that these problems were related to weight and sleep problems. Hence the interest of taking into account the emotional densification of the family context to adapt the interventions and avoid amplifying this intensification of the experiences even more.

2. - Reactions of the family

It is not possible to predict the exact outcome of the encounter between the subject and the event that is his cancer. It is equally difficult to say what the family's reaction to it may be. Reactions depend, to a large extent, on the previous family organization and the personality of the individuals and can only be predicted in an approximate way.

More broadly, every family has its own way of reacting to events, to illness and to death, according to experiences that are lived, shared and transmitted, and that condition the attitudes of its members. The reality of family ties is thus woven by the set of reciprocal influences, of all kinds, that are exerted between the members. Depending on the intensity of these links, any change occurring in one partner affects the whole family group in its balance.

In his extensive review of the literature, Litman (1974) concluded that "family solidarity" generally remains unchanged when a family member is ill with cancer. Nevertheless, in many cases, family life changes radically, making it easier to understand the reality of this change, and through it, the reactions of the people in the family. To better understand the reality of this change we must focus attention on a "model system" that has been extensively studied (Wellisch 1981, Lichman et al. 1984, Lichman, Taylor, & Wood,1988), on a specific widespread pathology that has a great clinical and social impact. Breast cancer.

Although some authors (Weisman & Worden, 1979) have postulated that oncology patients are often - albeit unintentionally - "victimized" by family members and friends, numerous controlled studies (Grandstaff, 2000, Mills & Klark,1979, Funch,1998, Bloom,1982, Kohen,1983) have found that most breast tumor patients report receiving adequate support from their families, particularly

their husbands. Lichman et al (1984), Lichman, Taylor, Wood (1988) assessed patient-husband and patient-child reactions in two controlled studies with a large sample of patients and families.

Regarding the relationship with the husband, three quarters of the patients said that the support received from the husband reached the highest level of the "social support" scale. Only in less than half of the cases were there episodes of isolation or even rejection by the family. This was usually a feeling of blame and guilt. One third of the patients reported communication difficulties, mainly due to an unfulfilled desire to talk freely and unreservedly about their illness. It is interesting to note that the husbands reported that they avoided communicating about their wives' illness for fear of embarrassing them. On the other hand, the wives perceived this attitude (on the part of their husbands) as a desire to "get over" the experience of the illness and the anxiety associated with it before they themselves felt able to do so in the first place. In the words of a recent mastectomy patient, "*It takes five years before you are considered cured. Well, as far as his peace of mind is concerned, it's already over. He doesn't want to hear about it anymore. He doesn't want to hear about it anymore*" (Lichtman, Taylor and Wood 1988, (p. 18)).

On the other hand, the husbands clearly perceived a change in their role towards greater responsibility in the home and in the relationship between the couple. The husbands did not feel guilty about their wives. The alteration of family roles is one of the fundamental elements of the disorganization-reorganization process that occurs during the phases of serious illness (Guex, 1998).

Depending on the circumstances, the sudden change in the functioning of one of the partners will create a disruption of balance, preventing an adequate reaction to the illness, sometimes with paradoxical phenomena.Overall it can be concluded that marital relationships in breast tumor cases are influenced mainly by four factors:

(a) stability of the relationship prior to the onset of the disease;

b) the clinical characteristics of the disease (severity, degree of disability, intensity of treatment and effort required);

c) Spouses' attitudes towards cancer itself;

d) patients' ability to adapt to the disease.

It has been observed that the support received from patients was proportional to their adaptation, whereas the ability of husbands to empathize with their wives was correlated with the marital situation prior to the illness rather than with the characteristics of the illness itself. In this sense, Claudine Herzlish (1984) showed very well that the indices of seriousness for the patients are perceived more in the relationship that they have with the disease, than in the characteristics themselves. Finally, the average "*marital satisfaction*" was mostly improved compared to the period before the illness.

Regarding the relationship between sick mothers and children. The experimental survey. (Lichman et al. 1984) found that in almost half of the cases (46%) the relationship had not changed because of the illness. When there was a change, however, most patients reported that the change was positive (more sincere, more open, closer). In cases where a deterioration in the relationship had occurred, the factors that played the most important role in this negative outcome were again the patients' adaptation to the disease, the clinical severity and the type of treatment.

The reasons for this have been explained in different ways. From the patients' point of view, the mothers' envy of their daughters' healthy bodies (Wellisch, 1981). From the daughters' point of view, the fear of inheriting their mother's predisposition to cancer (Litchman et al, 1984), From the relational point of view, the creation of greater expectations of support from the daughters when a relative estrangement from the sons is not usually stigmatized by the family (Litman, 1971)

3.- Patient-family relationships

The patient-family relationships observed for breast tumor are quite similar to those observed for most tumors. The emotional adjustment of patients is stronger the better the relationship with the family before the diagnosis. It depends on the attitude of both the patient and the family members towards the cancer. It is influenced by the clinical characteristics of the disease and by those of the therapeutic intervention. Sometimes cancer creates conflicting reactions in family members (Wortmanc & Dunkel-Schetter, 1979) : and rejection of the heartbreaking event which is accompanied by the belief that appropriate behavior towards the patient requires a facade of optimism and serenity.

The conflict between these reactions may produce ambivalence and anxiety in the interaction with the patient. Family members may try to physically avoid the patient, or they may "*forbid"* any open communication about the illness. But the discrepancies between positive verbal and negative non-verbal behavior may lead the patient to feel rejected or abandoned or even to respond to this ambiguous or negative relational feedback with reduced self-esteem and feelings of rejection. Two attempts can be made by the patient to stop this maladaptive relational circuit: to amplify the negative aspects of the situation, to try to evoke a greater empathic response, or to hide some of the symptomatology in order to be more accepted. Both of these coping attempts are naturally negative because they prevent the free expression of the patient's true feelings.

In a small percentage of cases, patients have isolated experiences of guilt and denial. This is frequently due to the failed attempt of family members to combat their own feelings of guilt and the inability to communicate in an appropriate manner and to be able to help the patient in a concrete way. Without changing the fact that three quarters of the families of cancer patients report that their relationship situation is unchanged or even improved after the diagnosis of a tumour (Taylor S. , 1983) it should be noted that a large part of the causes of relational discomfort are due to the people and their relationships rather than to the pathology itself.

Weisman & Worden, (1979) were able to differentiate patients into 2 categories on the basis of their adaptation to the disease: "*Highly Emotionally Disturbed*" and "*Lowly Emotionally Disturbed*", discovering in the first category patients with marital and family disagreements prior to diagnosis, while in the second, family relationships prior to the diagnosis were harmonious

This study also recorded an increase in harmony and closer family emotional relationships after diagnosis, with respect to marital relationships. On the other hand, one factor that may contribute to a loss of marital harmony is the development of a specific problem in the healthy spouse. Often the tasks of the healthy spouse are multiplied by the change in roles imposed by the disease and this causes tension, irritation and fatigue. The lack of communication leads to a lack of role flexibility, less family cohesion and a more tense and conflicting climate. More often than not, there is an increased emotional closeness: the healthy spouse idealizes the disease and his or her adaptation to cancer is experienced as an exceptional, "*heroic*" quality.

It has been observed that within certain limits, the family's response to cancer is also a function of clinical severity. It is therefore reasonable to expect that increased pain and disability, debilitation that may extend to cachexia, are factors that may contribute to the development of family problems (Lichtman et al. 1984; Lichtman, Taylor, Wood 1988).

Certain characteristics of treatments play a similar role: chemotherapy and radiotherapy with their side effects, surgical treatments with their mutilations (serious at the somatic and symbolic level). Even with patients in the final stage, it is possible to repeat what has already been stated for tumors in the initial state or in remission. A real disturbance, a real "pathology" of family life only occurs when relational functions existed prior to the disease. This observation is also confirmed by the classic clinical studies of (Kubler- Ross, 1969): the adaptation of family members and of the patients themselves to the impending mourning is completely related to each personality and to the relationships within the household.

What these families teach us is above all that the human personality can not be determined by external events. An illness, especially a disease like cancer, influences and disturbs the people with whom it comes into contact. But their reactions are essentially based on their personality and their history.

4. The psychologist-patient-family relationship

The role of the psychologist in relation to the families of oncology patients is particularly delicate and in many ways goes beyond the already complex psychologist-patient relationship. A whole series of feedbacks tend to be established in these families, with important effects on adaptation to the disease (Azieze, 2018). Within the family unit, all relationships are reciprocal. As we have just seen in the case of the breast tumor, they depend on the state of the individuals before the disease and their relationships, as well as the mutual reinforcement of these attitudes. Each attitude of the parties involved provides a context for the other and is indissolubly linked to it. If a negative attitude prevails, poor adaptation by the patient will produce detachment from family members and worsen the adaptation and so on. If "positive" interactions prevail, the patient's well-being and family support will reinforce each other. The psychologist enters powerfully into this system. In many illnesses of lesser impact, the psychologist-family relationship is of low intensity and the relationships are represented by a classic psychologist-patient model.

In the case of cancer, the emotional burden and involvement of all those affected by the disease leads to an inevitable reinforcement of the links and feedbacks. The model becomes a circular psychologist-patient-family interaction where the interactions of the parties involved are balanced or mutually reinforcing and where the physician is no less involved than the family members. The model is made even more complex by the role of health and non-health institutions such as the professional or social environment that come into play at different times in the course of the illness.

It would be a mistake for the psychologist to consider only the responses of the ill person (Magnen-Desdoits & Flahault, 2012). A similar error of perspective can lead to "inexplicable" cases of low compliance, to subjective discomfort not consistent with the state of the disease, or even to an inability to react to events, with hesitations and backtracking that can have negative results and delay events where speed is needed. It becomes a duty for the doctor to observe the patterns that are created in the families, to pay particular attention to the cases of (collective) denial of the seriousness of the disease or to the cases of marked emotional discomfort and to intervene if necessary with actions of support or, at the very least, simple advice, with the whole family as the objective. A simple intervention can have important positive effects in this sense.

5.- Study of the family emotional climate

Emotional Expression and the study of the family emotional climate through: the Expressed Emotion (EE or Emotional Expression) allows to define the family emotional climate. The first completed studies on EE were developed in the context of social psychiatry in the 1960s. With the advent of neuroleptics, a large part of the population of psychiatric patients returned to their social environment to resume daily life with their loved ones.

It has been shown that a family atmosphere marked by high expressed emotions favours the emergence of psychic symptoms that may lead in some cases to psychiatric hospitalization. The term "high expressed emotions" refers in particular in these studies to intrusive and repeated ways of establishing contact within the family or giving unsolicited and often critical advice as well as emotional responses marked by anger or acute stress (Burbach, 2013).

For example, it was found that schizophrenics who returned to their families were subject to more frequent symptomatic relapses than those who did not live in the family environment. The risk of relapse may be increased if there is prolonged contact between family members ((Bebbinggton & Kuipers, 1994; Weader, 2000). For example, it was found that for families living in the same household as a young adult diagnosed with a psychotic disorder, prolonged contact (>35 hours per week) increased the risk of symptom recurrence when the family emotional climate was marked by strong negative emotions (Bebbinggton & Kuipers, 1994). The focus then shifted from the influence of the general social environment to that of the family environment. The quantity and quality of relationships between patients and family members emerged as key variables in their social reintegration. Families characterized by a climate of high emotionality seemed to be particularly conducive to relapse (Peris & Miklowitz, 2015) a degree of emotionality has always accompanied mental illness and the family environment and constitutes, par excellence, the first sounding board. On the other hand, it will be underlined that a warm emotional climate can play a protective role in preventing the appearance of certain psychological disorders (Butler, Berry, Varese, & Bucci, 2019). An instrument was therefore developed to evaluate this variable which, after undergoing some modifications, became the Emotional Expression, still used today

Families are assessed using the Camberwell Family Interview (CFI), a semi-structured interview lasting approximately one hour with each adult family member. The information requested concerns the behaviors and activities of the patient, while the assessment focuses on the emotional reactions caused by the disease and its impact on the family environment.

The EE assessment is based on 5 scales, 2 of which are frequency scales (Criticism and Positive Remarks) and 3 of which are global assessments (Emotional Over involvement (EOI), Hostility and Warmth); for the former, the sum of the different statements is taken, while the global scales express the overall emotional attitude that was manifested during the interview. The EOI, Criticism and Hostility indicate the likelihood of symptomatic relapse.

The "*EOI*" assesses the overall emotional response of the interviewee, which may be manifested by excessive devotion or self-sacrifice, or protective or controlling hyperphrenia, towards the schizophrenic family member. Excessive "*EOI*" may reveal symbiotic or hyper-identifying situations, and may be

expressed by a pronounced dramatization of content (Dauchy, Doleault, Marx, Kimmel, & Pellicier, 2005). Criticism" highlights statements of clear disapproval or resentment of the behavior of the persons concerned. These comments, if numerous, are often accompanied by Hostility which indicates a more generalized and deeper negative attitude towards the subject: one disapproves and does not tolerate the person for what he or she is even before criticizing what he or she does.

"Warmth" reflects attitudes of genuine interest in the person with schizophrenia, and "Positive Remarks" are spontaneous comments of approval and satisfaction with the person and/or his/her behavior. If one or more family members living with the schizophrenic exceed the empirically established thresholds for "EOI" and/or "Criticism", the family is defined as *"high EE*"; if not, "*low EE*".

The correlation between high family EE and the frequency of relapse has been confirmed in different studies (Brooks, et al., 2020). It is only recently, however, that research has been under taken into the nature of this factor and its clinical significance within each family. In this respect, SE can be seen as an *"index*" of the family's "emotional temperature", a sign of the intensity of a given family member's emotional responses over a period of time. Moreover, the relationships of the spouses with each other and with the patient constitute a network, an overall "pattern". In order to study this, it is necessary to compare the EAs and all the spouses, the behaviors of the sick spouses and all the mutual relationships.

The EE can thus represent not only a simple *"risk factor*", but also a clinical and therapeutic parameter whose reading can be used successively for the orientation of the treatment and the evaluation of its effectiveness, thanks to the global understanding of the family in question, its way of acting and its various balances and needs. In order to achieve this, it is naturally necessary to go beyond a simple subdivision of families *("high" EE versus "low" EE*) and the strict correlation of this index with the recidivism rate (Brooks, et al., 2020).

6.- Therapeutic implications

Cancer is one of the most serious traumatic events. It affects approximately one in three individuals and three in four families. Cancer patients face worsening physical conditions, not to mention the often debilitating effects of treatments

such as chemotherapy and radiation. On the other hand, patients whose disease is in remission combine permanent physical disabilities and infirmities with the fear and anxiety of a recurrence of the tumor and the fatal outcome of the disease. Therefore, can appropriate social support actions help them to fight against pain, anguish, resignation?

Social support is any transaction between people involving one or more of the following:

1) emotional involvement (affection, empathy),

2) concrete help (services, rehabilitation tools),

3) information about relationships with others,

4) information support (especially about the disease).

Support may come from spouses or partners; children of other family members; friends and health workers; social structures or extra-institutional support groups.

The main type of support perceived as most useful by 81% of patients was emotional support, followed by information (Braubach, 2007). Concrete help and information were not perceived as useful by a large number of patients. Moreover, while emotional support was equally useful whether it came from family and friends or from health personnel, information and advice were perceived as useful only if offered by medical personnel and as useless and inadequate if offered by family or friends. The usefulness of concrete assistance, on the other hand, did not depend on the source.

Recent analyses (Wortmanc, 1986) have found that such actions can be downright harmful: for example, information about illness provided by family members rather than medical personnel often has the opposite result and increases stress (Cohen & Mckay, 1988).

It is therefore logical that various researchers have experimented with methods to provide cancer patients with the necessary social support (Beugnot & Roy, 2010). In particular, patient groups were used extensively to create solidarity and mutual encouragement among patients with the same disease and to provide them with information about their disease. The information had the effect of removing the fantasy of disease and death and thus making this event

cognitively accessible and controllable (Brooks, et al., 2020). In support groups for male patients with Hodgkin's lymphoma, there was some reduction in anxiety, which was even greater (along with patient satisfaction) if their wives attended the sessions. Once again we see the weight of the family interactive experience. In fact, a large number of studies highlight the greater effectiveness of support groups conducted with the family or with spouses.Compared to patient-only groups, it seems that adherence to the latter only occurs when family support is absent or weak, or when medical staff are absent or lacking in psychological support.

These data confirm the importance of the family in psychosocial support. It shows the usefulness of targeted treatment not only for the patient, but also for the family, especially if the family is at risk.

At-risk families include those with poor marital and family relationships prior to diagnosis and those where the patient has undergone devastating surgery or where the prognosis is severe. These families can benefit remarkably from clinical intervention.

Recent clinical-experimental studies in this area (EE or Emotional Expression) have emphasized the importance of highlighting the spouse's reactions and even more so the positive expressions for both the patient and the family member (Wong, et al., 2020).

In the marital relationship, the husband of a woman with a tumor often feels it is necessary to always put up a façade of optimism with his wife, while inwardly he lives in daily fear of the disease. In reality, the ability to express these fears can be helpful. Communication difficulties are therefore the main issues to be addressed in a clinical intervention. If the husband's minimization and concealed fear is not understood by the ill woman, this may create intolerance of both the disease and the husband. The sick woman may interpret this behavior as a refusal of the person and live in the only way she can perceive: being chronically ill (Weader, 2000). The husband must therefore be helped to understand that it is fear that keeps him away from the subject and that it is useful to move away from hesitation and openly share his concerns with his wife.

There are other interventions that have positive effects. These are those that involve children. Children with an ill parent are particularly vulnerable to role

conflict, tension and low family cohesion. This is why it is often necessary to involve outside helpers to understand the changes in roles and tasks (e.g., child care or household management).

At present, it is possible to have a scientifically reliable guide for family intervention. We refer to the Emotional Expression which allows to quantify, for each family member, variables such as Emotional Hyper involvement, Criticism or Hostility, all of which are predictive emotional parameters for both individual and family coping. In addition to improving communication and homogenizing perceptual patterns regarding the disease, it is possible to reduce emotional attitudes, which in children can, for example, hold back personal growth and the potential to define oneself and conduct interpersonal relationships.

Hyper reactivity, identification, regressive and symbiotic fusion with the patient, underlined by a high "*EOI"*, can be reorganized according to more functional models for coping and for a better quality of life.

Conclusion

In general, the onset of cancer will lead to a telescoping and dramatization of the stages of a family's life. I worked for some time with the parents of a daughter with a tumor, focusing primarily on developing their relationships with each other and with their own parents, so that they could see that even if their daughter died, they still had things to share...

The family members of a cancer patient live a double condition: they are active subjects and passive subjects of social support. Active subjects of psychological support for the patient, which is essential for a better self-perception and an adaptation to the disease. Passive subjects, insofar as it is right that they receive appropriate support because they are directly confronted with the fear of anxiety at the time of the diagnosis of their sick relative and insofar as, confused, they can badly manage a relationship whose positive management is an indispensable condition, if only for a better quality of life.

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