PARENTS’ ILLNESS PERCEPTIONS, MALADAPTIVE BEHAVIORS, AND THEIR INFLUENCE ON THE EMOTIONAL DISTRESS OF THE CHILD
A PILOT STUDY ON A ROMANIAN PEDIATRIC CANCER GROUP

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ABSTRACT

The aim of the present study was to find possible links between factors influencing the level of distress experienced by children with cancer. The first objective was to explore the relationship between children’s distress and their parents’ maladaptive behaviors. Using the Common Sense Model of Illness as a theoretical background we measured the child’s distress level, the parents’ perception of illness, and parental maladaptive behavior. The second objective was to explore potential causal relations between these three variables. The study is based on previous research demonstrating that negative emotional states of the children may be modulated, not by the illness itself, but by observing and empathizing with the parent. The parents who participated in our study completed the translated and adapted version of the “Cancer Behavior Inventory” and the Illness Perception Questionnaire. Children were administered the adapted version of the “Emotional Distress Profile”) in order to identify existing signs of distress. Results show that there is a strong correlation between the parents’ perceived severity of cancer and the levels of maladaptive behaviors exhibited by the parents. Secondly, we discovered that parents’ perception of the illness and their maladaptive behavior suppress each other’s effects on children’s distress. The present study would help in developing and planning intervention programs and specific strategies to aid diminish the distress of the children, as well as change the maladaptive illness perceptions and behaviors of parents with children affected by cancer.

KEYWORDS: illness perception, maladaptive behaviors, child distress, psychooncology, Romanian population.

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INTRODUCTION

There is an extensive literature on the factors that might trigger or modulate the feelings of emotional distress in cancer patients and their caregivers. These factors are mentioned as having different effects on treatment adherence and illness coping strategies. However, most theoretical articles and evaluation instruments concerning the perception of illness, self-efficacy, and coping models have only been developed based on studies with adult participants. This unidirectional approach is explained by the ease of conducting studies with adults when focusing on the assessment of emotions, cognitions, and the ability to explain and reflect on ones’ behavior.

More recent literature started to tackle certain problems concerning pediatric cancer. However, none of the above stated aspects can be thoroughly assessed until the child reaches 8 or 9 years of age, as we cannot yet speak of an accurate phenomenological evaluation of the illness experience (DeJong & Fombonne, 2006).

The negative affect and behaviors of chronically ill children represent important aspects of health psychology, concerning both children who lose their lives because of cancer and the ones that manage to survive (Stuber, Meeske, Gonzalez, Houskamp, & Pynoos, 1994a; Stuber, Meeske, Guthrie, Gonzalez, Houskamp, Pynoos, et al., 1994b). According to data collected by the World Health Organization (WHO, 2005), it appears that in Europe, for the age range of 0 to 14, there has been an important decrease in the mortality caused by all cancer types, from 6.41/million in 1980, to 3.4/million in 2005. Although in Romania, the medium mortality rates for the 1980-2004 period are overall higher than in the rest of Europe, a significant decline in the mortality rates can still be noticed, from 8.91/million in 1980, to 5.63/million in 2004. The latest WHO report (2008) shows that the Romanian standard cancer related death range has been rising rapidly since 2004, reaching 101.71/million for all people between 0 and 64 years in 2008. This can be regarded as a worrying situation in comparison with the rest of the European region, where for the same age group the standard death range is significantly lower, namely 77.04/million.

Considering the growing number of children who develop and survive cancer, and the growing number of adults that develop this illness, finding resources for their long-term psychological coping and well-being becomes extremely necessary. In what concerns the adult population of cancer patients, there are metaanalyses showing that the number of patients affected by psychiatric problems (such as clinical level depression or anxiety) varies between 23% and 66% (Nezu, Felgoise, & Zwick, 2003). There are studies supporting the idea of the existence of reduced number of emotional or adaptive problems in these populations, as well as studies stating that chronically ill patients are at greater risk of developing these types of problems. In a study conducted on 215 patients with mixed cancer diagnosis, more than half (53%) did indeed show a good adaptation
to the stress caused by illness. However, the rest of 47% showed psychological
problems at clinical level. About 68% had either generalized anxiety or major
depression, while the rest showed mental disorders of an organic nature,
personality disorders or other anxiety disorders (phobias, posttraumatic stress
disorder, etc.). Most of these problems (90%) were due to the particular
characteristics of the illness or treatment (Bukberg, Penman, & Holland, 1984).

In what concerns the pediatric population, studies mostly target how a
family responds to adversity and how these responses can influence the child’s
functioning, in a circular sequence of outcomes (Kreitler et al., 2007). In one
article, Patterson, Holm, & Gurney (2004), talk about a bidirectional effect that has
been observed in the correlations between parental psychopathology and
psychosocial dysfunction in child cancer survivors. Similarly, other authors focus
on the negative impact of this traumatic experience after treatment and remission
reporting significant correlations between posttraumatic stress disorder (PTSD)
symptoms in child cancer survivors and PTSD symptoms in their parents.
According to Balen, Fielding, & Lewis (1996), it seems that serious chronic
illnesses such as cancer have a detrimental impact on the self-concept and self-
esteeem of a child. The same authors conclude that children with cancer face
additional problematic adjustment because of the generally acute onset and life
threatening nature of the illness. Balen et al. (1996) also show that these children
tend to grow up to be more cynical and introvert in adulthood.

The effect this illness has on any type of caregivers (be it parents, siblings
or spouses in the case of adults) is also discussed throughout literature. In a study
conducted by Barg, Pasacreta, Nuamah, Robinson, Angeletti, and Yasko (1998) on
715 caregivers of cancer patients, 61% of the participants stated that caregiving has
become their only daily activity. Moreover, 58% reported giving up all working or
leisure activities they had up to that moment and that caring for the ill person
required full availability. Up to 89% of these people declared experiencing great
amounts of stress because of the responsibility they carried towards the ill person
in the family, stress that was associated with low self esteem, low health and a
lower perceived social support compared to the one perceived by the ill patient. In
another study, conducted by Kelly, Edwards, Synott, Neil, Baillie, & Battistutta
(1999), researchers reported that up to 67% of the caregivers of an ill person
exhibited eating or sleeping disorders and clinical level anxiety and depression. All
the above constitute reasons for choosing to investigate the extent to which
variables such as the caregivers’ perception of an illness as well as their behavior
may influence a child’s emotional adaptation to his/her illness.

Based on this issue, we set the first objective of this study. We aimed at
exploring the behaviors adopted by the caregivers (in our case, the parents) of
children with cancer. Grounded on the cited literature, the possible maladaptive
behaviors of the caregiver (i.e., not seeking any information about cancer
treatment, the level to which they share concerns, maintain their independence,
etc.) may influence the feelings of the child towards cancer or any other type of
illness (Eiser & Havermans, 1992). Thus, we expected to find a correlation between the scores obtained by parents who completed the “Cancer Behavior Inventory” (CBI, Merluzzi et al., 1997, 2001) and the ones obtained by children on the “Emotional Distress Profile” (EDP, David, 2006). Secondly, we explored a possible causal relationship between the parents’ perception of cancer, the behaviors they most often exhibit, and the actual distress experienced by the child. We based our research questions on the Common Sense Model of Illness (Hagger & Orbell, 2002) that identifies possible cognitive factors involved in the processing of information regarding illness. The model illustrates how this information is integrated in order to provide a view of the illness and how this view can guide coping behaviors and outcomes. The model is being used in the development of many instruments, including the “Illness Perception Questionnaire” (IPQ, Weinman et al., 1996), which describes the illness perception on different cognitive dimension such as identity, consequences, timeline, control/cure, etc. Consequently, we developed the hypothesis that the maladaptive way in which parents might perceive cancer will correlate with the level of maladaptive behaviors they exhibit, as evaluated with CBI. Moreover, we expected that the illness perception as measured with IPQ might have a mediating influence on the other variables, as shown in Figure 1.

**Figure 1**
Suggested relation between variables
METHOD

Participants
The ages of the 25 children included in our study varied between 9 and 16 years (M=7, SD=5.44). One of the reasons for choosing to administrate the EDP to children above nine is based on the problems encountered by Ellis and Leventhal (1993) in their study while trying to investigate the need of information about cancer in this population. In this study, the younger participants had great difficulties in understanding and answering the items of the questionnaires. About 56% of our pediatric sample was constituted of boys. The type of cancer they were all diagnosed with was acute lymphoblastic leukemia (ALL). The time from diagnosis varied between one month to 5 years (M=0.96, SD=1.49). Only 16% went through chemotherapy, radiotherapy and surgical intervention, 52% only had chemotherapy (being in the first stage of the illness), while 32% had not been introduced to any type of treatment at the time of our study. The ages of the 25 participating parents varied between 26 and 48 years old (M=34, SD=5.11). In our sample, 88% were women, and many of them were married or had a stable partner (96%).

Measures

The Cancer Behavior Inventory (CBI)
Merluzzi and Sanchez elaborated the inventory in 1997, as a method to evaluate the self-efficacy concerning coping with cancer in adult patients. Initially, in 1997, CBI only had 6 factors and 51 items, while the version published in 2001, by the same authors has 7 factors and 33 items (Merluzzi et al., 2001). For each of the 33 items participants rated, on a scale from 1 (no confidence) to 9 (fully confident) the extent to which they were confident they could adopt and maintain certain behaviors. The final consistency score of the last published CBI is $\alpha=0.94$, while the test-retest coefficient is 0.74. The originally identified scales are as follows:
1. Maintaining activity and independence (5 items): represents the ability to maintain the normal activity level despite the side effects of the illness and treatment. These items refer to the actual work activities and maintaining daily routines.
2. Seeking and understanding medical information (5 items): refers to the degree of confidence the person has towards asking the medical staff for information regarding the illness and the level of cognitive interest they show towards seeking and understanding the given information.
3. Stress management (5 items): refers to the stress associated with the anticipation of medical visits. It also refers to stress that might influence the medical decisions to be taken throughout the treatment.
4. **Coping with treatment side effects** (5 items): refers to the less pleasant physiological effects of the illness and treatment and the limitations they bring on the patient’s well being.

5. **Accepting the illness, maintaining a positive attitude** (5 items): represents a double psychological implication of the illness: firstly, maintaining hope and a positive attitude, and secondly accepting the reality of the existence of the illness. The idea of maintaining hope is assimilated to the concept of positive illusions related to the illness.

6. **Affective regulation** (5 items): contains items that reflect the ability to express negative feelings, and the attempts to deny or take distance from the situation. Both types of coping reactions were described in Nezu (2003) and Merluzzi et al. (1997). It seems that both denial and self-distancing facilitate the reduction of anxious and depressive feelings.

7. **Seeking social support** (3 items): reflects the strategies one uses to initiate social contacts, to ask for social support and the perception one has about these.

   All the items in the scale were rated by the participants on a 1 to 9 confidence scale regarding the adoption of the specified behavior, from 1 (not at all confident) to 9 (totally confident). We calculated the mean for each scale, while the overall score was obtained by adding up all the scale scores. In the CBI case, the lower the overall score, the more maladaptive behaviors the parent will exhibit throughout the child’s illness, and the bigger the score, the greater the probability that he/she will display adaptive behaviors towards his child’s illness.

**The Illness Perception Questionnaire (IPQ)**

This questionnaire is based on the Common Sense Model of Illness and measures the cognitive representations of illness (Hagger & Orbell, 2003). Usually when faced with depressive symptoms associated with chronic illnesses, the type of attributions one makes leads to the passive acceptance or denial of the clinical symptoms of illness. Internal, stabile, and global explanations are more frequent and make cancer adaptation difficult (Manne, Miller, Meyers, Wollner, Steinherz, & Redd, 1996). In short, the instrument evaluates the following components:

1. **Identity**: rates the number of symptoms that the patient sees as part of the illness (nausea, dizziness, stiff joints, fatigue etc.).
2. **Cause**: what patients believe are the main triggering factors of the illness (germs or viruses, pollution, stress etc.).
3. **Timeline**: the patients’ estimation of the potential duration of illness (if the illness is likely to be permanent rather than temporary or if the illness might last for a long time).
4. **Consequences**: the possible effect the illness might have on the patient (whether the illness will have major consequences on one’s life or not, if it is a serious condition).
5. **Cure-control**: the perceived efficacy of the treatment for curing the condition (if there is little that can be done to improve the illness; or if the treatment will be effective).

The Identity scale contains 12 items, the Time-line scale contains three items, the Consequences scale has seven items (with items 3 and 4 having reversed scorings), and the Cure-Control scales contains six items (with items 3 and 5 have reversed scorings). Each participant rated these items on a 1 (very frequent) to 4 (never) Likert scale. The Cause scale contains 11 items, each representing a specific causal belief, either external or internal, which are added separately. The total score was obtained by summing up all the scales items and dividing the obtained score by the number of items.

**The Emotional Distress Profile (EDP)**

The EDP is a scale with 26 items that measures negative functional and dysfunctional feelings on two main dimensions: fear and sadness. With EDP one can add up a general distress score, as well as four other different scores for the intensity and quality of the feelings. It was translated and adapted to the Romanian population by David (2006).

**Procedure**

All three questionnaires were administered to the participants, individually in paper-pencil format. Children were asked to complete the EDP, while parents were asked to complete the CBI and IPQ, either during hospitalization, or during their follow up visits to the hospital. The children were assessed independently from their parents, in order to avoid possible distortions of the answers. All undergraduates who administered the instruments received prior training and reading materials in order to be able to properly communicate with and assess both parents and children.

**RESULTS**

**Bivariate and Partial correlation results**

Our first objective was to explore the existence of a possible relationship between the level of distress experienced by the child, as assessed with EDP and the maladaptive behaviors of the parent as evaluated with CBI. Table 1 shows the correlations between the global scores the participants received during the evaluation:
As can be seen in Table 1, our initial hypothesis that the level of child distress might correlate with the possible maladaptive parental behaviors, was not confirmed. On the other hand, we found a significant negative correlation between the extent to which parents perceive cancer as being a severe and life threatening problem and the type of behavior they exhibit ($r=-0.45$, $p<0.05$).

In what concerns our second objective of exploring a possible causal relationship between all three variables, we conducted a partial correlation on all three variables: child distress score, parental perception of cancer and parental maladaptive behaviors in order to search for a mediating relation (Baron & Kenny, 1986). The following table shows the results obtained for the partial correlation:

For both predictors, the set criterion was the parents’ score on IPQ, while the predictors were the scores obtained by the parents on the CBI and by the children on EDP. When comparing the result obtained on the partial correlation in modules, we observe an increase in the relationship between the distress of the child and the parents’ illness perception, and between the parental behaviors and their illness perceptions. Both zero order correlations between IPQ and
EDP ($r_{IPQ,PDE} = -.051$), as well as between IPQ and CBI ($r_{IPQ,CBI} = -.451$) have lower values than the partial correlations ($r_{IPQ,PDE} = -.308$, and $r_{IPQ,CBI} = -.460$), suggesting a suppressing effect due to the illness perceptions of the parent, as evaluated with IPQ. By calculating the main characteristics of the presented correlations, we reach the conclusion that the relation between the illness perception and parental behaviors represent display a reciprocal suppression effect on the child’s distress (Lancaster, 1999). In such cases, the variables behave in indirect ways, by improving the prediction of the criterion when suppressing the irrelevant variance in the predictor variables (in our case there is a very small difference between the zero order and partial correlation between IPQ and CBI). Thus, the predicting variables indirectly allow for a more concise estimate of the relationship between the dependent and independent variables, even though the suppressor directly predicts none or almost none of the criterion’s variance ($r_{PDE,IPQ} = -.051$). In our case, illness perception suppresses irrelevant variance in the behavioral variable, allowing for a slightly increased relationship between the parental maladaptive behavior and their perception of the illness ($r_{IPQ,CBI} = -.451 < -.460$), which translates itself in an increase in the partial correlation between the child distress and their parents’ illness perceptions ($r_{IPQ,PDE} = -.051 < -.308$). Thus, the relationship between the parental illness perceptions, the maladaptive behaviors of the parent, and the distress felt by the child, results in the relationship shown in

**Figure 2**
The relationship between variables

**DISCUSSION**

The main question of the present study was whether certain factors such as parental cancer perception and maladaptive behavior do in any way influence the level of distress experienced by a chronically ill, hospitalized child. Thus, our first objective was motivated by the wish to identify the potential relationship between
the child’s level of distress and the parents’ maladaptive behaviors. We did not find a significant correlation between these two variables. However, results show that, there is a significant link between the perceived severity of cancer and the maladaptive behaviors of the parent, as described by the Common Sense Model of Illness (Hagger & Orbell, 2002).

The second objective concerned the existence of a possible causal relationship between all three variables: child distress, parental perception of cancer, and parental maladaptive behaviors. The hypothesis in this case was that there would be a mediating relationship between these variables. However, our findings show that instead of a mediating effect, there is a reciprocal suppression effect owed to the parental illness perception and parental behaviors. The parental illness perception has a low influence on parental behaviors, which in turn have a more powerful influence on the distress experienced by the child. Thus, the illness perception in itself does have an influence on the level of distress experienced by the child, but to a lower extent. This relationship becomes more evident only when controlling the IPQ variable allows for a more concise estimation of the actual relationship between the behaviors exhibited by parents and the distress levels of their children. IPQ suppresses unnecessary variance in the other variables (in our case in the CBI) allowing for the direct effect of parental behaviors on child distress to become more evident.

Consequently, we believe that the prevention of developing negative feelings of distress in pediatric patients could gain from offering illness coping models and teaching adaptive patterns of behavior to parents. We hold this belief as many other studies conducted so far postulate that the emotional states and behavioral patterns of the parent, both toward ill and healthy siblings can modulate the present and future illness coping strategies of the child (Chao, Chen, Wang, Wu, & Yeh, 2003; Svavarsdottir & Sigurdardottir, 2005). Some of the stress factors faced by these families and especially by the parents of these children can be summarized in: talking and explaining to the child some aspects of the illness, learning new treatment and lifestyle routines to be maintained at home, sustaining and managing intra and extra familial duties (Streisand, Kazak & Tercyak, 2003). Unfortunately, most of the data was gathered from disparate countries with very different cultures, and there are no psychological studies that inquire about these sorts of problems in the Romanian population, where emotional and behavioral consequences might be very specific owing to cultural factors. For example, greater religiosity, access to different types of therapy, a different child-parent or parent-doctor relationship have been found to be cultural factors that determine different chronic illness coping behaviors (Suzuki & Kato, 2003; Massimo, Wiley, & Caprino, 2008). We should take note of the fact that the present paper is a presentation of a pilot study and the small number of participants might have biased the results. This is one of the reasons why we recommend the future replication and continuation of this type of research in other clinics in Romania, as well as a thorough investigation of the possible cultural factors that might trigger
different coping cognitions, behaviors, and emotional coping strategies in response to the onset of a chronic illness. Future replications of the present study should focus on using the same specific measurements of distress, illness perception, and illness maladaptive behaviors for both target groups (children and their parents). These types of replication studies would help with making stronger causal inferences between the cognitive appraisals of situations, behaviors, and distress and on how these variables might influence each other in both parent and children groups.

In line with our results, we suggest the elaboration of intervention and prevention programs on the same dimensions as evaluated by both Illness Perception Questionnaire and Cancer Behavior Inventory. The targeted cognitive changes could include the development of a more accurate appraisal of the characteristics of the illness (in terms of identity, timeline, causes, consequences, and possible control of the symptoms). The consequent behavioral changes could focus on the maintenance of daily routines the parent had before the onset of the child’s illness, encouraging a more relaxed attitude during treatment, teaching parents how to deal with the physiological changes the child undergoes and last, but not least, supporting them to avoid premature mourning behaviors. These factors could translate themselves in cognitive and behavioral strategies for intervention and prevention programs aimed at diminishing the levels of distress felt at the onset or relapse of the illness.

ACKNOWLEDGMENTS

The authors would like to acknowledge the important contribution of Doctor Popa G. and the medical personnel of the Pediatric Hospital No.2 of Cluj-Napoca, Romania.

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