

Parents with cancer: Searching for the right balance between telling the truth and protecting children

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ABSTRACT

Objective: Recent scientific approaches to cancer patients draw attention to the psychological aspects of the disease and the involvement of their families, who are forced to reorganize themselves in order to manage the patient's illness. Functional responses to a stressful event facilitate open communication between family members and empathy for the patient's children, who need to be involved and informed about the illness in a clear and open fashion. The primary goal of this observational study was to explore the communication styles used by cancer-stricken parents with their children and to identify a correlation with the patient's levels of anxiety and depression and their ability to cope. We also sought to understand whether location, severity, and time from diagnosis influenced communication, coping, anxiety, or depression.

Method: From September of 2011 to July of 2015, 151 questionnaires were given to patients who had received at least one course of chemotherapy. The instruments that we employed were the Openness to Discuss Cancer in the Nuclear Family Scale, the Hospital Anxiety and Depression Scale, and the Mini-Mental Adjustment to Cancer Scale. **Our** sample included patients with children aged from 3 to 18 years. The patients had different types of cancer, mainly gastrointestinal and breast cancer. Their disease was at the metastatic stage in approximately 20% of patients.

Results: Our results showed statistically significant correlations between higher levels of anxiety and depression and more closed communication styles. The coping styles "hopelessness/helplessness," "cognitive avoidance," and "anxious preoccupation" were associated with a closed communication style that is correlated with higher levels of anxiety and depression. Tumor location, time from diagnosis, and stage of disease did not show statistically significant correlations with anxiety, depression, coping mechanisms, or communication styles.

Significance of results: Our study confirmed what has been reported in the literature: high levels of anxiety and depression affect communication among family members. Not surprisingly, the "fighting spirit" coping style engenders open communication.

KEYWORDS: Cancer, Communication, Children, Psychological support

INTRODUCTION

It is estimated that ~1,000 new diagnoses of cancer (excluding skin cancers) were made every day in Italy

during 2015 and that about 10% of these patients were between the ages of 0 and 49 years. Before the age of 50, 1 in 29 men and women will develop cancer. Breast cancer is the most common cancer in women, and is particularly relevant for younger people: 1 in 45 women will develop breast cancer before the age of 50. Just under 500 people die every day from cancer (AIOM–AIRTUM, 2015). It is reasonable to

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assume that a considerable number of children and adolescents are deeply, directly or indirectly, affected by the psychosocial consequences of the diagnosis and treatment of cancer in a parent.

As a part of the simultaneous supportive care dedicated to these patients, it is critical to also attend to the needs of their children, first, by providing adequate information about anything related to their parent's illness, and, second, by supporting and helping them to cope during the course of treatment and eventually during the last days of life. "Supportive care" is a concept that should also be expanded and applied to children of the approximately 3,000,000 long-term survivors of cancer who currently live in Italy (AIOM–AIRTUM, 2015).

A recently developed scientific approach to cancer patients draws attention to the psychological aspects of the disease and the involvement of their families, who are forced to reorganize their lives in order to manage the illness and its consequences (Yoshida et al., 2010). This is a very hard time for family members, as the diagnosis of a parent's cancer has a profound influence on everyone, especially dependent children, and puts all members at risk for psychological distress. Moreover, most families do not have the necessary knowledge about how best to respond to the needs of children during this unsettled time (Buchbinder et al., 2009).

The children of cancer patients must adapt suddenly to suspension of family roles and rituals, to the temporary loss of the ill parent due to the onset of symptoms, to the side effects of treatment, and to the threat of permanent loss (Welch et al., 1996). These children have an elevated incidence of psychological difficulties and troubled behavior, often related to changes in parenting practices (e.g., decreased emotional availability, lack of supervision, and poor communication) (Osborn, 2007).

Several studies have confirmed that the children of parents struggling with cancer are more at risk for anxiety, depression, feelings of helplessness, guilt, troubled behavior, and difficulties with school and relationships (Hasson-Ohayon & Braun, 2010). An adolescent coping with a parent's illness is considered susceptible to negative psychosocial outcomes, and often demonstrates high levels of anxiety, fear, and frustration about the experience (Philipps et al., 2015).

Parents are always confused and worried about telling children the truth, and thus being transparent and sincere, as they wish to protect their children from the effects of the illness and the treatments involved. After a cancer diagnosis, the main objective of a parent is often to shield children from pain and encourage them to feel as secure as possible. Studies have shown that parents may have difficulty in

talking with children about their illness because they are afraid of frightening them and depriving them of hope (Aamotsmo & Bugge, 2013). In general, parents avoid communication and filter information from their children to protect them and minimize difficulties (Semple & McCance, 2010).

Little attention has been paid as to whether, what, and how children should be told about a parent's illness. Parents prefer to avoid direct questions about cancer and death in order to prevent feelings of distress in the children, to preserve family memories, and to avoid causing confusion. In contrast, many parents have confirmed that open communication can be very helpful in alleviating distress in their children, because children who receive a sincere explanation of their parent's illness can place more trust in family members (Barnes et al., 2000).

In a literature review, Semple and McCance (2010) focused on three recurrent themes regarding parenting and cancer. The first theme dealt with the patient's guilt about not being a good parent, the second focused on the importance of maintaining routines at home as a way of protecting children and the family routine, and the third highlighted the struggle for parents to understand how best to talk to their children about the illness. These issues are significant and provide an important message for clinicians who are caring for patients with young children. Parents need to be informed and supported by professionals in this difficult time of family role reorganization, when guidance can be so hard to find (Rauch & Muriel, 2004).

MATERIALS AND METHODS

Our study design was exploratory and descriptive. From September of 2011 to July of 2015, we administered 160 questionnaires to consecutive patients who received at least one cycle of chemotherapy at the Unit of Medical Oncology at the Fondazione Poliambulanza. All participating patients had children between the ages of 3 and 18 years. Among the 160 potential participants, 2 refused to participate because they felt too stressed to complete a questionnaire, and 7 other questionnaires were not completed. The purpose and method of our study were explained in detail by the psychologists on the team, and written informed consent was obtained.

The aims of our study were to explore the communication styles used by cancer-stricken parents and identify correlations with their levels of anxiety and depression, and to assess their ability to cope. We also hoped to understand whether location, severity, and time from diagnosis influences communication, coping, anxiety, and depression. We utilized the following instruments: the Hospital Anxiety and

Depression Scale (HADS, Italian-validated version) (see Appendix 1); the Openness to Discuss Cancer in the Nuclear Family Scale (ODCF, Italian-translated version; Todaro, 2010) (see Appendix 2); and the Mini-Mental Adjustment to Cancer Scale (Mini-MAC, Italian-validated version; Grassi et al., 2005) (see Appendix 3).

The HADS is a widely used 14-item measure of self-reported generalized emotional distress (Zigmond & Snaith, 1983) and consists of two subscales, with seven items in each, which assess a respondent's levels of anxiety and depression. All items have four response options, ranging from 0 ("not at all") to 3 ("very much"). A result greater than 10 on either subscale is indicative of possible clinically significant levels of anxiety and depression.

The second instrument we employed was the Openness to Discuss Cancer in the Family (ODCF) Scale, which was developed to assess cancer patients' communication styles with members of their nuclear family about their experience of the illness (Mesters et al., 1997). The instrument includes nine items with four response options, ranging from 1 ("strongly disagree") to 4 ("strongly agree"). A total score is obtained by summing all results, which can range from a minimum of 9 (indicating an open communication style) to a maximum of 36 (indicative of a closed communication style).

Our study also employed the Mini-MAC Scale (Mini-Mental Adjustment to Cancer Scale) to assess coping strategies (Greer & Watson, 1987). This instrument includes 29 items with 4 response options, ranging from 1 ("strongly disagree") to 4 ("strongly agree"). It measures five coping strategies: "fighting spirit," "hopelessness/helplessness," "fatalism," "anxious preoccupation," and "cognitive avoidance" (Grassi et al., 2005).

Data Analysis

Descriptive statistical examination of each variable was undertaken, which included a frequency calculation of answers for every test administered and a correlation analysis between answers, using the Pearson correlation coefficient (ρ) and assuming a level of significance at $p < 0.05$. All tests were conducted using SPSS statistical software.

RESULTS

We studied a total of 151 patients, 49.7% of whom were male and 50.3% female. The median age was 45 years (range = 31–60). Patients had different types of cancer—mainly gastrointestinal (22.5%) and breast cancer (55%). All remaining types are presented in Table 1. The cancers of most patients were at a localized

Table 1. Patients' characteristics (n = 151)

	Mean	SD	Range
	45.21	5.83	31–60
Age	Number	%	
Sex			
Male	75		49.7
Female	76		50.3
Site of primary cancer			
Sarcoma	4		2.6
Gastrointestinal	34		22.5
Liver and pancreas	6		4
Urinary tract	3		2
Lung	3		2
Breast	83		55
Testicle	4		2.6
Female reproductive	13		8.6
Other	1		0.7
Stage of cancer			
Local	77		51
Local-regional	44		29.1
Systemic (metastatic)	30		19.9
Length of disease			
0–3 months	108		71.5
3–6 months	23		15.2
6–12 months	11		7.3
>12 months	9		6
Marital status			
Not married	3		2
Separated	23		15.2
Widower	3		2
Cohabitant	9		6
Married	113		74.8
Job			
Worker	110		72.8
Not working	17		11.3
Housewife	19		12.6
Retired	4		2.6
Invalid	1		0.7
Education			
Elementary school	2		1.3
Junior high school	48		31.8
High school	75		49.7
University	26		17.2
Number of sons			
1	46		30.5
2	77		51
3	24		15.9
4	4		2.6

stage (51%), 29.1% were at a local-regional stage, and 19.9% were metastatic. Most had been affected by cancer for 3 months (71.5%), while 15.2% had been diagnosed for 3 to 6 months. Only 6% had been affected for more than 12 months. Some 74.8% of participants were married, 72.8% were working, and 49.7% had earned at least a high school degree. Most had two sons (51%), 30.5% had one son, 15.9% had three children, and 2.6% had four children. We did not analyze each age category and thus avoided spreading our results to too many small clusters without statistical

significance. A complete descriptive analysis of our population is presented in [Table 1](#).

HADS Results

All patients were evaluated with the Hospital Anxiety and Depression Scale (HADS). We considered anxiety and depression separately when conducting statistical tests. According to our results, 22.5% of patients showed anxiety (score ≥ 11), and 26.5% were borderline anxious (score = 8–10). We found that 13.2% of patients had depression (score ≥ 11), and 21.2% were borderline depressed (score = 8–10).

Mini-Mental Adjustment to Cancer Scale Results (Mini-MAC)

We administered the Mini-MAC to all 151 patients. Each of the five domains were analyzed separately. To identify the prevalent domain in the Mini-MAC, we looked at the domain (or domains in case of equality) with the highest mean score for each patient. For this reason, the total number of cases was higher than 151 (23 patients had multiple domains with equally high scores). We found that fighting spirit was the prevalent domain in our population (50.57%), followed by cognitive avoidance (27.01%), anxious preoccupation (10.34%), fatalism (10.34%), and helplessness/hopelessness (1.72%).

Results with the ODCF Scale

All 151 patients completed the ODCF. We found a mean score of 17.58 ± 5.29 (range = 9–34). All test results are summarized in [Table 2](#).

Correlation Analysis

We calculated bivariate correlations for every variable in our population using a two-tailed Pearson correlation coefficient (ρ) and assuming a p value ≤ 0.05 as significant.

We found a significant positive correlation between age and the Mini-MAC fatalism domain ($\rho = 0.219$, $p < 0.001$) and between the state of the cancer and the HADS depression domain ($\rho = 0.228$, $p < 0.001$). In addition, we found a significant negative correlation between education and HADS anxiety ($\rho = -0.196$, $p < 0.05$), HADS depression ($\rho = -0.181$, $p < 0.05$), and Mini-MAC helplessness/hopelessness ($\rho = -0.189$, $p < 0.05$).

Regarding the anxiety domain, we observed a significant positive correlation with the HADS depression domain ($\rho = 0.713$, $p < 0.001$), Mini-MAC helplessness/hopelessness ($\rho = 0.533$, $p < 0.001$), Mini-MAC anxious preoccupation ($\rho = 0.644$, $p < 0.001$), and Mini-MAC fatalism ($\rho = 0.166$, $p < 0.05$). In addition, the HADS anxiety domain had a significant negative

Table 2. Test results

	Mean score	SD	Range
HADS			
Anxiety	7.74	4.04	0–21
Depression	6.17	3.81	0–17
Mini-MAC			
Helplessness/hopelessness	1.54	0.62	0–4
Anxious preoccupation	2.5	0.66	1–4
Fighting spirit	3.23	0.64	1–4
Cognitive avoidance	2.83	0.68	1–4
Fatalism	2.74	0.55	1–4
ODCF	17.58	5.3	9–34

ODCF = Openness to Discuss Cancer in the Nuclear Family Scale.

correlation with the Mini-MAC fighting spirit domain ($\rho = -0.284$, $p < 0.001$).

As for the HADS depression domain, we found a significant positive correlation with Mini-MAC helplessness/hopelessness ($\rho = 0.599$, $p < 0.001$) and Mini-MAC anxious preoccupation ($\rho = 0.607$, $p < 0.001$), and a significant negative correlation with Mini-MAC fighting spirit ($\rho = -0.369$, $p < 0.001$).

Finally, we found that ODCF scores had a significant positive correlation with the HADS anxiety and depression domains ($\rho = 0.363$, $p < 0.001$; $\rho = 0.353$, $p < 0.001$), Mini-MAC helplessness/hopelessness ($\rho = 0.361$, $p < 0.001$), Mini-MAC anxious preoccupation ($\rho = 0.314$, $p < 0.001$), and Mini-MAC cognitive avoidance ($\rho = 0.227$, $p < 0.001$). In addition, we observed a significant negative correlation with Mini-MAC fighting spirit ($\rho = -0.209$, $p < 0.001$). All these correlations are summarized in [Table 3](#).

DISCUSSION

Communication is one of the key factors in helping children adapt to a parent's cancer. Functional responses to a stressful event facilitate open communication between family members and engender empathy for children, who need to be involved and informed of a parent's illness in a setting of open and transparent communication. When children are told of the diagnosis, their anxiety levels are lowered and communication within the family is improved, though such factors as a child's age have not been studied in detail. When parents choose a more open communication style, children are better able to cope with this new information. Furthermore, an open communication style increases trust between parents and children, while a closed style can reinforce feelings of exclusion, fear, threat, and isolation (Semple & McCaughan, 2013).

Table 3. Pearson bivariate correlation (two-tailed)

	HADS anxiety	HADS depression	HH	AP	FS	CA	F	ODCF
HADS anxiety		0.713**	0.533**	0.644**	-0.284**		0.166*	0.363**
HAD depression	0.713**		0.599**	0.607**	-0.369**			0.353**
HH	0.533**	0.599**						0.361**
AP	0.644**	0.607**						0.314**
FS	-0.284**	-0.369**						-0.209**
CA								0.227**
F	0.166*							
ODCF	0.363**	0.353**	0.361**	0.314**	-0.209**	0.227**		

HH = helplessness/hopelessness; AP = anxious preoccupation, FS = fighting spirit, CA = cognitive avoidance, F = fatalism, ODCF = Openness to Discuss Cancer in the Nuclear Family Scale.

* $p < 0.05$.

** $p < 0.001$.

Our observational study of 151 parents with cancer confirmed recent findings in the literature and highlighted significant correlations between coping styles and anxiety/depression. Our research aimed to understand the impact of anxiety and depression and coping styles on family communication. Psychological and emotional coping can be defined as thoughts or actions designed to resolve or mitigate a problematic situation. Coping is not a fixed attribute, but is rather the dynamic capacity to apply effective methods to control or prevent distress. In our study, anxiety and depression correlated significantly with two coping styles: helplessness/hopelessness and anxious preoccupation. The helplessness/hopelessness style is characterized by feelings of “giving up,” of being engulfed by despair after knowledge of the diagnosis. The anxious preoccupation style is characterized by a constant preoccupation with cancer and feelings of devastation, anxiety, fear, and apprehension (Watson et al., 1988). Furthermore, our results show that the fatalism style correlates significantly with the anxiety domain. A sense of fatalism means that patients put themselves in the hands of God and choose passive acceptance. Studies have shown that reliance on fatalism is associated with poorer adjustment and higher levels of emotional distress (Ferrero et al., 1994).

Our results with the ODCF Scale have a significant positive correlation with HADS anxiety and depression, as well as Mini-MAC helplessness/hopelessness, anxious preoccupation, and cognitive avoidance. These results could be explained by the fact that higher levels of worry and uncertainty compel parents to hide their diagnosis and treatments. They prefer to avoid their children’s questions and thus alleviate distress and anxieties. Furthermore, parents avoid addressing questions about death and fears about the future. Corresponding with previously published research on this topic, our results indicate that an open family communication style is facilitated by a fighting spirit coping

style and lower levels of anxiety and depression. Fighting spirit style is characterized by a determination to combat the illness. It comes with an optimistic attitude and has a significant negative correlation with anxiety and depression (Watson et al., 1988). Parents who face their illness with determination display a more optimistic attitude and actively seek more information. The attitude of doing everything within their power to face the cancer enhances communication with their children and facilitates openness and self-disclosure. When parents inform and speak openly with children about the illness and possible death, the children are encouraged to ask questions and be more engaged in family matters. Supportive open communication among family members can be of crucial importance with respect to the psychosocial well-being and adjustment of cancer patients (Mesters et al., 1997). The children are free to cope in their own ways and are more likely to access support (Aamotsmo & Bugge, 2013).

Children need information that they can understand, and the information needs to be appropriate to their developmental stage and level of psychosocial function (Turner et al., 2007). Even if children are not told about the illness, they soon become aware of changes in the atmosphere at home and notice changes in their parent’s health. They are known to have greater potential for understanding illness than many professionals had previously thought possible and, like adults, have consistent coping styles. Of course, it may be important to consider a child’s age and their developmental issues to facilitate optimal communication (see Table 4).

The issues of whether, how, and how much to tell the children of cancer patients about the illness is approached differently in various countries and cultures. Moreover, the modalities of family involvement are different, because in some countries, like Italy, families are consulted before revealing a diagnosis to the patient, and they can take a decision for an uninformed patient (Locatelli et al., 2013).

Table 4. Children's cognitive and emotional developmental stages (Cancer Council New South Wales, 2007)

Age	Cognitive and emotional function	Behavior
Infants (0–2 years)	Infants have an egocentric perspective. They have a little awareness of illness and are afraid of separation. When a parent has cancer, children feel the changing of family atmosphere and routines, but they can't understand what's happening because they don't have the cognitive concept of illness.	Their reaction to a family's changing mood could be irritability, sleep disturbance, and feeding alterations.
Preschool age (3–6 years)	Children in this age group begin to understand the difference between being well or being sick. They often think the world revolves around them and believe in magical thinking. So they could believe they caused the cancer or can get the cancer. They could feel blame and guilt.	They could be naughty and wayward and be reactive to simple family rules about attending school, bedtime, and feeding.
School age (7–12 years)	School-age children are more involved in family routines and have more emotional resources and cognitive skills to understand what's happening around them. Some children know about cancer but maybe don't know about its causes. They have simple cause-and-effect logic, and they can worry a lot about a parent's illness. They can also begin to understand about death and ask questions about it.	This age group can feel guilty about things they have done or said. Some difficulties could appear about sleeping, eating, school performance, and relationships with friends, with a tendency to retirement. Frequent somatization (e.g., headache, bellyache) can appear, caused by higher anxiety levels.
Preadolescents and adolescents (13–18 years)	Teenagers have abstract thinking and an adult understanding of cancer, so they need to receive detailed information about a parent's illness. They can then reflect on the possible outcomes and their impact on family members. Teenagers are eager to become adult and independent, but they need to feel protected and guided at the same time. This ambivalence can be very turbulent for many families, and when a family member has cancer this difficult balance can be very troubled. Teenagers have to take the responsibility to become more involved in family management, but they also need to seek independence and separation. This conflict is very difficult and can make them feel guilty and frustrated.	Teenagers can react in different ways: they can become very lonely and elusive with their parents or extremely protective and willing to be engaged in family and illness concerns. They can prefer staying at home for long periods of time or, on the contrary, being outside with friends most of the time. Some teens can also have mood problems, undertake risk-taking behavior, and engage in substance abuse.

Italy is known to have a paternalistic vision of the patient–doctor relationship and to attribute a protective role to the family. This approach can be also explained by the diffuse policies of nondisclosure that also affect close communication with children (Surbone et al., 2004).

The strengths of our study include its sufficiently large sample size and the use of specific instruments to assess cancer patients' family communication. However, there are several limitations that prevent generalization of our results to all cancer patients. For instance, our population was entirely Italian, our participants were employed, and they had a medium to high level of education. In addition, we included patients with different types of cancer, but

we did not find any significant correlation among the duration and seriousness of the disease and coping styles and communication. Moreover, we could not find significant correlations between children's age and parents' coping and communication styles. Finally, the tumor's location, time from diagnosis, and stage did not yield statistically significant correlations with anxiety, depression, coping skills, and communication styles.

CLINICAL IMPLICATIONS

Our findings offer several useful insights for clinicians working with families affected by cancer. For patients with children, facing the illness means

Table 5. *Communication strategies for parents*

1. Don't be afraid to talk about cancer: Although you may want to protect your children from fear and other difficult feelings, it is important to talk openly with them about your diagnosis and treatment.
2. Be indulgent with yourself. There is no the absolute right way, but the best way you can do.
3. Find out what they already know.
4. Let your children ask any questions they wish to ask.
5. Keep family routines and time and try to keep your children's daily schedules as normal as possible.
6. Be honest and open. It is important to provide information that is appropriate for your children's ages and temperaments, aiming to help them understand the situation without overwhelming them.
7. Show your love and emotions. Talking about your feelings with honesty, sincerity, and openness greatly reduces the stress that cancer places on relationships.

taking into account the impact of the illness on their family. Parents need to consider how to tell (or not tell) their children and how to manage family responsibilities during treatment. Talking to children about cancer can be very a difficult undertaking, but there is strong evidence that open and honest communication is the best course of action in terms of helping children cope with a parent's cancer diagnosis.

In our setting, we developed the "Rainbow Project" with the objective of supporting parents in this difficult task of simultaneously living with cancer and raising children. Psychologists trained in developmental matters meet with patients who have children and offer them clinical counseling, including communication strategies and information about children's coping skills. The aim of this counseling is to offer parents the option of speaking appropriately with their children and explaining to them that open communication about cancer within the family is associated with positive psychosocial function in children. Parents made it quite clear that they wanted information about the most appropriate language to use with their children and sought guidance on ways to communicate effectively.

During our project, we were able to collect several parents' experiences, which we then used to create a simple guide for parents dealing with illness: "Between Parents and Children: How to Cope with Cancer Together." With this simple guide, parents can find useful advice and various strategies for supporting open communication with their children. Simple suggestions have been developed using parents' experience, which become valuable tools for living with this painful experience (see Table 5). Such advice should always take account of children's age,

family communication style, and feelings about illness and treatments, as well as parents' ability to cope with children's needs and reactions.

Our purpose was to offer parents psychological support and guidance to prevent parental distress, family dysfunction, and behavioral and emotional problems for the children. These findings have significant implications for oncologists and healthcare professionals, who are greatly concerned about a patient's family during the course of treatment. Helping clinicians to be comfortable with parenting and child-related issues is an important added value that helps parents to share their concerns and worries about their children. As this matter is very complex and vitally relevant, further studies are called for and should be highly valuable.

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- a. Sempre
- b. Non sempre
- c. Solo alcune volte
- d. Mai
3. Sono spaventato/a dal fatto che mi possa accadere qualcosa di terribile:
- a. Sempre, e ciò mi preoccupa moltissimo
- b. Spesso, e ciò mi preoccupa abbastanza
- c. Talvolta, ma ciò non mi preoccupa
- d. Per nulla
4. Riesco ancora a ridere e a vedere il lato divertente delle cose:
- a. Come sempre
- b. Ora non molto spesso
- c. Ora raramente
- d. Mai
5. Ho la mente piena di preoccupazioni:
- a. La maggior parte del tempo
- b. Molte volte
- c. Talvolta, ma non spesso
- d. Solo occasionalmente
6. Mi sento allegro/a:
- a. Per niente
- b. Un po'
- c. Abbastanza
- d. La maggior parte del tempo
7. Riesco a stare tranquillo/a e a sentirmi rilassato/a:
- a. Sempre
- b. Spesso
- c. Talvolta
- d. Per nulla
8. Mi sento fiacco/a:
- a. Quasi sempre
- b. Molto spesso
- c. Talvolta
- d. Per nulla
9. Ho la sensazione fastidiosa di crampi allo stomaco:
- a. Per niente
- b. Occasionalmente

APPENDIX 1

Hospital Anxiety and Depression Scale (Italian Version)

ISTRUZIONI: Nel presente questionario vengono riportate alcune affermazioni circa ciò che le persone possono provare quando si ammalano sul piano fisico. La preghiamo di leggere ogni affermazione e di segnare con una crocetta la sensazione che maggiormente si avvicina a come si è sentito/a in quest'ultima settimana, incluso oggi.

1. Mi sento teso/a “come una corda”:

- a. La maggior parte del tempo
- b. Molte volte
- c. Qualche volta o occasionalmente
- d. Mai

2. Riesco ancora a godere delle cose che mi sono sempre piaciute:

- c. Abbastanza spesso
 d. Molto spesso
10. Ho perso interesse riguardo al mio aspetto fisico:
- a. Decisamente o molto
 b. Abbastanza, ma non vi do l'importanza che dovrei
 c. Un po' e non vi do molta importanza
 d. Per nulla o non ho affatto perso l'interesse
11. Mi sento irrequieto/a come se fossi costretto a muovermi:
- a. Moltissimo
 b. Abbastanza
 c. Un po'
 d. Per niente
12. Guardo con gioia a ciò che mi può capitare:
- a. Come al solito
 b. Un po' meno del solito
 c. Molto meno del solito
 d. Per nulla
13. Ho improvvise sensazioni di panico:
- a. Molto spesso
 b. Abbastanza frequentemente
 c. Raramente
 d. Mai
14. Riesco a godere della lettura (libro, giornali) o dell'ascolto di un programma alla radio o alla televisione:
- a. Spesso
 b. Talvolta
 c. Raramente
 d. Molto raramente o mai

Adapted from Zigmond and Snaith (1983)

APPENDIX 2

Openness to Discuss Cancer in the Family Scale

Questionario sulla Comunicazione in Famiglia (Italian Version)

ISTRUZIONI: Di seguito è riportata una serie di affermazioni riguardanti le possibili modalità di comunicazione della sua malattia in famiglia con il partner e/o con i figli.

È pregato/a di indicare, per ciascuna affermazione, il grado con il quale lei si sente d'accordo in questo momento, ponendo una crocetta in corrispondenza del numero per lei più appropriato. Se per esempio l'affermazione non corrisponde per niente al suo modo di reagire, dovrà segnare il numero 1, se l'affermazione corrisponde esattamente al suo modo di reagire dovrà segnare il numero 4. Per risposte intermedie potrà segnare il numero 2 o 3. Faccia comunque riferimento allo schema qui di seguito riportato:

1 = Completamente in disaccordo

2 = In disaccordo

3 = D'accordo

4 = Completamente d'accordo

- 1) Parlo il meno possibile della mia malattia perché non voglio creare disagio in famiglia 1 2 3 4
- 2) Al mio partner non piace che io parli dei miei problemi 1 2 3 4
- 3) Ai miei figli non piace che io parli dei miei problemi 1 2 3 4
- 4) Se parlo della mia malattia, gli altri sorvolano 1 2 3 4
- 5) La mia famiglia vuole sempre sentirmi dire che io sto bene 1 2 3 4
- 6) Parlare delle emozioni riguardanti la mia malattia turba la mia famiglia 1 2 3 4
- 7) Il mio compagno/partner spesso non sa cosa dire o fare quando mi sento giù 1 2 3 4
- 8) I miei figli spesso non sanno cosa dire o fare quando mi sento giù 1 2 3 4
- 9) Sono io la maggior parte delle volte che, in famiglia, inizio un discorso riguardo alla mia malattia e ai miei problemi 1 2 3 4

APPENDIX 3

Mini-Mental Adjustment to Cancer Scale (Italian Version)

ISTRUZIONI: Di seguito è riportata una serie di affermazioni riguardanti le possibili reazioni di fronte alla malattia.

È pregato/a di indicare, per ciascuna affermazione, il grado con il quale lei si sente d'accordo in questo momento, ponendo una crocetta in corrispondenza del numero per lei più appropriato. Se per esempio l'affermazione non corrisponde per niente al suo modo di reagire, dovrà segnare il numero 1, se l'affermazione corrisponde esattamente al suo modo di reagire dovrà segnare il numero 4. Per risposte intermedie potrà segnare il numero 2 o 3.

1 = Completamente in disaccordo

2 = In disaccordo

3 = D'accordo

4 = Completamente d'accordo

1 2 3 4

1. Per ora vivo alla giornata
2. Vedo questa malattia come una sfida
3. Mi sono messo nelle mani di Dio
4. Ho voglia di lasciar perdere tutto
5. Mi sento molto arrabbiato per quello che mi è capitato
6. Mi sento completamente perduto su cosa fare
7. Provo sensazioni terribili
8. Tengo conto di ciò che ho di buono
9. Ho paura che il tumore ricompaia o si aggravi
10. Tento di combattere la mia malattia
11. Quando mi vengono in mente pensieri che riguardano il tumore cerco di distrarmi
12. Non riesco a controllare la situazione
13. Sono preoccupato
14. Non ho molta speranza per il futuro
15. Sento che non c'è nulla che posso fare per aiutarmi
16. Mi pare che il mondo mi stia crollando addosso
17. Il non pensarci mi aiuta a reagire
18. Sono molto ottimista
19. Mi sento che ogni giorno mi è stato regalato
20. Sento che la vita è senza speranza
21. Non riesco a far fronte alla situazione
22. Sono sconvolto da questa malattia
23. Sono determinato a sconfiggere il tumore.
24. Da quando mi è stato diagnosticato il cancro ho capito quanto sia preziosa la vita e cerco di approfittarne
25. Mi è difficile credere che questo sia capitato a me
26. Mi sforzo di non pensare a questa malattia
27. Scaccio volutamente i pensieri riguardanti il tumore
28. Mi sento molto in ansia per questa malattia
29. Sono un po' spaventato