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Chapter 01

Depression, Anxiety and Stress in Adult Children Caregivers of Oncological Patients

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Abstract

The aim of this study is to describe levels of depression, anxiety, and stress in adult offspring of cancer patients; and to analyze gender differences in psychological morbidity, as well as the association between psychological morbidity and traumatic symptomatology. This study is correlational with a sample of 214 adult offspring who completed the Depression, Anxiety and Stress Scales (DASS-21) and the Impact of Event Scale-Revised (IES-R). The results revealed that 6-60% of the participants showed 'normal' or 'mild' levels of stress, anxiety, or depression; 15-26% 'moderate' levels; and 4-12% 'severe' or 'extremely severe' levels. Women had higher levels of anxiety and stress than men. Positive correlations were found between the DASS-21 and the IES-R. In conclusion, some adult offspring caregivers reveal severe levels of psychological morbidity. The results show a need for psychological intervention in this population, particularly in the female gender.

Introduction

There is a growing recognition that the diagnosis and treatment of cancer not only causes significant discomfort to patients but also to their families. Increasingly, family members are becoming the leading providers of informal care for cancer patients [1,2], and some researchers have thus begun to see family members as 'co-sufferers' in the fight against this disease [3]. Studies have shown that the diagnosis of cancer very often causes distress in patients and informal caregivers, in the forms of depression, severe levels of anxiety and stress [4,5]. The aim of this chapter is to describe levels of depression, anxiety, and stress, to analyze gender differences in psychological morbidity, as well as the association between psychological morbidity and traumatic symptomatology in adult offspring of cancer patients.

Psychological Distress in Adult Offspring Caregivers of Oncological Patients

Cancer occurs in the context of a family system, producing negative effects on the functioning of the system and on each of its elements. Considering that, in a system, the behavior of each of its members is inseparable from the behavior of the others; there is a circularity in the relationship between patient and family [6,7]. The diagnosis of cancer in an individual is capable of affecting the entire family system, and its elements. The more or less adjusted and adapted members react will have a positive or negative effect on the patient. The negative impact on the family system is associated with the crisis that might arise when cancer is diagnosed. This corresponds to a situation in which the adaptation of the internal or external balance of a system is disturbed, or of an individual, and triggers a set of structural, psychological, economic and social changes, at a family and individual level [6,8,9]. According to Lewis [10], families of patients with cancer, experience the same requirements and challenges as patients. The way families adapt and cope with one's illness has a major impact on the physical and psychosocial well-being of their members, as well as on the clinical course of the disease itself [11].

As mentioned above, the scientific literature has increasingly viewed family members as 'co-sufferers' in the fight against cancer [12], although many processes are still unknown through which cancer can affect the family [2,12]. The most recent research, is focused predominantly on the impact of child cancer on their parents [13-18], on the impact of parental cancer on children and adolescents [19-26] and, still overwhelmingly, in the patients' spouses [27-32].

The psychosocial impact of parental cancer on offspring has been the subject of considerable research. As Lewis [33,34] points out, when cancer appears in the parental subsystem, it is crucial to note how members of the filial subsystem are affected. The most relevant studies, since the 1990s, were carried out on samples of children and/or adolescents, and little relevance was given to offspring in adult-

hood [1,35]. Still, the work by Mosher and Weiss [36], only referring to research with this population, should be highlighted.

In a literature review, Phillips [24] examined the experiences of parents diagnosed with advanced cancer and their adolescent children. The results revealed that adolescents living with a parent with advanced cancer showed significantly higher levels of distress, anxiety, and depression than their peers. Moreover, a recent systematic review with adolescents and young adult offspring of parents with cancer concluded that they showed higher levels of anxiety, depression, and stress [26], when compared with samples without parental cancer. Nevertheless, according to the meta-analysis by Hodges, Humphris, and Macfarlane [37] on psychological distress in the relatives of cancer patients, most studies do not address adult offspring. Of the 21 studies analyzed, in 17, participants were exclusively spouses, and in the remaining 4 studies, the overwhelming majority included spouses with adult children (and other family caregivers such as mothers, sisters, siblings, nephews, etc.), representing less than 5% of the sample. Even so, it is well known that the provision of informal family care in oncology, is assumed by children, especially females, comprising an extremely vulnerable population, according to several authors [38]. In the case of daughters, and depending on the type of cancer, they are simultaneously confronted with two stressors: the parental disease and the fears inherent to their own vulnerability [39]. In this context, Baider, Ever-Hadani, and Kaplan De-Nour [40] conducted a study with a sample of 230 healthy women using the Brief Symptom Inventory (BSI) and the Impact of Event Scale (IES), relating them to the history of breast cancer in the family (in the mother or sister). Considering the latter, the authors divided the sample into three groups: women with maternal cancer, women with fraternal cancer, and women with maternal and fraternal cancer. The results showed that higher distress, and the intrusion dimension of traumatic stress, were both prevalent in all groups, especially in the latter. According to the authors, these data highlight the importance of genetic counseling and informational support to women with breast cancer in the family. Furthermore, in the abovementioned systematic review by Walc-

zak et al. [26], the authors found that higher distress was associated with higher levels of posttraumatic stress disorder (PTSD) symptoms measured by the IES, in adolescents dealing with parental cancer.

Despite the volume of research with caregiver spouses, some studies also included children (small children, adolescents and adults) as participants. Lowenstein and Gilbar [41] analyzed the perception of burden among caregivers of elderly people with cancer. Although most participants were spouses, the authors also included children in adulthood; the spouses were defined as the primary caregivers, and the children as secondary caregivers. The authors found that the spouses and children reported emotional problems of the same magnitude and were even higher than those of the patients. It is interesting to note that, in this research, adult children (25-56 years of age) did not live with their parents. More recently, a cross-sectional study conducted by Rainville, Dumont, Simard, and Savard [42] that analyzed the experience of adolescents living with a parent with advanced cancer, found higher psychological distress, compared with the general population, especially if the children were older. Matthews and colleagues [3] studied the impact of cancer among spouses, middle-aged adult children, and other family members (i.e., mothers, fathers, siblings, etc.). The sample also included patient friends. Although limited, an important contribution of this quantitative study was that caregivers presented higher levels in all measures of physical and emotional distress (i.e., uncertainty about the future and fear of recurrence) than patients themselves. In addition, the average outcome of caregivers, in terms of pessimistic expectations, was also significantly higher than that of patients. The results of Matthews and colleagues [3] are similar to those showed by Bowman, Rose, and Deimling [43]. These authors found that the relatives of cancer patients, both spouses and adult children, assessed the cancer experience as more stressful than patients, during diagnosis, treatment and remission. This assessment remained for years after the completion of treatment. In this study, family members were described as a single group, aged between 29 and 86 years old, although adult children and spouses were known to have different responsibilities, obligations and needs regarding car-

egiving [44]. In the same line of research, Boyer and colleagues [45] explored distress and PTSD symptoms among daughters (15-71 years of age) of breast cancer patients (40-95 years of age). In this study, daughters (who were mostly middle-aged and married), reported visiting the mother once a week, and close to 40% reported little or no involvement in care. Still, the vast majority of daughters (92%) had thoughts about diagnosing stressors, and 13% had symptoms consistent with PTSD. Cohen and Pollack [46] expanded the study of Boyer and colleagues [45], adding immunological measures. Daughters (24-40 years of age) were assessed in blood (plasma cortisol), urinary and hormonal parameters. The results of this study revealed that daughters whose mothers had higher levels of distress, reported greater impairment of the immune system. Daughters' distress was also associated with their perceived overload in caregiving, i.e. the daughters who were most frequently with their mothers (once in 15 days or once a week) reported greater psychological distress and burden than the daughters who were with the mothers in periods over 15 days.

As reviewed, spouses and other family members, including children, are key elements in the family and social support system for the cancer patient, evidencing that the majority handles well the role of caregiver. However, as noted by Pitceathly and Maguire [47], an important minority shows high levels of distress, developing affective disorders. Caregiver gender also appears to be a particularly important variable in caregiver studies, since the most vulnerable appears to be females, especially women with a history of prior psychological morbidity, who tend to present a more negative perception of the impact of the disease on the family life [48]. The distress in the caregiver also presents an association with the evolution of the disease for palliative care [49-53]. In the case of caregivers, the lack of support networks [51,54-57] and the existence of relational difficulties with the patient are also considered risk factors [58-61].

Considering the literature reviewed, the present chapter aims to describe and reflect on the levels of depression, anxiety, and stress of adult offspring of cancer patients, when using the DASS-21 (Depres-

sion, Anxiety and Stress Scales), to analyze gender differences in psychological morbidity, as well as the association between psychological morbidity and traumatic symptomatology.

Method

Participants and Procedures

The sample consisted of 214 adult children of patients undergoing chemotherapy. The sociodemographic and clinical data collected about parents, was completed by their adult children. Of these adult children, 74% were women, with a mean age of 33.1 years (SD = 9.1; range = 18–61 years); 47% had a partner; and 63% had less than high school education level. Concerning clinical information, 60% registered the disease duration of the parent as less than one year, 69% reported that the parent was on chemotherapy for less than one year, and only 39% provided care for more than a year. Only 21% of adult children perceived the parent in treatment as completely reliant on their caregiving. Considering the parents, 57% were female, with an average age of 62.1 years (SD = 9.2; range = 42–85 years), and 78% were married. Regarding the type of cancer, 60% of parents had cancer of the digestive system, 21% of the reproductive system, 7% of the respiratory system and 12% in other areas.

This was a cross-sectional study approved by the Ethics Committees of three general hospitals in northern Portugal. Participants were adult children who, during the period of data collection, accompanied the parent diagnosed with cancer to chemotherapy. This was a convenience sample with voluntary participation. Inclusion criteria required that participants be age ≥ 18 years, have a parent (or both) in chemotherapy, accompany the parent to the hospital for treatment (minimum criterion for defining the adult offspring as a “caregiver”), and not suffer from oncological, psychiatric, or neurological disease. All participants were invited to participate in the study, informed about its purpose and were assured of anonymity and confidentiality, signing an informed consent.

Measures

Depression, Anxiety and Stress Scales. The Portuguese version of the Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, [62]; Pais-Ribeiro, Honrado, & Leal, [63]) was used. This is a 21-item questionnaire that includes three subscales: depression, anxiety, and stress. The DASS-21 employs a 4-point scale (0–3), with higher scores indicating greater negative affective state. This scale has specific qualities: is short, easy to apply in clinical and non-clinical settings and can be used for the simultaneous evaluation of depression, anxiety, and stress in adolescents and adults (> 17 years old). The three subscales of the DASS-21 can be considered consistent with the tripartite model of Clark and Watson [64], since depression is characterized by reduced self-esteem, reduced incentive and hopelessness; anxiety by physiological hyperstimulation; and stress from persistent tension, irritability, and a low threshold to frustration. In this sample, Cronbach's alphas were appropriate: total scale "distress" ($\alpha = 0.94$), depression ($\alpha = 0.89$), anxiety ($\alpha = 0.82$), and stress ($\alpha = 0.87$). In addition, the scale allows an evaluation of the severity of distress symptoms by calculating the percentages of responses related to the severity of affective-emotional states, with the cutoff points suggested by Lovibond and Lovibond [62]. The study of Crawford and Henry [65] in the United Kingdom refers to its use, and in Portugal, Apóstolo, Mendes, and Rodrigues [66], and Apóstolo, Ventura, Caetano, and Costa [67] used the same methodology.

Impact of Event Scale-Revised. The 22-item Portuguese version of the Impact of Event Scale-Revised (IES-R; Weiss & Marmar, [68]; Pereira & Teixeira, [69]) was used. This is a measure of current subjective distress for a specific traumatic event. Respondents are asked to rate on a 5-point scale (0–4) how distressing symptoms of avoidance, hyperarousal, and intrusion have been in the past 7 days. The IES-R has already been used in cancer patients [70]. Higher scores indicate higher number of traumatic stress symptoms. In this sample, Cron-

bach's alphas were 0.93 for hyperarousal, 0.74 for intrusion, 0.70 for avoidance, and 0.93 for the total scale.

Data Analysis

For the statistical analysis of the data, the IBM SPSS Statistics, version 22 was used. Descriptive statistics were performed for the sociodemographic variables, followed by Pearson coefficient analysis of the variables under study (distress and PTSD symptoms). T-tests for independent samples were performed to analyze gender differences.

Results

Considering the severity of psychological morbidity, 6-60% of the participants showed 'normal' or 'mild' levels of stress, anxiety, or depression; 15-26% 'moderate' levels; and 4-12% 'severe' or 'extremely severe' levels of stress, anxiety, or depression (Table 1).

Table 1: Severity of psychological morbidity in adult offspring caregivers.

	<i>Normal</i>	<i>Mild</i>	<i>Moderate</i>	<i>Severe</i>	<i>Extremely severe</i>
Depression ¹	(0-9)*	(10-13)*	(14-20)*	(21-27)*	(28+)*
	---	---	---	---	---
	60.3%	13.6%	15%	5.1%	6.1%
Anxiety ¹	(0-7)*	(8-9)*	(10-14)*	(15-19)*	(20+)*
	---	---	---	---	---
	55.1%	5.6%	25.7%	3.7%	9.8%
Stress ¹	(0-14)*	(15-18)*	(19-25)*	(26-33)*	(34+)*
	---	---	---	---	---
	47.7%	15.9%	18.7%	11.7%	6.1%

Note. N=214. ¹DASS-21. *Reference values reported by Lovibond and Lovibond [62], and used in Portuguese samples [66,67].

When analyzing gender differences (Table 2), statistically significant values were found for anxiety, stress, and total distress. Thus, women showed higher indicators of anxiety, stress, and total distress than men. There were no significant differences between women and men in terms of depression.

Table 2: Gender differences in the variables of depression, anxiety and stress in the adult offspring caregivers.

	Women (n=158) <i>M (SD)</i>	Men (n=56) <i>M (SD)</i>	<i>t (212)</i>
Depression ¹	10.27 (9.97)	7.71 (6.01)	-1.810
Anxiety ¹	8.69 (8.35)	5.75 (5.77)	-2.439**
Stress ¹	17.18 (9.25)	14.32 (8.82)	-2.016*
Distress (total) ¹	36.16 (25.04)	27.78 (16.90)	-2.321*

Note. N=214. *p<0.05. **p<0.01. ¹DASS-21.

The correlation analysis showed statistically significant values (Table 3) with strong positive correlations (r-values between 0.426 and 0.898, p<0.001) among all the variables from the DASS-21 and the IES-R.

Table 3: Pearson correlations between DASS-21 and IES-R.

	1	2	3	4	5	6	7	8
1. Depression ¹	-	.730***	.668***	.898***	.461***	.579***	.561***	.609***
2. Anxiety ¹		-	.701***	.896***	.489***	.514***	.604***	.613***
3. Stress ¹			-	.889***	.426***	.451***	.576***	.556***
4. Distress (total) ¹				-	.511***	.576***	.648***	.662***
5. Avoidance ²					-	.666***	.688***	.884***
6. Intrusion ²						-	.628***	.864***
7. Hyperarousal ²							-	.890***
8. PTSD symptoms (total) ²								-

Note. N=214. ***p<0.001. ¹DASS-21; ²IES-R.

Discussion and Conclusions

The diagnosis of cancer continues to represent a huge impact both on the life of the patients, but also on the life of the family member and/or caregiver [71], with almost 30% of families showing clinically significant levels of psychological distress requiring professional intervention [72]. Although a recent systematic review with adolescent and young adults facing parental cancer found that they showed higher levels of anxiety, depression, and stress [26], the present study found *normal to moderate* levels of depression, anxiety, and stress in adults who cared for their parents. This finding suggests that most adult offspring are able to meet the many challenges associated with caring of an adult with cancer, without experiencing severe psychological debilitations. These results are in accordance with those of Rodrigue and Hoffmann [73]. However, 11% showed worrying levels (severe or extremely severe) of depressive symptoms, 14% of anxiety symptoms and 18% of stress, being consistent with previous research on caregivers of chronic cancer patients [74,75].

Results also showed that women reported higher levels of anxiety, stress, and total distress, than men. These results are in accordance with existing literature, not only in 'general' cancer caregiving [12,48], but also in adolescent and young adult offspring's cancer caregiving [76,77]. Also a study conducted with spouses and offspring caregivers of cancer survivors found that women assessed their caregiving experience as stressful and, the daughters, in particular, reported the highest levels of stress [78]. Sons, in turn, showed the lowest levels of caregiving stress [78]. These gender differences may be explained by the multiple demands of the several roles that adult daughters have to manage, in addition to their caregiving role. In fact, these women have been called the "sandwich generation", because they often have to balance employment outside their home with family and children, household tasks, social life, as well as caring for the parent with cancer [1]. Thus, it makes intuitive sense to provide psychological interventions focused on the distress to adult daughters of oncological patients.

Finally, the results showed that higher levels of psychological morbidity were strongly associated with PTSD symptoms, confirming previous studies in adolescent children of parents with cancer [26]. A diagnosis of parental cancer is a life-threatening event that may be considered traumatic and contribute to the development of PTSD symptoms. The offspring of parents with cancer, not only the suffering of a loved one, but also have to cope with their own vulnerability (e.g., potential genetic risk) and mortality, which may lead to the development of anxiety, depression, and stress symptoms [1,79,80].

This study's main limitations are the higher prevalence of women in the sample (almost 75%); the fact that the reference values reported by Lovibond and Lovibond [62], and used in Portugal by Apóstolo and colleagues [66,67] just for classification purposes, may be out of date for the Portuguese cancer caregiving reality; and the cross-sectional design of the study. Therefore, future studies should include longitudinal designs and address how distress and traumatic symptomatology change over time in adult offspring of oncological patients.

The findings of this study suggest that the offspring caregivers of cancer patients need intervention programs designed to help them deal with distress and traumatic symptoms. Therefore, intervention should provide emotional and instrumental support to minimize and help them adapt to the situation. According to the results, it would be also important that the intervention be offered in the context of the dyad patient-caregiver. Particular attention should be paid to women caregivers, since they showed higher levels of distress, particularly anxiety and stress.

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