

## Effectiveness of psychological interventions intended to promote adjustment of children with cancer and their parents: an overview

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**Título:** Eficacia de intervenciones psicológicas dirigidas a promover el ajuste de niños con cáncer y de sus padres: una revisión.

**Resumen:** Esta revisión tiene como objetivo ofrecer un panorama general sobre la eficacia de las intervenciones psicológicas destinadas a promover el ajuste psicológico de niños aquejados de cáncer y de sus padres. Con este fin se revisaron los artículos publicados entre 1998-2010, empleando las siguientes palabras-clave: intervención psicosocial, psicoterapia, ensayo, tratamiento, ajuste, bienestar, adaptación, cáncer, cáncer infantil, cáncer pediátrico, ansiedad y depresión (combinándolas entre sí) en las siguientes bases de datos: Psycinfo, Medline, Scielo, Lilacs, Psycodoc y Psycarticles. Se localizaron un total de catorce artículos, de cuyo análisis se concluye que la mayoría de las intervenciones utilizadas resultan de alguna utilidad para mejorar el ajuste psicológico tanto de los niños como de los padres, aunque el número de tratamientos que pueden considerarse realmente eficaces es más limitado. Se discute sobre la conveniencia de que la intervención psicológica dirigida a este tipo de población se centre más en las fortalezas y en la promoción de la salud y deje de apoyarse exclusivamente en modelos de tratamiento basados en déficits y psicopatología. Posiblemente, este cambio de orientación contribuirá a fomentar cambios clínicamente relevantes en relación al estrés que acompaña al cáncer y su tratamiento.

**Palabras clave:** Ajuste psicológico; intervenciones; cáncer infantil; revisión.

**Abstract:** This article aims at providing a general overview of psychological interventions intended to promote psychological adjustment of children with cancer and their parents. To achieve this goal, we reviewed published articles between 1998-2010, using a combination of the following keywords: psychosocial intervention, psychotherapy, trial, treatment, adjustment, well-being, adaptation, cancer, childhood cancer, pediatric cancer, anxiety and depression in the electronic databases: Psycinfo, Medline, Scielo, Lilacs, Psycodoc and Psycarticles. Fourteen articles were found and analyses show that most interventions had some efficacy in the psychological adjustment of children and their parents; nevertheless, there is a limited number of treatments that can in fact be considered effective. The convenience of psychological interventions is discussed and how they must comprehend strengths and the promotion of psychological health and should not be based solely on deficits and psychopathological models. Possibly, this re-orientation will help fostering significant clinic changes regarding the stress associated to cancer and its treatment.

**Key words:** Psychological adjustment; psychological interventions; childhood cancer; overview.

### Introduction

Childhood cancer is the second cause of death worldwide, after accidents only. According to data from the Spanish National Statistics Institute (2011), the incidence of cancer in the 0-19 years-old population in 2008 was 124 cases per million inhabitants, with 36,31 deaths per million. These rates are very similar to those of the European Union, where mortality rates are approximately 34,5 per million children (Eurostat, 2011).

The disease's diagnosis involves a wearing process, generating high levels of stress, and causing changes in all areas, including health-related behavior (Valencia, Flores & Sanchez, 2006). Treatment is also a difficult process, since it includes invasive and painful medical procedures, some of which imply a life threat (Aldridge & Roesch, 2007). In spite of such evidence, survival rates for children between 0 and 14 years-old in Spain are good: 79% of cases 3 years after diagnosis and 77% of those within five years after diagnosis (National Institute of Statistics, 2011).

With regard to family's adjustment, research shows higher vulnerability to anxiety, depression and physical illness. This is particularly significant for mothers, who are the main caregivers and have to handle with, in addition to daily demands, healthcare demands, fear of death and other family or financial issues (Sahler et al., 2005).

### Cancer and psychological adjustment

A large body of research on psychological adjustment of children with cancer (under treatment or survivors) indicates that this population is well adapted to the situation, suggesting that: i) they do not show higher levels of anxiety, depression, worse body image or lower self-esteem than same-aged "healthy" children; ii) they do not have fewer social peer relationships, are less popular, or have a worse quality of life than "healthy peers". Both conclusions hold in the early stages of the disease and in the long-term, considering different ages (Barakat et al., 2003; Barakat, Kazak, Gallagher, Meeske & Stuber, 2000; Bragado, Hernández-Lloreda, Sanchez-Bernardos & Urban, 2008; Chao, Chen, Wang, Wu & Yeh, 2003; Fuemmeler, Brown, Williams & Potter, 2003; Langeveld, Stam, Grootenhuis & Last, 2002; Kazak, 2005; Meeske, Ruccione, Globe & Stuber, 2001; Newby, Brown, Pawletko, Gold & Whitt, 2000; Orbuch, Parry, Chesler, Fritz & Repetto, 2005; Phipps, Jurbergs & Long, 2009; Seitz, Besier & Goldbeck, 2009; Sorgen & Manne, 2002). These findings are usually interpreted through the prism of resilience, generally defined as the ability to cope and function normally in adverse contexts (Bragado, 2009).

However, some studies suggest that the good adjustment found in these children could be attributed to the use of a "repressive" coping style (which would lead them to report fewer symptoms than they have actually experienced). This way of coping with their condition implies that these children are not fully aware of their symptoms, or that scientific

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approaches have used insensitive measures to their psychological problems (such as PTSD measures). In line with this argument, several papers report that children with cancer employ a repressive or a denial style at higher rates than healthy controls, and that this style is likely to remain until adulthood (Erickson & Steiner, 2001; Fuemmeler et al., 2003; Phipps, Larson, Long & Rai, 2006; Phipps et al., 2009). Nonetheless, this coping style should not always be considered as a negative feature, since data suggest that avoidant strategies may be very adaptive in certain situations, such as those included in cancer treatment (diagnosis, painful medical procedures) (Aldridge & Roesch, 2006; Phipps, 2007). Hence, as Kupst and Patenaude (2005) point out, it seems that there are not optimal coping strategies, but different ways of dealing with the situation, which may vary according to specific circumstances and individual characteristics.

In a similar vein, Maurice-Stam et al. (2009) suggest that this good adaptability may be due to a "response shift", meaning that the experience of having cancer may change the way children conceptualize problems, so that they see fewer problems than before. It is also possible that these children's adjustment is a consequence of using appropriate family coping strategies, as we can see on survivors of childhood cancer, who report an emotional growth after the disease, as well as feelings of happiness, well-being, hope, life satisfaction, greater proximity to family, greater appreciation of life, more future perspectives and higher quality of life (Chao et al., 2003, Erickson & Steiner, 2001; Meeske et al., 2001).

Despite this overall good performance, there is a small subgroup (10% - 30%), generally comprehending children who have suffered some damage in the CNS (as a result from the tumor or the treatment), who have a wide range of clinical significant psychological problems, such as: depressive symptoms, somatic, anxiety and low self-esteem, ineffective coping, school, family, social or work problems (Barakat et al., 2003; Grootenhuis & Last, 1997; Kazak, 2005; Kazak et al., 2003, Maurice-Stam, Oort, Last & Grootenhuis, 2008; Newby et al., 2000; Patenaude & Kupst, 2005; Robinson, Gerhardt, Vannata & Noll, 2009; Seitz et al., 2009).

### Parents' psychological adjustment.

Having a child diagnosed with cancer is one of the most severe stressors parents may experience during parenting process (Jurbergs, Long, Ticona & Phipps, 2009). Some studies have found high rates of PTSD symptoms in parents of children with cancer, ranging up to 60% when assessing the overall stress (Kazak et al., 2004, Robinson et al., 2009). In general, according to several studies, it could be stated that parents have more adjustment problems than their children (Phipps et al., 2006), as they present elevated levels of PTSD. These symptoms tend to remain stable up to two years after diagnosis, even though they usually decline after

this period, reaching levels of stress comparable to the ones of the general population (Phipps, Long, Hudson & Rai, 2005).

On the other hand, other publications present a better scenario, indicating that parents are optimistic and that the experience of having a child with cancer made them become emotionally stronger, selecting new priorities in life and giving them a greater sense of personal force, an improvement in relationships and a better management of other stressors (Barakat et al., 2003, Barakat et al., 2000, Fernandez et al., 2009; Grootenhuis & Last, 1997; Jurbergs et al. 2009, Maurice-Stam et al., 2008). Kazak et al. (2007) believe that parents' stress can be adaptive, since it alerts their social environment that they are in need of emotional support. Denial or avoidance can be also adaptive, helping these parents to tolerate stress and to fulfill their parental responsibilities, coping with emotional and treatment demands.

Therefore, childhood cancer affects physically and psychologically not only the child, but his/her entire family. This is the reason why it is necessary to develop effective interventions that promote health and help mitigating the psychological consequences of the disease, as well as reducing associated healthcare costs. Research in this field has experienced a remarkable, though slow, growth, probably due to the increase of survival rates in addition to higher scientific and government interest in improving health care for these children and their families.

### Research goal

This paper aims at providing an overview of the effectiveness of psychological interventions designed to promote children with cancer or survivors' adjustment and their parents'. To fulfill this purpose, we reviewed all published articles on this particular field within the 1998-2010 period.

## Method

### Materials

In order to achieve the proposed goal, our search focused on the following databases: PsycINFO, Medline, Scielo, LILACS, Psycarticles and Psycodoc. This particular choice is supported by the relevance and impact of publications contained in these repositories, thus representing sources for the most significant literature related to our assessment.

Key-word used to detect specific publications were: psychosocial intervention, psychotherapy, trial, treatment, adjustment, well-being, adaptation, cancer, childhood cancer, pediatric cancer, anxiety, and depression. These terms were combined in different ways, in order to provide our search with more robust results. These descriptors were chosen according to the thesaurus of different databases, restricting the search to articles published in scientific journals, including literature in both English and Spanish.

## Procedure

Out of the articles found with the above mentioned keywords, we excluded those related to interventions with siblings, teachers, doctors or parents with cancer, qualitative or descriptive studies, the ones exploring non-psychological aspects of the disease, as well as theoretical reviews or meta-analytical ones.

Articles' inclusion considered the following aspects: that the intervention would promote psychological adjustment of children with cancer (patients or survivors) or their parents', that the article had been published within the time range mentioned above and that it contained any of the selected keywords. Therefore, we included randomized and non-randomized controlled trials (longitudinal or cross-section) and pre-post studies (those that compare results obtained before and after the intervention).

Regarding participants, we considered only studies who used parents of children affected by cancer, survivors of cancer, or patients themselves (children or adolescents) aged below 18 years-old, in the case of patients, and not exceeding 21 in the case of survivors (defined as patients who remained in remission, without treatment, for at least one year).

Finally, journals containing articles with the above-mentioned descriptors were: *European Journal of Oncology Nursing*, *Health Education*, *Journal of Consulting and Clinical Psychology*, *Journal of Family Psychology*, *Journal of Pediatric Oncology Nursing*, *Journal of Pediatric Psychology*, *Psycho-oncology*, *Journal of Behavior Analysis and Scandinavian Journal of Caring Sciences*.

## Results

### Characteristics of selected articles

Fourteen articles met the criteria and involved a total of 509 children and adolescents, aged 6 months to 20 years-old (mean: 12 years-old), and 958 adults (parents or caregivers) aging 38 years-old on average. The most common children's diagnoses were hematologic malignancies (leukemia, lymphomas), followed by sarcomas and brain tumors. Most participants were from the United States (9 studies), while the remaining studies (5 assessments) were distributed among different countries: Canada, Netherlands, Australia, Iceland and Mexico.

Eight articles were RCTs, in which interventions' effects (present in the experimental group) were compared to control groups' changes. This latter group received either standard care (Hoekstra-Weebers, Heuvel, Jaspers, Kamps & Slip, 1998; Kazak et al., 2005; Sahler et al., 2005; Streisand, Rodrigue, Houck, Graham-Pole & Berlant, 2000), a psychological placebo (Hinds et al., 2000, Schwartz & Drotar, 2004), or remained on the waiting list without treatment (Butler et al., 2008; Kazak et al., 2004). Six studies used a pre-post de-

sign without control groups (Barakat et al., 2003; Barrera, Rykov & Doyle, 2002; McCaffrey, 2006; Svavardottir & Sigurdardortti, 2005; Thygeson, Hooke, Clasp saddle, Robbins & Moquist, 2010; Valencia et al., 2006).

42.85% of the reviewed articles focused on interventions only for parents or caregivers (Hoekstra-Weebers et al., 1998; Kazak et al., 2005; Sahler et al., 2005, Schwartz & Drotar, 2004; Streisand et al., 2000; Svavardottir & Sigurdardortti, 2005), while 35.71% were intended only for children / adolescents (Barakat et al., 2003; Barrera et al., 2002, Butler et al., 2008; Hinds et al., 2000, McCaffrey, 2006). The remaining 21.43% approached both cohorts (parents and children), with joint or separate sessions (Kazak et al., 2004; Thygeson et al., 2010, Valencia et al., 2006). A summary of the most relevant outcomes of these studies is offered in Appendix 1.

### Evaluation

Regarding the assessment instruments (outcomes) one aspect that deserves attention concerns its diversity. Few researchers used the same instruments to assess similar psychological variables (stress, self-esteem, quality of life and negative affect). Only four instruments were used in more than one study: the State-Trait Anxiety Inventory-STAI (4 studies), Impact of Events Scale - Revised - IESR (3 studies), the Revised Children's Manifest Anxiety Scale - RCMAS (2 studies) and the Profile of Mood States - POMS (2 studies).

### Intervention

In the same vein of assessments, intervention procedures were also diverse. Most (77.7%) interventions undertaken with parents focused on reducing stress and emotional distress caused by cancer diagnosis (4 studies) or children's hospitalization (3 studies). Treatments included teaching a myriad of coping skills: problem solving, communication skills, stress inoculation, writing about the experience and cognitive restructuring. The latter item represented the most widespread technique within our sample of articles (4 studies).

Cognitive restructuring strategy was also the most used technique with children (3 studies), followed by social skills training, teaching coping strategies and / or self-care and relaxation, where each approach was applied in two studies. Interactive music therapy and cognitive rehabilitation could be identified in one approach each.

The number and duration of sessions, in both cases (children and parents), was highly variable, ranging from a single 40-minute session (Hinds et al., 2000) up to twenty 2-hour sessions (Butler et al. 2008), hampering the extraction of an overall pattern in this regard. Sessions were mostly individual (83.3% of the reviewed articles - see Appendix 1).

### Interventions' effectiveness

To assess interventions' effectiveness, the total or partial achievement of therapeutic goals was taken as a benchmark. With this concept in mind, our results suggest that the majority (75.21%) of the proposed treatments had some effect on the participant's psychological adjustment. Specifically, 35.71% of the interventions were effective, since they produced significant changes in all outcome measures and therefore objectives were achieved. A similar percentage (37.5%) had partial or mixed effects, meaning that they produced changes only in some measures but not in others. The remaining interventions (28.57%) had no effect on adjustment measures, hence classified as ineffective. However, this scenario becomes rather blurry if the analysis of results focuses exclusively on randomized controlled studies: 50% of these interventions were ineffective, against 25% of fully-effective ones and another 25% of partially-effective ones.

Concerning children's interventions (patients or cancer survivors), most of them (62.5%) produced mixed results (Barrera et al., 2002; Butler et al., 2008; Kazak et al., 2004; McCaffrey 2006; Thygeson et al., 2010). The best results were obtained through the interventions proposed by Barakat et al. (2003) and Valencia et al. (2006), which could be classified as effective (25.5%). The worst attainments were related to the work of Hinds et al. (2000), which had no significant effects on the outcome measures (12.5%).

Regarding the "effective" interventions, Barakat et al. (2003) improved functioning and social skills of 13 survivors, mean age 10.7 years-old, who had been treated for a brain tumor. The authors used a social skills training program (communication, giving and receiving compliments, conflict resolution, empathy and cooperation), reinforced with a parental component. Valencia et al. (2006) were able to increase adherence, self-care behaviors, assertive skills and optimism in a group of 6 children (5-15 years-old). They used a cognitive-behavioral program, that consisted on cognitive restructuring, skills training and assertive and de-catastrophizing training and also problem solving, reinforced with teaching parents the basics of behavioral analysis. However, it must be highlighted that evidence on the effectiveness of these interventions is mainly for pre-post studies, which may raise some concerns about the practical contribution of these findings.

None of the treatments offered to children included in the three randomized controlled studies can be considered effective, since two had mixed results (Butler et al., 2008; Kazak et al., 2004) and the other (as previously mentioned) provided no improvements (Hinds et al., 2000). In the latter case, the authors did not find statistically significant differences between the experimental treatment (information on self-care coping teaching coping strategies using filmed modeling and behavioral rehearsal) and control group (placebo care), in any of the adjustment measures, or any of the post-intervention measurements (3 time points).

In relation to results obtained with parents, evidence seems more consistent. 44.44% of psychological treatments produced positive and statistically significant effects on outcomes, compared with those found in control groups (Kazak et al., 2005; Sahler et al., 2005) or with previous levels of the participants at baseline (Thygeson et al., 2010, Valencia et al., 2006). 22.22% obtained mixed results (significant changes in some adjustment measures, but not in others) (Kazak et al., 2004; Svavardottir & Sigurdardortti, 2005) and 33.33% produced no effects (Hoekstra-Weebers et al. 1998; Drotar & Schwartz, 2004; Streisand et al., 2000).

Unlike the results with children's interventions, 33.33% of parents' RCTs (6 studies) showed that these treatments were effective in achieving their objectives (Kazak et al., 2005; Sahler et al., 2005), while 16.7% produced mixed results (Kazak et al. 2004) and 50% did not yield any therapeutic benefits (Hoekstra-Weebers et al., 1998, Schwartz & Drotar, 2004; Streisand et al., 2000).

The two "effective" treatments had the intention of reducing posttraumatic stress and emotional symptoms on parents of newly diagnosed children. Kazak et al. (2005) used a modification of Surviving Cancer Competently Intervention Program, developed by the authors, mainly composed of a cognitive restructuring strategy and discussion of personal growth and future. Sahler et al. (2005) used problem solving training, which consisted on discussing the problems that really disturbed parents during this phase of disease.

### Discussion

As previously outlined, the underlying goal of our assessment is to review the effectiveness of psychological interventions designed to improve the adjustment of children suffering from cancer and their parents'. We have identified a total of 14 articles that met the inclusion criteria. Considering the results as a whole, they are promising but inconclusive and difficult to interpret, due to the high variability regarding the objectives between studies, the interventions used to achieve them, the measures chosen to measure the effects and the selected samples. Therefore, it is not surprising that, although most interventions showed some therapeutic effect, the ones that can be defined as effective are few. Only one quarter of interventions targeting children produced statistically significant changes in all measures of adjustment, compared to almost twice of those offered to parents. However, this general pattern can be misleading: if we take into account only randomized trials, we can verify that none of the treatments applied to children was fully effective, but mostly they produced mixed results. For parents, data seemed more consistent, suggesting that they benefit more from psychological interventions than their offspring.

In general, our results are consistent with those reported in other published works (Davey & Neff, 2001; Pai, Drotar, Zebracki, Moore & Youngstrom, 2006; Robinson et al., 2009; Seitz et al., 2009). Specifically, the meta-analysis per-

formed by Pai et al. (2006), using 12 articles published between 1983 and 2005, indicated that interventions targeting children had no significant effect on distress or adjustment measures, while those employed with parents showed a modest, but statistically significant effect. Meanwhile, Seitz et al. (2009) reviewed psychological interventions' effectiveness to reduce psychological distress and / or improve psychosocial adjustment of adolescents with cancer. Of four articles, only one presented statistically significant changes when comparing the experimental treatment with a waiting list control.

It is possible that the small number of effective interventions for children and adolescents is related to their psychological status before the intervention. As previously stated, recent research data indicate that most children with cancer are psychologically well adapted to the disease and its treatments, while most parents suffer from adjustment problems for at least two years after diagnosis. This suggests that psychological treatments used with children were not fully effective for a possible "ceiling effect", i.e., children already presented a good adjustment before starting the treatment and, consequently, it had few significant changes, perhaps because there was nothing else to improve. Instead, more significant effects were obtained with parents because they probably had some clinical psychological problems before the intervention.

On the other hand, considering the elevated number of mixed results with children, it is also possible that therapeutic goals were not well defined, and maybe they do not meet the real needs and concerns of the child, and this is a possible explanation for why these interventions have caused only partial effects. Several researchers have drawn attention to the need of adapting interventions to specific demands of this specific population as well as to a better definition of therapy focus (Butler et al., 2008, Hastings & Beck, 2004; Patenaude & Kupst, 2005).

One aspect that deserves consideration related to therapy focus is whether the involvement of parents in their children's treatment - or dealing with psychological problems of both of them at the same time - would improve the effectiveness of interventions. It seems well established in the scientific literature that children's emotional distress symptoms (anxiety, depression and PTSD) are highly associated with their parents' suffering (Phipps et al., 2005; Robinson, Gerhardt, Vannatta & Noll, 2007; Robinson et al., 2009). As a consequence, it is predictable that intervening on both parents and children would produce greater therapeutic effect. Although data from our review do not clarify this issue completely, they do point in this direction, since one third of the studies with positive results (efficient or mixed) intervened with parents and children at the same time, while none of the ineffective did. Unfortunately, it is unknown whether efficient treatments directed only to parents or only to children had any effect on psychological well-being of the other side, since this feature was not considered in the ob-

jectives of studies and therefore appropriate measures were not included.

However, the greatest restraint to draw more conclusive results comes from methodological difficulties, common in this research field and that limits the comparison between studies. The first problem is related to the study design. Much of the improvement (total or partial) comes from pre-post studies, hindering us to know whether changes in the adjustment measures are due to the intervention's effect or to other circumstances, since there is not a control group to compare with. Indeed, interventions that showed no significant changes in adjustment measures were randomized studies. The control type used in these randomized studies is another point to be considered: although eight from the total reviewed articles applied this design, only two used a placebo-care group equivalent to the experimental group; others chose a waiting list or standard care. As pointed out by other authors (Pai et al., 2006; Scott Harmsen, Sowden & Watt, 2008), a waiting list cannot control nonspecific effects derived from the intervention, so that it cannot be assessed if the simple fact of offering qualified care by the therapist at a particularly stressful situation is enough to improve participants' adjustment. This issue hampers the evaluation of the exact extent of the treatment. Interestingly, the only two studies using psychological placebo to determine experimental treatments' effectiveness found no differences between groups (Hinds et al., 2000, Schwartz & Drotar, 2004), reinforcing the need of more robust methodologies.

The second problem that limits our comparison and generalization of the results is related to samples' heterogeneity, both in relation to children's age (highly dispersed), and to the situation in which they were at the time of the study (survivors, newly diagnosed, hospitalized for various reasons, etc.), with significant differences between them, even with the ones that are in the same situation. For example, the time that survivors were without treatment ranged from one to twelve years, the reasons for hospitalization were very irregular: diagnosis, chemotherapy, treatment side effects, bone marrow transplant, relapse, etc. All this variability, together with the interventions' diversity (treatments, number and duration of sessions, etc.), makes it almost impossible to define properly which treatment is more effective and for which patients.

Also, it is not an easy task to establish if the outcomes of interventions that showed some therapeutic effect are maintained in the long term. Out of six studies that reported pre-post favorable results (total or partial), only one evaluated the treatment effect nine months later. And while all randomized trials that obtained positive results (4 studies) conducted a follow-up, the mean duration of it was less than four months (range 3-6 months).

It is likely that most of these methodological limitations are determined by inherent difficulties of psychological research, particularly in psycho-oncology. Both recruitment process of the initial sample as its long-term maintenance represent particularly arduous tasks, taking into account the

situation of the affected individuals (parents and children), and its expensiveness, personally and economically. These difficulties may increase if we try to randomize participants for treatment or control groups. The moderate acceptance rate found in most of the reviewed articles, which tends to be below 60% of contacted individuals, supports this idea. The most common reasons given for not cooperating were: lack of time to meet the research's demands, feeling overwhelmed and lack of interest. To ensure participants' collaboration, some researchers (Sahler et al., 2005) resorted to financial compensation, delivering \$ 100 to each participant at the end of the evaluation, making the rate of acceptance rise (75%). A debatable, but considerable solution, in order to encourage participation in future researches.

Also considering future studies, efforts should be made in order to improve the offer and effectiveness of interventions for both children and parents. For this purpose, it is necessary to first identify what are their needs and demands, and then develop a treatment plan designed to meet them, analyzing its effects in the short and long terms. According to this perspective, some authors (Hinds et al., 2000; Hoekstra-Weebers et al., 1998; Kazak et al., 2005, Pai et al., 2006, Robinson et al., 2009) suggest that psychological treatments should be more flexible and responsive to participants' concerns, their specific set of coping styles, taking into account the treatment phase and focusing on achieving specific results and not general ones. Other authors (Aslett, Levitt, Richardson & Gibson, 2007; Kazak, 2005; Hobbie et al., 2000) suggest that psychological interventions should avoid relying solely on treatment models based on deficits or psychopathologies, as the posttraumatic stress model. Although this model has been influential in this field of study, it has also been questioned by several researchers (Erickson and Steiner, 2001; Jurbergs et al., 2009; Phipps et al., 2009) who propose focusing on strengths and psychological health promotion, in order to achieve clinically relevant changes in stress derived from cancer and its treatment. In this sense, Kazak et al. (2007) discussed the need for a general therapeutic model that should offer preventive and innovative treatments that are also targeted to the real needs of the child and his family. This model should include psychosocial interventions addressed on promoting family's competence and identifying families who are at psychological risk. As pointed out by these authors, the ultimate goal of psycholog-

ical care and cure of childhood cancer is that children and adolescents suffering from the disease could reach adulthood in the best possible conditions: with resilience, autonomy, quality of life and accepted by the society at the same level as their peers.

## Conclusion

The first remarkable conclusion from our review is that most of the psychological interventions offered to children and parents produced some therapeutic benefit, although the number of really effective treatments is limited, especially the ones offered to children. This result raises some questions about the objectives' appropriateness, the techniques employed and the selected measurement instruments. Determining therapy focus or its convenience are two pending issues in pediatric psycho-oncology field that have caused some debate among experts, including some believing that it is unnecessary to improve psychological adjustment of children, as they are particularly well adapted to cancer circumstances. About this issue, our review suggests that the effectiveness of children interventions could be improved if we involve parents in the process, something which there is little consensus about. Some researchers argue that parents care would be sufficient to improve the children's adjustment (Hastings & Beck, 2004), while others seem to be favorable to a joint intervention (Barakat, Lutz, Nicolaou & Lash, 2005; Fuemmeler et al., 2003; Klassen et al., 2011, Landolt, Vollrath, Niggli, Gnehm & Sennhauser., 2006) and a third group claims that there is no relationship between improvement of children and parents (Grootenhuis & Last, 1997; Lutz, Barakat, Smith-Whitley & Ohene-Frempong, 2004; Robinson et al., 2007).

The small number of articles found in our approach, as well as the great variability regarding treatment techniques, number of sessions, outcome measures and samples, hinders drawing specific conclusions and highlights the importance of continuous investigation in this area. Future research should clarify the concept of psychological adjustment and the relevance of interventions, and to embrace a long-term approach of interventions' effectiveness, thus overcoming the methodological difficulties mentioned in the discussion.

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#### Appendix I. Psychological treatments addressed to children with cancer and their parent. General summary of all reviewed articles.

Author	Participants	Objectives	Design	Measures	Intervention	Results
Barakat et al. (2003)	13 survivors (8-14 years-old, $\bar{X}$ : 10.7 years-old) and their PP (13 mother and 8 fathers)	Improving social functioning and SS of children treated and their PP for brain tumors. - Reducing behavior problems (children).	Pre-post T2: 9 ms PI	- Social Skills Rating System. - CBCL. - Youth Self Report. - Teacher Report Form. - Miami Pediatric Quality of Life Q. - WISC-III.	6 group-sessions (3 groups, 1/week). PP and children separately. - <b>Children:</b> SS training: non-verbal communication; start, maintain and finish conversations; giving and receiving compliments; empathy and conflict resolution; cooperation. - <b>Parents:</b> Information and encouragement of their children's SS; discussion about the disease.	- Significant improvement in social competence. - Significant decrease of internalizing behavioral problems. - Tendency of improvement of most externalizing behavioral problems. - Better verbal and non-verbal functioning, associated to improvement on SS and decrease of behavioral problems.
Barrera et al. (2002)	65 hospitalized children (6 months-17 years-old, $\bar{X}$ : 7 years-old)	Reducing negative mood. Increasing well-being and play activities on hospitalized children.	Pre-post	- Faces Pain Scale. - Play-Performance Scale. - The Satisfaction Questionnaires	- Interactive music-therapy; variable number of individual sessions (1 to 3), 15-45 min. duration, according to patient's needs.	- Significant improvement of positive mood. - Significant increase of adolescent (11-17 years-old) participation on play activities; tendency to increase in younger children (0-5 years-old); no effect on school-aged children (6-10 years-old). - Positive impact on well-being (qualitative data).
Butler et al. (2008)	161 survivors (6-17 years-old) EG: 108 ( $\bar{X}$ :10, 8 years-old). CG: 53 ( $\bar{X}$ :11,1 years-old).	Improving cognitive (especially attention deficit) and academic functioning of children treated for brain tumors.	Multicenter RCT CG: waiting list T1: BL T2: PI T3: 6 ms PI	- Battery of neuropsychological tests to assess cognitive functioning and academic achievement. - Conners' Parent and Teacher Scales. - Culture-Free Self-Esteem Inventory.	Twenty 2-hour individual sessions (1/week). - Cognitive Remediation Program (CRP), that includes: hierarchically graded massed practice, strategy acquisition and cognitive-behavioral interventions;	- Significant improvement of EG's academic achievement. - No significant differences between Gs on: attention, memory, vigilance, learning strategies and self-esteem. - Less cognitive problems, better attention and less



Author	Participants	Objectives	Design	Measures	Intervention	Results
Hinds et al. (2000)	78 adolescents newly diagnosed (12-21 years-old). EG: 40 ( $\bar{X}$ : 16,4 years-old). CG: 38 ( $\bar{X}$ : 15.6 years-old).	- Facilitating coping and self-care. - Determining their effects on hopefulness - optimism, hopelessness, self-esteem, self-efficacy, symptom distress and treatment's toxicity.	RCT CG: placebo care T1: pre-intervention (12 days post D) T2: PI (5 weeks post D) T3: 3 ms post-D T4: 6 ms post-D	- Nowicki-Strickland Locus of Control Scale. - Hopefulness Scale for Adolescents. - Hopelessness Scale. - Rosenberg Self-Esteem Scale. - Self-Effectiveness Scale. - Symptom Distress Scale. - The NCI Common Toxicity Criteria Scale.	One 40-min. individual session. - Information about self-care coping. - Filmed modeling (useful strategies to cope with cancer). - Rehearsal of those strategies observed and selected by the patients. - CG: discussion about several topics selected by the patients.	- attention – hyperactivity symptoms in EG, according to parent's information; no differences according to teachers. - No differences between Gs in any variable at any measurement point.
Hoekstra-Weebers et al. (1998)	81 parents (24-53 years-old, $\bar{X}$ : 36.6) of newly diagnosed children. EG: 39. CG: 42.	- Reducing psychological distress. - Regulating the intensity of emotions. - Helping them to obtain social support.	RCT CG: standard intervention. T1: 14 days post-consenting T2: PI T3: 6 ms PI	- Goldberg General Health Q. - Symptom Check List. - State-Trait Anxiety Inventory (STAI). - Social Support List-Discrepancies. - Self-designed intensity of emotions list.	Eight 90-min individual sessions, each 3 weeks. - Expression of emotions. - CR strategy - Encouragement of problem-focused coping skills. - Communication and assertiveness skills. - Information about treatment's sequelae.	- No differences between Gs in all outcome measures (neither in post-treatment nor in follow-up). - Significant distress decrease in both G with the passage of time.
Kazak et al. (2004)	150 survivors (10-20 years-old) and their PP: 146 mothers ( $\bar{X}$ : 42.9 years-old) and 106 fathers ( $\bar{X}$ : 42.2 years-old). EG: 76 ( $\bar{X}$ : 14.62 years-old). CG: 74 ( $\bar{X}$ : 14.6 years-old).	- Reducing PTSS (arousal, intrusive thoughts and avoidance) in adolescents and parents. - Exploring its effect over anxiety.	RCT CG: waiting list T1: BL T2: 3-5 ms PI	- Impact of Events Scale – Revised (IESR). - Post-Traumatic Stress Disorder Reaction Index. - STAI. - Revised Children's Manifest Anxiety Scale (RCMAS).	SCCIP. Four 1-day sessions: 2 in the morning (children, fathers and mothers separately) and 2 in the afternoon with each family. - Discussion about traumatic events that are associated to cancer and identification of stressful memories. - CR strategy: adversity-beliefs-consequences (ABC-model); accepting the uncontrollable; focusing on the controllable; using positive thinking. - Discussion about cancer's effect on the family, health and future.	- Significant decrease of arousal symptoms in the survivors, and intrusive thoughts among fathers; no changes in mothers. - No effects on avoidance symptoms in any of the participants. - No significant changes in anxiety on survivors and mothers; marginal significantly effect in fathers.
Kazak et al. (2005)	19 couples of PP/caregivers (20 F and 18 M) of	- Reducing or preventing PTSS. - Decreasing an-	RCT CG: standard care	- Acute Stress Disorder Scale.	SCCIP-ND (Newly Diagnosed). Three individual 45-min	- Significant decrease of PTSS and anxiety-state in EG.

Author	Participants	Objectives	Design	Measures	Intervention	Results
	newly diagnosed children. EG: 9 couples ( $\bar{X}$ : 40 years-old). CG: 10 couples ( $\bar{X}$ : 39 years-old).	anxiety states.	T1: preintervention T2: 2 ms. After last treatment's session	- IESR. - STAI. - Intensity of Treatment Rating.	sessions with each couple. - Identification of beliefs about cancer and its treatment (model ABC). - CR strategy (modification of thoughts to improve family functioning). - Discussion about family growth and the future.	
McCaffrey (2006)	20 children (6-17 years-old; $\bar{X}$ : 12.9) under treatment (n = 7) or without it (n = 13).	- Reducing anxiety and improving self-concept.	Pre-post	- Self-records of positive life events. - Self-rating scales: relaxation and stress control. - Heart rate. - The About Myself Test of Self-concept. - RCMAS. - Individual Feeling Great Logbooks.	Modified Feeling Great Program (MFGP). Number of sessions: not clear. - Relaxation/ imagery. - Concentration. - Goal setting. - Building and performing exciting activities. - CR strategy (pay attention to the positive thinking and getting rid of negative thoughts).	- Significant effects on 5 from 11 dependent variables: anxiety's reduction (worry/ hypersensibility, social concerns/ concentration), increasing frequency of positive events, heart rate's normalization and relaxation. - No changes in self-concept.
Sahler et al. (2005).	429 mothers of newly diagnosed children. EG: 217 ( $\bar{X}$ : 35 years-old). CG: 212 ( $\bar{X}$ : 36 years-old).	- Reducing stress and negative affectivity (anxiety-depression).	Multisite RCT. CG: usual psychosocial care. EG: usual care + experimental. T1: before randomization T2: PI T3: 3 ms PI	- NEO Five-Factor Personality Inventory. - Social Problem-Solving Inventory - Revised. - Profile of Mood States (POMS). - Beck Depression Inventory II. - IESR.	Eight 1-hour individual sessions. - Training on real-life problems-solving skills. Bright IDEAS system (Identify, Define, Evaluate, Act, See).	- Significant decrease of distress, avoidance style, negative orientation to problems, depression and PTSS. - Changes are maintained in follow-up.
Schwartz and Drotar (2004)	54 caregivers of children with chronic illness who were hospitalized (42 with cancer)  EG: 29 ( $\bar{X}$ : 35.16 years-old). GC: 25 ( $\bar{X}$ : 38.32 years-old).	- Improving perceived QV and reducing distress and anxious-depressive symptoms in the long term.  - Reducing physical symptoms in the short and long term.  - Reducing perceived stress and increase coping.	RCT CG: placebo care. T1: preintervention T2: PI T3: 3 ms PI	- The Essay Evaluation Measure. - Mood and Anxiety Symptom Q. (MASQ). - POMS-Short Form. - Short Form Health Status Q. (SF-36). - Caregiver Appraisal Scale (CAS). - Pennebaker's Psychological Scale. - Brief Mood Rating Scale.	3 days in a row (20 min. each day) - EG: write about the most traumatic and upsetting experiences of their entire life and about emotional thoughts associated to them (emotional disclosure). - CG: write about neutral experiences (activities from the previous summer).	- Significant more physical symptoms in EG than in CG (both at T2 and T3). - No significant differences between G on distress and anxious-depressive symptoms. - No significant differences between G on positive or negative affect. - No significant differences between G on perceived; more vitality for the CG than the EG. - No significant differences between G on stress appraisal.
Streisand et al. (2000)	22 mothers of hospitalized children.	- Reducing stress, through the teaching	RCT. CG: standard	- Daily Stress Inventory.	One 90-min. individual session.	- No significant differences between G, although EG

Author	Participants	Objectives	Design	Measures	Intervention	Results
	dren undergoing bone marrow transplantation. EG: 11 ( $\bar{X}$ : 37.2 years-old). CG: 11 ( $\bar{X}$ : 36.5 years-old).	of coping strategies.	care. T1: (1-47 days before admission- BL) T2: PI (7 days before transplantation) T3-T6: 0, 7, 14, 21 days after transplantation	- Parenting Stress Index. - Semi-structured interview.	Stress inoculation: - Education. - Relaxation. - Communication training.	used more coping strategies than CG. - Stress decrease in both G with the passage of time (before admission –after transplantation).
Svavarsdottir and Sigurdardottir (2005)	10 mothers and 9 fathers ( $\bar{X}$ : 38.45 years-old) of newly diagnosed adolescents.	- Improving psychological well-being, coping behavior, hardiness and adaptation.	Pre-post	- Cancer Factor Index. - General Well-Being Schedule. - Family Hardiness Index. - Coping Health Inventory for Parents. - Family Adaptation Scale.	Adaptation of “Calgary Family Intervention Model”; interactive intervention through internet (duration: 6 months). - Education- information. - Interactive support (sharing the experience with other PP and the therapist). - 1 or 2 emotional support interviews with the therapist, ranging from 60 to 90 min. (according to PP’s needs).	Significant improvement of psychological well-being of both fathers and mothers. - No significant changes in coping behavior, hardiness and adaptation.
Thygeson et al. (2010)	16 hospitalized patients: 11 children (6-12 years-old), 5 adolescents (13-18 years-old) and 33 PP ( $\bar{X}$ : 37.42 years-old).	- Reducing anxiety of children, adolescents and parents.	Pre-post	- STAI. - STAIC.	One 45-min session; children and PP separately. - Yoga (relaxation imagery)	- Significant decrease of anxiety in parents and adolescents, but not in children.
Valencia et al. (2006)	6 patients (5-15 years-old, and their families: 4 fathers (30-50 years-old), 5 mothers (29-39 years-old) and 4 siblings (7-21 years-old). It is not clear if children are under treatment or not	- Establishing self-care behavior, adherence and SS in the children. - Improving perceived QV and optimism in PP and children.	Pre-post	- Self-records of adherence behaviors. - Social Satisfaction Questionnaire Treatment Outcome - Behavioral interview. - General evaluation of the treatment’s components; - Content Analysis of Verbatim Explanations Technique. - Pediatric Quality of Life Inventory.	“The Optimism Game”. Six 60 min. Individual sessions with the children and 7 with the PP (separately). - Informative session. - CR strategy (identifying negative thoughts and replacing them for positive ones). - Decatastrophizing skills. - Problem-solution. - Assertive skills. - Teaching basic concepts of behavior analysis (only PP).	- <b>Children:</b> significant improvement of adherence behaviors, perceived QV, pro-treatment and self-care behaviors, optimism and assertive skills. - <b>Parents:</b> significant improvement of perceived QV and optimism. - No information about siblings.

**Key:** PP: parents; PI: post-intervention; T: evaluation time; CBCL: Child Behavior Checklist; Q: Questionnaire; SS: social skills; EG: experimental group; CG: control group; RCT: randomized controlled trial; BL: baseline; D: diagnosis; G: groups; CRS: cognitive restructuring strategy; PTSS: posttraumatic stress symptoms; SCCIP: Surviving Cancer Competently Intervention Program; QL: .quality of life.