



# Psychosocial Intervention Programs for Parents of Children with Cancer: A Systematic Review and Critical Comparison of Programs' Models and Development

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## Abstract

Intervention programs have been developed to help parents cope with their child's cancer. Despite some studies reporting a high level of evidence, it is unclear how these programs build on each other. Appraising models of change is critical to advance scientific knowledge and provide evidence-based interventions. This review aims to identify existing programs, explicitly formulate their underlying models, evaluate how they translate into concrete activities, as well as identify and discuss their development process. Eleven programs based on models of change from cognitive-behavioral, systemic and counselling theories were identified. Many models included a sound theoretical framework, targeted outcomes, as well as implementation strategies. In most cases, preliminary development studies were conducted, but details were rarely provided on how development stages informed the redesign of intervention programs. Acceptability and treatment fidelity were not available for one-third of the programs. Future reports should document the development and design redesign stages prior to conducting efficacy trials, as this step would provide crucial details to critically appraise programs.

**Keywords** Pediatric cancer · Parents · Psychosocial · Intervention program · Systematic review

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## Introduction

### Psychosocial Challenges for Parents in Pediatric Oncology

Recent reviews have highlighted a high frequency of emotional distress among parents of children treated for cancer (Vrijmoet-Wiersma et al., 2008). Parental distress is characterized by a wide range of symptoms, such as stress, uncertainty, loss of control, anxiety, depression, and traumatic symptoms (Picoraro, Womer, Kazak, & Feudtner, 2014; Sultan, Leclair, Rondeau, Burns, & Abate, 2016; Vrijmoet-Wiersma et al., 2008). Post-traumatic stress (PTS) rates of 51% and 40%, respectively, have been observed in mothers and fathers 2 weeks after the diagnosis (Patino-Fernandez et al., 2008). During treatments, parents are subjected to multiple pressures and reorganizations (family, professional, financial, etc.) that generate distress and a sense of loss of control. This feeling of significant loss of control is explained by difficulties in adapting to the oncological situation and an overflow in the management of daily life

(Varni et al., 1999). Although most parents achieve normative levels of long-term well-being (Tremolada, Bonichini, Schiavo, & Pillon, 2012), studies have shown that nearly one-third of parents suffer from psychological distress 5 years after diagnosis (Vrijmoet-Wiersma et al., 2008). Additionally, it has been shown that lack of control and parental distress can also lead to adjustment difficulties in children themselves (Robinson, Gerhardt, Vannatta, & Noll, 2007). In fact, mixed parental distress (anxiety, depression and trauma) have been associated with long-term distress in children (Maurice-Stam, Oort, Last, & Grootenhuys, 2008), adjustment difficulties (e.g., verbal, perceptual, motor skills problems; Barrera, Atenafu, Andrews, & Saunders, 2008) as well as alterations in school functioning (Yagci-Kupeli, Akyuz, Kupeli, & Buyukpamukcu, 2012). It is, therefore, crucial to support parents and treat their distress as early as possible to optimize the resilience for all family members facing childhood cancer.

Manualized intervention programs to improve parental coping have been developed and evaluated (Ussher, Perz, Hawkins, & Brack, 2009). A variety of programs are available (e.g., Kazak et al., 2005; Manne, Mee, Bartell, Sands, & Kashy, 2016; Mullins et al., 2012). Following a critical assessment of results and potential for dissemination, the US National Cancer Institute (NCI) now recommends these programs (Kazak et al., 2005; Sahler et al., 2013). Others have low efficacy and are not readily transferable to clinical settings (Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip, 1998). It is, therefore, useful to examine whether these programs are consistent with the recommendations for intervention program development (Craig et al., 2008; Czajkowski et al., 2015).

### Scientific Evidence on Program Development

Recommendations from program development experts stress the importance of carefully selecting the program's clinical components, adapting them to the target population and the clinical context to facilitate its implementation (Byrne, Mc Sharry, Meade, Lavoie, & Bacon, 2018). For these reasons, authors should provide an accurate definition of the supportive intervention concept and document its social validity and feasibility (Barlow, Bullis, Comer, & Ametaj, 2013). It is also essential to understand whether existing programs rely on each other or offer new approaches to modifying targeted behaviors. This information would enable new studies to gradually improve programs' validity and transferability. Social validity, i.e., the program's acceptability and relevance, facilitates patients' participation and improves collaboration between patients and providers (Kazdin, 2005). When developing a program, it is equally important to identify and refine a transparent and evidence-based model of change, clearly operationalize relevant constructs, support

the program with a sound theoretical framework, and allow for concrete actions (APA, 2006). Recent guidelines have underlined the importance of documenting preliminary steps before conducting efficacy studies. The Obesity-Related Behavioral Intervention Trials (ORBIT), initially developed within the framework of an obesity management program, is a comprehensive behavioral program evaluation model that explicitly describes the preliminary stages of program development (Czajkowski et al., 2015). This model recommends four phases of behavioral intervention program development: I-program definition phase, II-preliminary tests, III-efficacy studies and, IV-effectiveness studies. According to Phase I, intervention programs should follow successive phases during which the concept, program components and targeted behaviors are identified, and its acceptability and effectiveness are evaluated.

### Stages and Essential Variables on Program Development

This review aims to identify and compare the content of manualized programs for parents of children undergoing cancer treatment. It is part of an evolving scientific context in which methodologies for behavioral interventions' development and evaluation are better defined (Craig et al., 2008; Czajkowski et al., 2015). In accordance with recommendations on the objectives of a systematic review (Hagger, 2012), the current review aimed to synthesize relevant information related to program development phases, make available important information that is often not explicitly mentioned in research to the scientific community, and assist researchers and clinicians in comparing different programs. More specifically, we aimed to (1) identify available programs, (2) identify their underlying models, (3) evaluate how each program's interventions can be translated into concrete activities, and (4) identify and discuss their development process.

## Methods

### Data Sources

We conducted a systematic review using MEDLINE, EMBASE, CINAHL, and PsycINFO databases. The search was performed for all entries before February 2017 and the four following keywords and their reformulations were used to find relevant articles: "cancer," "pediatric," "parents," and "support intervention". Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses recommendations (PRISMA)—a list of evidence-based items to be included in systematic reviews and meta-analyses—we completed this research by searching for grey literature related to

this type of program (Moher, Liberati, Tetzlaff, & Douglas, 2009). The same procedure was conducted on Google and Duckduckgo as well as in the largest francophone library for users in pediatric oncology. We also contacted all authors of the identified programs by electronic search to retrieve any unpublished documents and sent a request via the Society of Pediatric Psychology's listserv (APA div 54). This systematic review was recorded on the Prospero platform on 19/05/2017 (CRD42017067475).

## Study Selection

To be eligible, studies had to report any data regarding manualized psychosocial programs for parents of children (0–18 years) with cancer. Both quantitative and qualitative studies published in peer-reviewed journals were included. Any grey literature item describing a psychosocial program for parents of children (0–18 years) with cancer (unpublished manuals, case reports, unpublished pilot studies, preliminary reports, master or doctoral thesis) were also included in this review. Intervention studies that had not

been manualized in a program, that were not intended for parents of children with cancer, or that were not conducted in pediatric oncology were excluded (Fig. 1).

After removing duplicates, two reviewers (DO and RR) independently rated all retrieved titles and abstracts for relevance. Disagreements were discussed with a third author (SS), and a joint review of the full articles was conducted until consensus was reached. Once agreement was achieved on the selected review articles, the reference lists from all identified articles were examined. The resulting articles were considered eligible for this review. These articles were read and data extracted.

## Data Extraction

This review's primary aim was to perform a qualitative analysis of models of change and their translation into concrete actions. It was therefore not intended, as most systematic reviews are, to compare intervention programs' effectiveness. The search was not limited to randomized trials, as preliminary studies on program development and grey literature

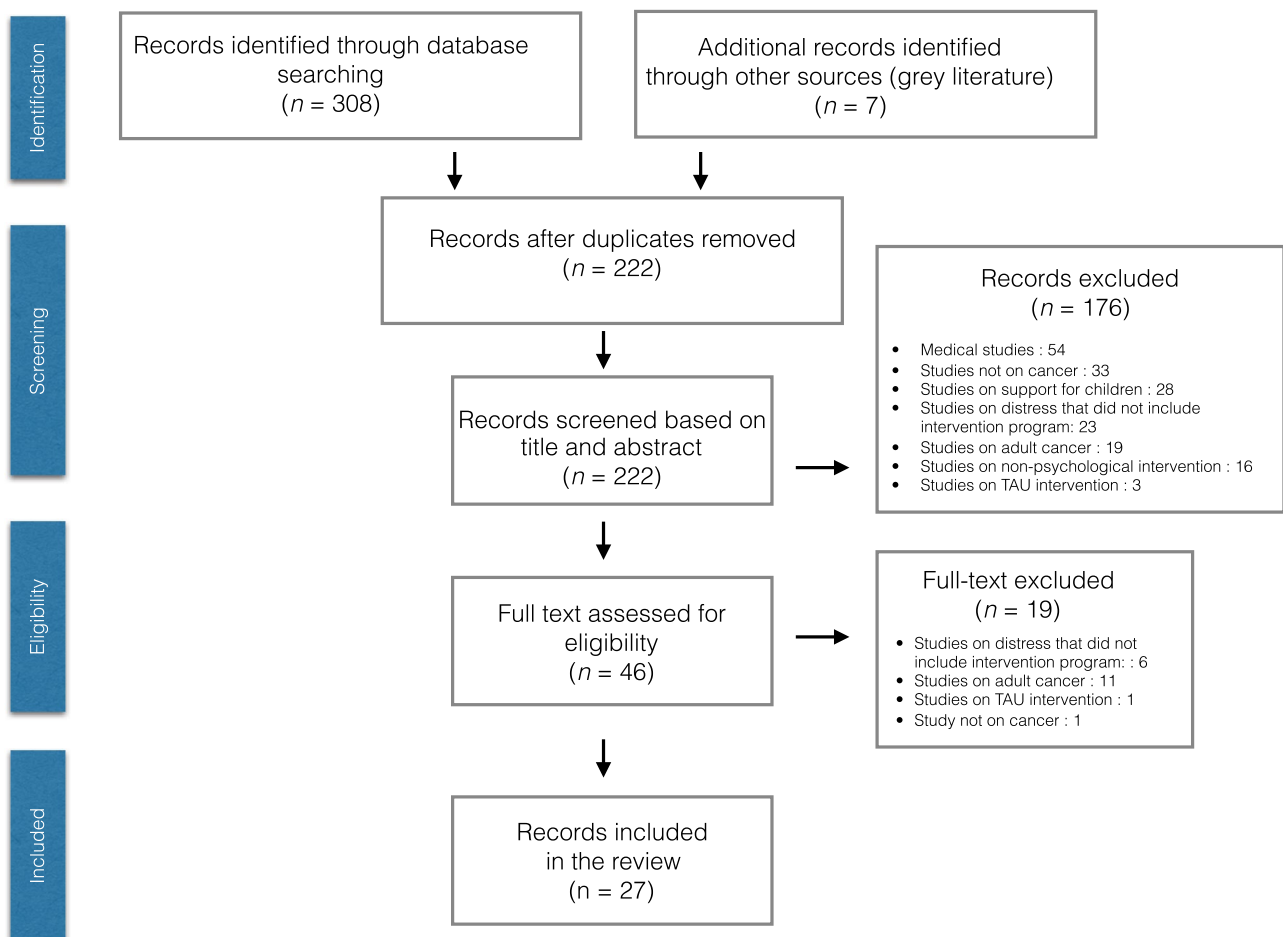


Fig. 1 PRISMA flow chart of paper selection

bear a lot of information on programs' development process. Given our primary aim, the general guidelines for systematic reviews could not be applied unaltered. Since the search method was systematic, we still tried to adhere to as many PRISMA criteria as possible.

To extract the data, we referred to the ORBIT model which provides recommendations for the development and study of behavioral programs (Czajkowski et al., 2015). This model consists of four phases: two preliminary phases (I—design definition and II—preliminary test) and two final phases (III—efficacy evaluation and IV—effectiveness assessment). Phase I consists of defining (Ia) and refining (Ib) design stages by studying the different therapeutic models and their effects on the targeted population. Phase II involves preliminary tests (including a pilot test) to assess feasibility, fidelity, and preliminary results on the program's effects.

For aim 1, we identified the intervention programs described in the articles selected through the literature review. Two authors (DO and RR) performed this systematic search independently and shared their results.

For aim 2, we extracted information from the selected articles' introduction on (1) the programs' primary outcomes and (2) the theoretical models explaining the difficulties experienced by the parents. From the articles' "Methods" section, we extracted the data about (3) the models of change adopted to modify targeted behaviors and (4) the specific intervention implemented in the program.

For aim 3, we identified the program implementation according to ORBIT's phase Ia (Czajkowski et al., 2015). We examined whether the programs were based on a data-supported model of change and if they were consistent with current guidelines in pediatric oncology (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Procedures also had to be sequential, useful, and based on past experiences. Furthermore, programs had to be described as socially acceptable and safe for the population (APA, 2000a).

This procedure was carried out for every article separately. Since some programs had been described in more than one article, the articles were then grouped by program. Two authors (DO and RR) then extracted and rated the data independently according to the same criteria. Both raters discussed and reached full agreement of the analysis.

## Critical Appraisal

Aim 4 was related to the evaluation of intervention programs' development process and their effects. We evaluated on the basis of ORBIT's preliminary Phase II trials criteria for feasibility, acceptability and pilot studies (Czajkowski et al., 2015). According to these criteria, the programs should: (1) be based on a written manual to ensure the intervention's fidelity and (2) have a clinical impact on

the outcomes associated with a pre-post intervention change that could possibly be replicated in other pilot projects and efficacy trials.

## Results

The original search identified 308 articles through electronic databases and seven additional records through the grey literature. These seven items consisted of one unpublished article, three manuals, two working documents obtained from the original authors, and one website identified by browsing the Internet. No additional documents were obtained following the email request sent to the SPP listserv (div 54 APA) or following manual searches on the basis of reference lists. After removing duplicates, 222 independent hits remained. These items' titles and abstracts were reviewed, and 176 were excluded. These excluded records did not fit the research question; they either did not deal with a support program, were not related to cancer, did not concern ill children's parents, were reviews, or were non-manualized psychological intervention programs. Before the articles were read in their entirety, 46 of them met the inclusion criteria. After the articles were read, 19 of them were excluded due to a lack of a pediatric cancer context and/or manualized program. As a result, 27 records (20 research articles and seven items found in the grey literature) were selected for this systematic review (see Table S1).

## Identified Manualized Programs

Among the 27 records, 11 manualized programs were identified (see Table 1). Five programs were original: Intervention Program for Parents of Pediatric Cancer (IPPPC) (Hoekstra-Weebers et al., 1998); Surviving Competently Cancer Intervention Program (SCCIP) (Kazak et al., 2004; Kazak et al., 1999); Internet-based guide to self-help (IBG) (Cernvall, Carlbring, Ljungman, & von Essen, 2013; Cernvall, Carlbring, Ljungman, Ljungman, & von Essen, 2015; Cernvall et al., 2017); Cope Adapt Survive life after CANcer (CASCADE) (Wakefield et al., 2016; Wakefield et al., 2015); Brief psychological intervention on quality of life for parents of children with cancer (BPIQOL) (Safarabadi, Maarefvand, Biglarian, & Kuhubchandani, 2016).

Six/eleven programs were adapted from existing programs in oncology or another clinical domain. The Surviving Competently Cancer Intervention Program—Newly Diagnosed (SCCIP-ND) (Kazak et al., 2005; Stehl et al., 2009) is a short version of the SCCIP (with three sessions instead of four). Bright IDEAS (Askins et al., 2009; Sahler et al., 2013; Sahler et al., 2005; Sahler et al., 2002) is an adaptation of problem-solving training to an oncological population (Nezu, Nezu, & D'Zurilla, 2013). Parents-based interdisciplinary intervention

**Table 1** Developmental characteristics of intervention programs to support parents with a child undergoing cancer treatment

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Intervention Program for Parents of Pediatric Cancer Patients (IPPPC)	Hoekstra-Weebers et al. (1998)	Parents	The cancer diagnosis causes distress in parents which is related to difficulties with adjustment, uncertainty, and feelings of loneliness	To decrease parents' distress to improve their adjustment to their child's cancer and to normalize emotional reactions by reducing automatic negative thoughts (thought control and problem-oriented coping.) To reduce uncertainty by acquiring information about the disease To avoid feelings of loneliness by training parents to better recognize and understand each other's emotions and to communicate effectively within the couple	Eight 1.5-h sessions Delivered by a psychologist Procedures derived from CBT: • Cognitive restructuring: identifying and reducing negative automatic thoughts and encouraging the expression of problem-oriented coping in order to favor the parents' adjustment • Communication and assertiveness training to help cope with the feeling of loneliness Counselling is used to provide information about the disease and its consequences. This will support parents when faced with uncertainty Primary outcome: distress (CHG, SCL)	N/A	64%	N/A

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Surviving Cancer Competently Intervention Program (SCCIP)	Kazak et al. (1999, 2004)	Families: adolescents, siblings, parents	The cancer diagnosis may lead parents to develop post-traumatic stress associated with pre-existing anxiety, beliefs about cancer and its treatments. These symptoms affect the well-being of the whole family, including the sick child	To work on family beliefs about cancer to treat traumatic stress: identifying, understanding and reforming the impact that cancer has had in the past and will have in the future (thought control) To treat symptoms of intrusion, avoidance, and arousal through work focused on the cognitive and emotional aspects of traumatic memories	Four sessions (two 1-h and two 1.5 h) Delivered by a psychologist The procedures are derived from interpersonal therapies: • The multiple family discussion group allows family members to discuss their perceptions of cancer, in connection with a testimonial video, in order to change their beliefs about cancer (Ostross & Steinglass, 1996)	Evaluated 75–100%	96%	96%

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Bright IDEAS	Sahler et al. (2002, 2005, 2013, 2015, 2016) and Askins et al. (2009)	Mothers	The cancer diagnosis and its treatments causes heightened distress in mothers. Mothers are overburdened (assuming responsibility for medical care, experiencing socio-professional changes, financial difficulties), experience tension in their relationship with their spouse, and feel like they are abandoning their other children. They seek support to express their distress and are particularly sensitive to stressful events	To improve awareness of stressful situations (thought control) to help mothers in distress To improve problem-solving skills in mothers to reduce negative self-reporting when faced with barriers (problem-oriented coping) To restore optimism in mothers and to empower them in their ability to solve problems	Eight 1-h sessions Delivered by a psychologist The procedures are derived from CBT: <ul style="list-style-type: none"> <li>Inviting mothers to stop and think</li> <li>Problem-solving training. This procedure is based on five steps: identify the problems, define solution options, evaluate these options, carry out the solution, and see if it is effective (Nezu et al., 2013)</li> <li>Prescription of tasks to be performed at home</li> </ul> This program has been recently adapted to an electronic version: eight 1-h sessions on a tablet Primary outcome: distress (POMS)	Evaluated	61%	95%

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied	
						Acceptability	Feasibility
Surviving Cancer Competently Intervention Program—Newly Diagnosis (SCCIP-ND)	Kazak et al. (2005), Stehl et al. (2009), and Warner et al. (2011)	Parents	<p>The Theoretical models explaining the difficulties experienced by the parents for SCCIP-ND is the same as SCCIP. The cancer diagnosis may lead parents to develop post-traumatic stress associated with pre-existing anxiety, beliefs about cancer and its treatments. These symptoms affect the well-being of the whole family, including the sick child</p> <p>The behavioral change models for SCCIP-ND are the same as SCCIP. To work on couple beliefs about cancer to treat traumatic stress: identifying, understanding and reforming the impact that cancer has had in the past and will have in the future (thought control)</p> <p>To treat symptoms of intrusion, avoidance, and arousal through work focused on the cognitive and emotional aspects of traumatic memories</p>	<p>Three 45-min sessions Delivered by a psychologist</p> <p>The procedures are derived from interpersonal therapies:</p> <ul style="list-style-type: none"> <li>The multiple family discussion group allows family members to discuss their perceptions of cancer, in connection with a testimonial video, in order to change their beliefs about cancer (Ostroff &amp; Steinglass, 1996)</li> <li>Families are then encouraged to seek solutions together to better adapt to the context of cancer (Family oriented approach) (Kazak &amp; Simms, 1996)</li> </ul> <p>Procedures derived from CBT are then used based on the results of the previous approaches:</p> <ul style="list-style-type: none"> <li>Identifying and reducing false beliefs</li> </ul> <p>Primary outcome: Post-traumatic stress symptom (IES-R)</p>	Evaluated	88%	96%



Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
HERO +	Santacroce, Asmus, Kadan-Lottick, and Grey (2010)	Parents and AYA	The cancer diagnosis leads to uncertainty associated with delayed medical (e.g., cardiopulmonary) and psychosocial (e.g., depression, anxiety, PTSD) consequences. PTSD symptoms include avoidance, emotional and cognitive numbness, and hyperarousal. Avoidance is associated with a decrease in activities, relationships, and interactions between families and their peers, thus reducing support interactions that may be beneficial to families	To reduce uncertainty by providing information about cancer, treatments, and potential delayed effects To reduce uncertainty through training to better manage stress To focus on cancer uncertainty and include training techniques that will allow parents to better manage the stress related to the diagnosis (thought control and emotion-focused coping) To improve social interactions to better regulate emotions and treat PTSD symptoms	Seven 30-min sessions over the phone Delivered by a health professional with an expertise in childhood cancer The procedure is derived from counseling: <ul style="list-style-type: none"> <li>• Providing information on the disease in order to reduce uncertainty</li> </ul> Procedures derived from CBT also focus on uncertainty and aim to improve emotional regulation and family interactions: <ul style="list-style-type: none"> <li>• Relaxation training (breathing and guided imagery)</li> <li>• Cognitive restructuring</li> <li>• Family communication training</li> <li>• Problem-solving training</li> </ul> Primary outcome: uncertainty (MUIS-C)	N/A	65%	N/A

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Parents-Based Interdisciplinary Intervention (PBII)	Mullins et al. (2012) and Fedele et al. (2013)	Mothers	The cancer diagnosis causes significant distress and long-term adjustment difficulties for parents. They must integrate a great deal of information about the disease and its treatments, communicate with a number of health professionals, monitor medications and their side effects, and provide comfort to a child who is often in distress and undergoing treatment. The cancer context and the uncertainty are out of parents' control and lead to clinical and sub-clinical psychological symptoms that compromise their quality of life	To learn adequate ways to identify difficulties related to the child's illness and reduce uncertainty (thought control) To improve management of distress through communication training by developing either problem-solving skills or other skills that promote a different perception of the problem when problem solving is not possible (problem-based coping)	Twelve sessions (six 45-60-minute sessions face-to-face and six 15-30 min sessions over the phone) Delivered by a psychologist and a nurse Procedures derived from CBT: <ul style="list-style-type: none"> <li>They are centered on the illness uncertainty method, which proposes to work on the ambiguity, complexity, and lack of information on the disease</li> <li>Problem-solving training, cognitive restructuring, effective communication training, and social support aim to enable mothers to better manage distress and uncertainty</li> </ul> A procedure derived from counselling is suggested: <ul style="list-style-type: none"> <li>Providing mothers with information about the disease</li> </ul> Primary outcome: distress (SCL-90-R)	Evaluated	86%	N/A

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Internet-Based Guide to Self-Help (IBG)	Cernvall et al. (2013, 2015, 2017)	Parents	<p>The stressors in oncology include the diagnosis of cancer, its treatments and their complications, the information concerning the success or not of the treatment, the fear of recurrence</p> <p>While some parents are able to adapt, others develop a trauma that causes PTSD. PTSD is associated with phenomena of thought suppression, behavioral avoidance, rumination of worry, monitoring threats, anxiety, and depression</p>	<p>To promote the parents' natural ability to adapt to the difficult situation (traumatic growth)</p> <p>To allow parents to accept the child's medical situation and thus view life differently, in a more serene way</p> <p>To use of emotion-focused coping</p>	<p>Ten sessions online which corresponds to four hours per week</p> <p>Self-help program</p> <p>Each patient is assigned with a psychologist</p> <p>It suggests counselling procedures:</p> <ul style="list-style-type: none"> <li>• Providing information about the child's illness and emotions</li> </ul> <p>Procedures derived from CBT are also used:</p> <ul style="list-style-type: none"> <li>• Cognitive restructuring</li> <li>• Procedures based on emotion-oriented coping, relaxation, mindfulness, acceptance therapy, compassion, aim to help parents adapt and make them feel more serene in the way they experience their child's illness</li> <li>• Prescription of homework assignments to enhance training</li> </ul> <p>Primary outcome: Post-traumatic stress symptom (PCL-C)</p>	Evaluated	100%	N/A

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied	
						Acceptability	Feasibility
Cope Adapt Survive life after Cancer (CAS-CADE)	Wakefield et al. (2015, 2016)	Parents	<p>Parents' quality of life is impaired in post-treatment because of a fear of recurrence, feelings of isolation and loneliness, and unmet needs regarding information on monitoring for recurrence and on how to return to normalcy</p> <p>This altered quality of life can lead to adjustment problems that may compromise the parents' ability to provide the basic safety that children need during times of stress: parents may express more anger, listen to children less, etc</p>	<p>To improve parents' coping strategies (through thought control) and problem-solving training (problem-focused coping) to improve parents' quality of life and reduce the risk of depression and anxiety</p> <p>To improve communication with the health care team and within the parents' relationship in order to avoid dissatisfaction associated with a lack of information and feelings of isolation</p> <p>To foster mutual support</p>	<p>Four 2-h sessions online with six participants at once</p> <p>Delivered by computer</p> <p>Procedures derived from CBT:</p> <ul style="list-style-type: none"> <li>• Providing social support</li> <li>• Cognitive restructuring: reduction of negative thoughts</li> <li>• Encouraging problem-focused coping</li> <li>• Problem-solving training</li> </ul> <p>Procedures derived from counselling:</p> <ul style="list-style-type: none"> <li>• Providing information about cancer and its risks</li> </ul> <p>The combination of these procedures aims to improve the parents' adaptation to the context of the illness and to improve communication within the couple and with the health care team.</p> <p>A complementary session is offered a month later to identify the parents' challenges and their goals</p> <p>Primary outcome: quality of life (37-QOL)</p>	64%	87%

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied	
						Acceptability	Fidelity to manual
Parent Social Cognitive Processing Intervention Program (P-SCIP)	Manne et al. (2016) and Manne (2009, 2010)	Parents	Parents with a child undergoing HSCT are at risk of developing post-traumatic stress caused by high mortality and morbidity post-transplant	To integrate the meaning of the traumatic event and diminish the beliefs that parents have of the HSCT context (thought control) To allow parents to accept this medical situation, to better communicate, express their emotions, and seek support among family caregivers (problem-focused and emotion-focused coping)	Five 1-h sessions Delivered by a psychologist The procedures are derived from CBT: <ul style="list-style-type: none"> <li>Working on the traumatic event based on the social processing theory of adjustment to traumatic events which consists of exposing the parent to the stressor (Creamer et al., 1992)</li> <li>Relaxation training</li> <li>Improving problem-oriented coping</li> <li>Problem-solving training</li> <li>Promoting the communication of emotions</li> <li>Empowerment through learning</li> </ul> Primary outcome: Post-traumatic stress symptom (IES)	72%	60% 93%

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied		
						Acceptability	Feasibility	Fidelity to manual
Brief Psychological Intervention on Quality of Life for Parents of Children with Cancer (BPIQOL)	Safarabadi et al. (2016)	Parents	The quality of life of parents who are confronted with their child's cancer is impaired. They face economic difficulties, higher levels of family conflict, and a sense of burden related to the cancer situation. An impaired quality of life leads to higher risks of psychosocial issues such as depression, anxiety, and PTSD	To improve parents' quality of life by informing them about the disease through thought control, by providing them with social support, and improving their coping skills (emotion-focused coping)	Ten sessions (five 60- to 90-min sessions face-to-face and five 30- to 45-min sessions over the phone) Delivered by a social worker One procedure is derived from counseling: <ul style="list-style-type: none"> <li>• Providing information about the disease and treatment to reduce the emotional difficulties associated with uncertainty</li> </ul> Procedures derived from CBT: <ul style="list-style-type: none"> <li>• Cognitive restructuring</li> <li>• Providing support (attentive listening)</li> <li>• Empathy-based coping by learning stress management techniques</li> <li>• Training in self-care</li> <li>• Prescription of homework</li> </ul> Primary outcome: quality of life (CQOLC)	N/A	97%	N/A

Table 1 (continued)

Program name	References	Participants	Theoretical models explaining difficulties experienced by parents	Models of change	Concrete intervention techniques implemented	Criteria studied	
						Acceptability	Fidelity to manual
Brief Problem Solving Intervention for Parents of Children with Cancer (BPSI)	Lamanna, Bitsko, and Stern (2017)	Parents	The cancer diagnosis causes symptoms of stress (intrusive thoughts, avoidance) that affect parents' problem-solving abilities. Parents have difficulties with problem solving when they have to make important decisions (regarding treatments, etc.) and are overwhelmed (taking care of their other children, managing the financial aspects of the disease, etc.)	To learn concrete problem-solving skills to develop problem-focused coping	Two 60-min sessions Delivered by a psychologist The procedure is derived from CBT Five-step problem-solving approach: identify problems, define solution options, evaluate these options, carry out the solution, and see if it is effective (Nezu et al., 2013) Primary outcome: Post-traumatic stress symptom (IES-R)	Evaluated > 80%	76% 91%

AYA adolescent and young adults, *HSCT* hematopoietic stem cell transplantation

(PBII) (Fedele et al., 2013; Mullins et al., 2012) is an adaptation of an intervention program aiming to decrease uncertainty among parents of children with a chronic illness (Hoff et al., 2005), initially developed for patients with diabetes. HERO+ (Santacroce et al., 2010) is an adaptation of the HEROS program (Mishel, 1988) and consists of health education sessions aimed at reducing anxiety related to uncertainty. Parent Social Cognitive Processing Intervention Program (P-SCIP) (Manne et al., 2016) is an adaptation of the Social Processing Theory of Adjustment to Traumatic Events (Creamer, Burgess, & Pattison, 1992) which proposes to cope with the traumatic event following five steps (exposure, creation of a network, work on intrusion, avoidance, and implementation of the result). Finally, the brief problem-solving intervention for parents of children with cancer (BPSI) (Lamanna et al. 2017) is a program consisting of two problem-solving training sessions (Nezu et al., 2013) and an adaptation of Bright IDEAS.

## Theories on Program Development

### Primary Outcomes

We identified four different primary outcomes: PTS (in SCCIP, SCCIP-ND, IBG, P-SCIP, BPSI); emotional distress (in IPPPC, Bright IDEAS, PBII); quality of life (in CASCADE, BPIQOL); and uncertainty (in HERO+). These outcomes address the leading psychosocial needs in oncology that have been highlighted by studies on parental distress in pediatric oncology (Ljungman et al., 2014). Firstly, studies showed that PTS is associated with a sudden diagnosis (Patino-Fernandez et al., 2008). Second, studies have shown that nearly 30% of parents suffer from psychological distress 5 years after diagnosis (Maurice-Stam et al., 2008; Vrijmoet-Wiersma et al., 2008). Third, the broad domain of quality of life is mainly assessed in the clinical field and in many studies in pediatric oncology (Safarabadi et al., 2016; Wakefield et al., 2015). Indeed, adaptation difficulties to the oncological situation associated with an alteration of the family's quality of life and an overflow in the management of daily living are related to a significant sense of loss of control among parents whose child suffers from cancer (Varni et al., 1999). Fourth, uncertainty represents a large part of the difficulties experienced by parents during and after treatment (Hoff et al., 2005). Indeed, cancer recovery is not guaranteed as it involves regular medical monitoring, which is extremely stressful for parents.

### Theoretical Models Explaining Difficulties Experienced by Parents

Programs do not target the same outcomes. Therefore, depending on the outcome that was targeted by the program, the underlying models were logically different from

one another. However, some programs that use the same outcome, each offered different explanatory theories. Concerning PTS, some authors indicated that it was mainly produced by an emotional and cognitive overflow following diagnosis. According to two reports, life changes and treatment demands could create a burden, and this burden could be associated with feelings of loss of control, stress, anxiety, and distress (Manne et al., 2016; Mullins et al., 2012). Other authors described how PTS could also be caused by persistent anxiety and beliefs about the disease and treatments that affected the family over the long term (Kazak et al., 2005; Kazak et al., 1999). Findings from another study suggested that PTS could reduce parents' natural ability to recover from a traumatic experience and that this ability could be improved through appropriate treatment (Cernvall et al., 2015). Another study found that PTS could also be explained by parents' struggle in making difficult decisions in the context of their child's illness (e.g., treatment options) and by significant logistical and psychosocial overload (e.g., complex child care, oncological treatments' side effects, financial aspects) (Lamanna et al., 2017).

Authors whose research emphasized on emotional distress as a primary outcome modelled distress in different ways. Some of them defined distress as being produced by the feelings of uncertainty and loneliness experienced as a result of the diagnosis (Hoekstra-Weebers et al., 1998). Others described distress as the feelings of the burden and overload that parents endured as a result of the cancer diagnosis. These feelings were explained in five different ways: (1) critical changes in parents' role regarding their child's medical care (managing the child's distress, monitoring side effects), (2) parents' sudden socio-professional changes (having to stop working or to work part-time, etc.), (3) tensions experienced in parents' relationship as a couple, (4) parents' feeling that they were abandoning their other child or children, as well as (5) the adaptive difficulties related to the amount of information parents had to deal with and communication difficulties with professionals (Mullins et al., 2012; Sahler et al., 2002). As for changes in parents' quality of life, many articles provided similar explanations to the ones given previously. One author explained that parents' deteriorating quality of life was a consequence of two things: (1) a lack of information regarding their child's illness and treatment following diagnosis, and (2) the general burden brought about by their child's illness (economic difficulties, difficulties related to the child's care) (Safarabadi et al., 2016). Other authors emphasized that changes in parents' quality of life could be a consequence of isolation, loneliness, lack of information, and fear of recurrence (Wakefield et al., 2015).

According to one program, parental uncertainty is a consequence of the limited information received about the disease and its treatments (Santacroce et al., 2010). This



problem is also associated with a lack of communication between parents and medical providers. These authors also described parental uncertainty as a direct consequence of cancer diagnosis and as being associated with the fear of potential health complications. Santacroce et al. (2010) also found that uncertainty could cause psychosocial disorders such as PTSD, depression, and anxiety in both parents and children.

In summary, many authors developed different explanatory models for parents' psychological distress, such as emotional overload, loss of control, erroneous beliefs, parents' inability to adapt to the new situation, and feelings of uncertainty, loneliness and burden. By comparing these outcomes and authors' explanations with standards for psychosocial care of children and their parents in oncology (Czajkowski et al., 2015; Wiener, et al., 2015), a number of studies appeared to formulate plausible change mechanisms. Notably, three different outcomes (PTSD, distress, and impaired quality of life) were explained by the same theory, which could reveal a lack of accuracy in the programs' outcome definition (Manne et al., 2016; Mullins et al., 2012; Safarabadi et al., 2016; Sahler et al., 2002).

### Models of Change

Identified programs' models of change were based on cognitive and behavioral learning models, systems theory, and counselling.

All 11 identified programs claimed to be based on models of change from cognitive and behavioral theories. The programs sought to modify selected difficulties through several known psychological mechanisms. Ten programs highlighted the development of better thoughts control. This model of change aimed to reduce automatic negative thoughts, false beliefs, and uncertainty. It also aimed to alter traumatic memories' cognitive aspects (IPPPC, SCCIP, SCCIP-ND, Bright IDEAS, HERO+, IBG, P-SCIP, BPIQOL). The reduction of negative thoughts aimed to allow parents to regain some control over their child's care (PBII) or to help them realize that it is sometimes impossible to control medical situations (CASCADE). Seven programs implemented communication training. It aimed to promote better interactions with medical professionals (IPPPC, HERO+, PBII) as well as between parents and within the family (SCCIP, SCCIP-ND, P-SCIP, CASCADE). According to these authors, effective communication could improve parents' and families' adjustment to the oncological context, limit feelings of loneliness and isolation, and prevent avoidance, a main symptom of PTSD. Seven programs promoted Problem-focused coping such as problem solving. Problem-solving techniques aimed to improve parents' adjustment to their child's illness (IPPPC, P-SCIP, CASCADE) and favor a decrease of PTSD (BPSI), uncertainty (HERO+, PBII), and

the experience of the burden generated by the disease and treatments (Bright IDEAS). Encouraging emotion-focused coping, such as relaxation, was suggested in four programs (HERO+, IBG, P-SCIP, BPIQOL). Learning techniques promoting optimal emotion management aimed to foster parents' adaptive abilities as well as help them accept uncertainty and the challenging medical situation over which they have no control. Finally, one program mentioned the search for meaning (P-SCIP). By asking questions about the traumatic event and expanding its meaning, this model of change aimed to foster traumatic growth in parents, which in turn could improve their adjustment to their child's cancer and decrease their emotional distress.

Two programs used a combination of CBT components and systemic models (SCCIP, SCCIP-ND). On the one hand, these programs aimed to offer families the opportunity to talk about their experience with the illness, creating a sense of shared experience which contributed to decreasing parents' loneliness. This decrease in turn facilitated parents' ability to cope with their emotions. On the other hand, these programs also aimed to encourage families to work together (teamwork) to find effective solutions for the issues they were facing.

All programs included either information transmission or advice for parents. Some reports mentioned using formal procedures to educate or counsel parents (IPPPC, PBII, IBG, HGERO+, CASCADE, BPIQOL). This model aimed to minimize misinformation and misunderstanding amongst parents, thus decreasing parents' dramatization and emotional overload. This model allows parents to better understand important components when receiving an abundance of information.

The principles mentioned above, which are based on either cognitive, behavioral, or systemic theory, have found support in prior research, including in the reduction of negative thought (Hall, Kellett, Berrios, Bains, & Scott, 2016), in communication and assertiveness training (Brady, Kangas, & McGill, 2017), in emotion-focused and problem-oriented coping skills training (Nezu et al., 2013), as well as in the search for meaning and/or promotion of optimal communication within the family (Kazak, Rourke, & Crump, 2003). Topics of information transmission that were essential in these programs were not systematically described in all programs.

### Concrete Intervention Techniques Implemented

In this part of the review, we describe how the aforementioned models of change were translated into specific actions. Actions appeared to pertain to three broad traditions, i.e., CBT, systemic therapy, and counselling.

Six/eleven programs were based on individual programs (Bright IDEAS, PBII, IBG, BPIQOL, P-SCIP, BPSI). Two

programs were either specifically designed for mothers or primarily concerned mothers (Bright IDEAS, PBII). Only five programs used a couple or family-based approach (IPPPC, SCCIP, SCCIP-ND, HERO+, CASCADE). Most programs consisted of face-to-face sessions (IPPPC, SCCIP, SCCIP-ND, Bright IDEAS, HERO+, P-SCIP, BPSI). However, five programs were offered electronically and/or by phone: e-version of Bright IDEAS, IBG, CASCADE, PBII, BPIQOL. Sessions number varied with a median of seven meetings (min–max = 2–12), and a median session duration of 60 min for in-person sessions, 120 min for electronic sessions, and 30 min for phone interviews. Except for two studies which used multidisciplinary intervention programs involving nurses and/or social workers (PBII, BPIQOL), every provider was either a psychologist or a social worker.

### CBT Intervention Techniques

All programs used cognitive restructuring interventions as a means to help parents gain control over their beliefs. These programs suggested identifying and reducing automatic negative thoughts (IPPPC, Bright IDEAS, IBG, P-SCIP, BPIQOL, BPSI), false beliefs (SCCIP, SCCIP-ND), concerns, and uncertainty (HERO+, PBII, CASCADE).

Most intervention programs aimed to improve social skills ( $n=5$ ), problem-solving skills ( $n=6$ ), and emotion-focused coping ( $n=4$ ). Communication and assertiveness training was provided to enable effective communication between parents and with the healthcare team (IPPPC, HERO+, PBII, CASCADE, P-SCIP). Problem-solving training aimed to help parents cope with decisions, conflicts, and issues resulting from their child's illness. Problem-solving training can encourage parents to become more aware of the issues related to the illness and its treatment as well as to help them find solutions that could effectively decrease their distress (Bright IDEAS, HERO+, PBII, CASCADE, P-SCIP, BPSI) (Nezu et al., 2013). Procedures related to emotion-focused coping included relaxation training (HERO+, IBG, P-SCIP), positive thinking, (i.e., developing one's optimism) (BPIQOL), mindfulness, and acceptance (IBG).

The P-SCIP program is guided by the cognitive-social processing theory of adjustment to traumatic events (Creamer, Burgess, & Pattison, 1992). This procedure is designed to yield a re-evaluation of the traumatic event and a search for meaning. It is thought to promote parents' traumatic growth so that a reinterpretation of the impact of cancer can occur.

Task prescription was also commonly used across programs ( $n=5$ ; Bright IDEAS, PBII, IBG, P-SCIP, BPIQOL). This is a standard approach in CBT and other therapies to practice learned techniques and empower participants in their everyday lives.

### Systemic Intervention Techniques

Although less common, two programs made use of the "Multiple family discussion groups" (Ostroff & Steinglass, 1996) and the "Family oriented approach" (Kazak & Simms, 1996). These programs aim to encourage communication among family members concerning their difficulties. These procedures allow families to regulate their emotions, normalize traumatic distress through identification, and provide effective social support. In addition, it offers the family an opportunity to work together as a team to find practical solutions. It also decreases individual distress by reinforcing couple-level resources.

### Counselling Intervention Techniques

Most programs incorporated formal counselling techniques at either individual or group meetings during which information was provided (six programs; IPPPC, HERO+, PBII, IBG, CASCADE, BPIQOL). These techniques aim to improve family members' knowledge of the disease and related procedures. The idea underlying these techniques is that providing information to parents helps them feel more in control of the situation and reduces both their uncertainty and their misconceptions, therefore, limiting their distress.

In summary, the proposed techniques were very consistent with the underlying models of change. Importantly, the techniques used appear to be evidence based (Brady et al., 2017; Stewart & Chambless, 2009). Notably, all program structures called for a sequential approach as per the one used in CBT: (1) evaluation, (2) awareness, (3) intervention (e.g., thought control, training), and (4) tasks prescription (Young, Klosko, & Weishaar, 2005). In contrast, some programs called for a set of unrelated procedures (IPPPC, PBII, CASCADE, IBG, BPIQOL). For instance, PBII uses a succession of procedures that have little connection with one another (problem-solving training, cognitive restructuring, effective communication training, and social support) to improve the same outcome. As for educational and counselling actions, they appeared insufficiently formalized, especially in well-known evidence-based programs (SCCIP, SCCIP-ND, Bright IDEAS, P-SCIP). However, this finding does not mean that these programs do not provide information and/or counselling. This finding only suggests that these programs are not as systematized as other programs (IPPPC, HERO+, PBII, IBG, CASCADE, BPIQOL).

### Program Implementation

Some programs identified in this review documented the steps taken in their development, refinement, and

implementation. We focused on typical implementation outcomes usually documented in early evaluation trials (e.g. pilot studies), i.e. acceptability, feasibility, and treatment fidelity.

### Development and Refinement

Intervention programs' relevant constructs were explicitly defined. Nine programs also provided detailed information with regards to their development procedures. In two cases, the authors gave details on the different team members who worked on the project development, preparatory meetings, and time spent in group meetings (Kazak et al., 2005; Kazak et al., 1999). A careful elaboration of the programs targets and methodology enhances the credibility of these programs. Five programs (Bright IDEAS, PBII, IBG, CASCADE, P-SCIP) called for workshops with healthcare professionals to help define and refine these programs. Finally, the HERO+ and BPSI programs were based on existing programs (Mishel, 1988; Sahler et al., 2002). Unfortunately, we could not find any details on refinement procedures for two programs (IPPPC, BPIQOL).

### Implementation Outcomes

In preliminary evaluation phases, one could expect a report of programs' acceptability, feasibility, and treatment fidelity. As shown in Table 1, 8/11 programs (73%; SCCIP, SCCIP-ND, Bright IDEAS, PBII, IBG, CASCADE, P-SCIP, BPSI) assessed programs' acceptability. They showed very good acceptability, with a rough estimated average score of 80%. Note that since a variety of measures were used (with many home-made questionnaires), figures can only be estimated. However, we could not locate any acceptability or social validity information for 3/11 programs (IPPPC, HERO+, BPIQOL).

Regarding these programs' cultural diversity, only 1/11 program, BPIQOL, was developed outside the Western culture, more specifically in Iran. Among these 10/11 programs, only four were developed from outside the United States or adapted in another language. IBG and CASCADE were developed in Sweden and Australia, respectively (Cernvall et al., 2015; Wakefield et al., 2015). Bright IDEAS and P-SCIP, originally developed in English for the United States, were also adapted in Spanish (Manne et al., 2016; Sahler et al., 2013).

Treatment fidelity was documented for 7/11 programs (64%) (SCCIP, SCCIP-ND, Bright IDEAS, PBII, CASCADE, P-SCIP, BPSI). In these cases, fidelity estimates were either very good or excellent, 87–96%. Some programs did not document fidelity which raises concerns about their reproducibility and attribution of possible effects, as no data

suggest that the programs were administered as defined (IPPPC, HERO+, IBG, BPIQOL).

Every report provided data on the programs' feasibility. Authors reported widely different penetration rates (Mdn = 40%, range 7–69%). In most cases, retention was high (Mdn = 70%, range 60–100%). However, the retention rate was defined heterogeneously across programs. For instance, a minimum attendance of 75% was considered necessary for Bright IDEAS, whereas this proportion was down to 50% in the PBII. Several authors reported similar reasons for their programs' relatively high attrition rates: parents' lack of time, the burden associated with the program, a lack of interest, and the child's death. Overall, penetration and retention rates were optimal for four programs (rate > 88%) (SCCIP, SCCIP-ND, IBG, BPIQOL).

## Discussion

In this systematic review, we identified 11 manualized intervention programs designed to support parents whose child suffers from cancer. When describing the different development steps required to define these programs, we found that most of them appeared to be soundly developed with a high coherence between theories, outcomes, models of change, and component actions. Yet, this critical analysis revealed a limitation in these intervention programs' definition and implementation. A lack of cultural adaptation and discrepancies between the theory used to understand the primary and mediating outcomes, models of change, and therapeutic actions choices were noted for some programs. We also observed problems with their implementation, as some authors did not examine programs' acceptability, social validity, and feasibility.

### Program Design

There are a fair number of manualized programs to help parents in pediatric oncology especially when considering the low frequency of child cancer (11 programs, nine independent teams). With regard to the definition of these interventions' design, some limitations were observed and warrant discussion.

A first limitation is related to the target audience. Except for a few articles (Manne et al., 2016; Sahler et al., 2013), it was not clear whether the programs' structure or tools had been adapted for culturally diverse parents. The vast majority of programs were developed in a Western culture (10/11), and only Bright IDEAS (Sahler et al., 2013) and P-SCIP (Manne et al., 2016) were adapted in an additional language (Spanish). Only three programs were developed outside of the United States, i.e., IBG, CASCADE and BPIQOL, which were developed in Sweden, Australia, and Iran, respectively

(Cernvall et al., 2015; Safarabadi et al., 2016; Wakefield et al., 2015). As the emotional and practical difficulties encountered in pediatric oncology may be associated with cultural and geographic contexts (Gray, Szulczewski, Regan, Williams, & Pai, 2014; Klassen et al., 2012), then programs developed in some cultures might not be easily transposed to others.

Second, we observed limitations with program targets. In most cases, results suggested that intervention outcomes were selected by researchers according to parents' psychosocial needs (Ljungman et al., 2014). However, while most programs' outcomes were defined in detail, e.g., CASCADE and BPIQOL, a few outcomes lacked specificity (Wakefield et al., 2015; Safarabadi et al., 2016). In the latter cases, the outcomes were so broadly defined that their underlying theory and model of change were probably challenging to formulate. In addition, it is noteworthy that three conceptually distinct outcomes, such as post-traumatic stress, distress, and quality of life, were explained by essentially identical theories (overload and burden) (Lamanna et al., 2017; Mullins et al., 2012; Safarabadi et al., 2016; Sahler et al., 2002; Wakefield et al., 2015). It is possible that some outcomes were too widely defined (e.g., quality of life). In this situation, models assessing quality of life have called for an extremely wide array of factors, related to this outcome's complex definition. Quality of life combines physical (e.g., symptom of the disease), psychological (e.g., anxiety, depression), and relational components (Fallowfield, 2002). Research in this field would most likely benefit from an enhanced specificity. Notably, a lack of specificity in the choice of outcomes and models of change may lead to less-specific actions. Such is the case with the BPIQOL, which identifies five different actions of the CBT.

Third, we also noted limitations associated with the programs' versatility. For example, authors used cognitive restructuring as a primary tool to impact PTS, distress, and quality of life alike (Hoekstra-Weebers et al., 1998; Lamanna et al., 2017; Safarabadi et al., 2016). The current state of the evidence ranks cognitive restructuring as a recommended technique for stress management, but not for illness acceptance and its consequences (Norcross & Wampold, 2011).

Moreover, this also contrasts with experts' recommendation to select relevant proximal outcomes for participants in psychological treatments (Kazdin, 2009). This is of paramount importance, as targeting a specific outcome is associated with more consistent underlying theories of the difficulties and more consistent program development (Kazdin, 2007). Importantly, our results suggest that mediating outcomes were selected appropriately to reach the intended targets. For instance, in Bright IDEAS, using problem-solving training was found to reduce parental stress (Nezu et al., 2013). A number of studies included process variables (mediators) in their model and evaluation strategies. This

was the case for problem-solving (Lamanna et al., 2017; Manne et al., 2016; Mullins et al., 2012; Sahler et al., 2002; Santacroce et al., 2010; Wakefield et al., 2016), communication quality (Hoekstra-Weebers et al., 1998; Manne et al., 2016; Mullins et al., 2012; Santacroce et al., 2010; Wakefield et al., 2015), and family dynamics (Kazak et al., 1999; Manne et al., 2016; Sahler et al., 2002) that were conceptualized as process factors that explain changes in individuals' emotional issues.

The models of change used by these authors were otherwise all based on operating hypotheses that had previously received empirical support in the fields of CBT, systemic therapy, and counselling. An in-depth examination of concrete actions revealed that one program (P-SCIP) used training strategies with individuals to improve communication in couples, thus intervening with parents on an individual basis (Manne et al., 2016). The individual approach probably reflects the difficulty associated with recruiting both parents. Yet, previous experiences suggest that couple communication training is far more effective when delivered to the couple (Martire, Schulz, Helgeson, Small, & Saghafi, 2010).

False beliefs and lack of information have a significant role in parental distress (Dimatteo, 2004; Spinetta et al., 2002). Consistent with this observation, all programs included a counselling dimension. Yet, less than half of the 11 programs clearly reported what was being done to inform and/or counsel parents. This may be surprising, as the information is readily available, and its dissemination is probably easy to systematize (Canadian Cancer Society, s.d.).

Finally, a fourth limitation concern the way in which some programs' procedures were combined. In contrast to most programs which are sequentially and logically structured, some called for a variety of apparently unrelated procedures suggesting a piecemeal approach (Hoekstra-Weebers et al., 1998; Mullins et al., 2012; Wakefield et al., 2015). For example, Cascade included social support, cognitive restructuring, and problem-solving; however, the article on this program did not specify how these actions were to be carried out. Although integrative psychological treatments advocate for blending different approaches, such diversity within one unique program may hamper participants' cognitive focus and mental coherence. At the very least, the diversity would require some very strong articulation between components (Czajkowski et al., 2015). We could also imagine that it would be far more complex to train providers (Curry, 2014; Herschell, Kolko, Baumann, & Davis, 2010). It should be noted that the NCI (s.d.) recommends programs that are both specific and concise (Bright IDEAS, SCCIP-ND).

The findings concerning the concrete actions suggested by the programs revealed another aspect. Many programs included a variety of actions that led to an intense intervention (e.g., relaxation, mindfulness, and acceptance). Beyond a variety of means—which inevitably limits transferability

in real-world settings—this approach may also yield interpretation difficulties when one wishes to attribute the overall effect to an action (Cernvall et al., 2015; Mullins et al., 2012; Safarabadi et al., 2016). In this case, it would be impossible to attribute positive effects on distress to either relaxation, mindfulness, or the interaction between them.

## Implementation Outcomes

In addition to these programs' definition aspects, it is also useful to evaluate their implementation in the context of developing new intervention programs. Following this principle, the identified intervention programs were assessed in preliminary studies to examine their potential for implementation. These studies are essential because they assess the clinical interest of transferring the programs studied from the laboratory to the clinical settings, as in biomedical studies. According to the ORBIT model, implementation assessment is translated into preliminary tests which assess programs' feasibility, acceptability, and fidelity (Czajkowski et al., 2015). This review's results show that feasibility was examined in every program; however, acceptability and fidelity were not.

Concerning feasibility, results show that only 2/11 programs reported significant difficulties in participation (Manne et al., 2016; Sahler et al., 2002). To overcome this limitation, the intervention was considered completed if users participated in at least half of the sessions. It was difficult to find a rationale for these proportions in these reports. It is likely that the strict research methodology may have reduced study participation rates. Results suggest that preliminary acceptability tests were not conducted for four programs (IPPPC, HERO+, BPIQOL, BPSI), even though this is particularly important for endorsement by participants and ultimately retention rates. These four programs were evaluated by Randomized Control Trials (RCTs) at a very early stage. However, recommendations for intervention program development include preliminary testing to avoid costly RCTs that do not yield conclusive results (Lancaster, 2015). Acceptability and feasibility tests are typically designed to assess whether clinical implications and study protocols are consistent and acceptable to users. Based on the authors' findings, modifications may have to be considered for future RCTs.

Results also show a lack of treatment fidelity testing in four programs (IPPPC, HERO+, IBG, BPIQOL) despite the widespread recognition that treatment fidelity is essential to link the clinical signal to specific intervention content. Treatment fidelity is also a pillar for future reproducibility and homogeneous provider training. The lack of fidelity studies is problematic because, despite significant results on effects, there is no guarantee that the program was applied in the same way for all participants. The need

for fidelity studies is justified by the NCI's studies and recommendations (NCI, s.d.). Recommendations for treatment fidelity are intended to link theory and application in five areas: study design, training providers, treatment delivery, receipt of treatment, and treatment skills enactment (Bellg et al., 2004).

Finally, efficacy studies highlight the importance of preliminary design phases. Programs that rarely reported these preliminary development or evaluation phases (e.g., acceptability studies) were also those for which the reported effects were minimal: IPPPC, Cascade, and BPSI (Hoekstra-Weebers et al., 1998; Lamanna et al., 2017; Wakefield et al., 2015) (Results of effectiveness studies are available in Table S2).

## Future Directions

Results lead to several recommendations for future supportive program development and research in pediatric oncology. (1) Given the relatively large number of existing programs for a rare disease like pediatric cancer, future programs' development should consider existent components whose implementation and effects have already been documented. For instance, authors of the SCCIP-ND created their program by adapting an existing program to a new population (Kazak et al., 1999, 2005). These new programs or adapted versions should follow initial development phases such as redesign or pilot-testing, especially as acceptability and other implementation outcomes may differ with the adapted version of the program (Czajkowski et al., 2015). (2) At the very least, implementation outcomes for acceptability, feasibility, and fidelity should be documented to support further use or development. In case of need for improvement, we would expect a refinement phase refinement to occur. As in other domains, it may be optimal to include parent partners in the research team to optimize implementation quality (Amirav, Vandall-Walker, Rasiah, & Saunders, 2017). (3) The theory and model of change underlying the program should be as explicit as possible. Why was a specific outcome selected? How do the researchers think the program will impact the outcome? As not all the reviewed research reports have provided sufficient and organized information on outcomes, we urge researchers and editors evaluating intervention papers in this field to include a "model of change" paragraph in submitted manuscripts. (4) Finally, although many authors have included cultural diversity among the issues to be addressed, this research domain still lacks cross-cultural adaptations. For example, we found no manualized program available in Arabic, Chinese, French, German or Indian,

## Limitations

We must acknowledge some limitations of this review. First, it was surprisingly difficult to access complementary material, such as manuals, despite our efforts to contact the authors. It is thus possible that other existing documents or grey literature could complement the present review. Second, when searching for critical tools with regards to the program development, we realized that very few were available, and thus we had to rely on guidelines from other fields in health research (APA, 2006; Czajkowski et al., 2015). Finally, this review was limited to the available text in each intervention programs. It is possible that many programs had gone through certain stages of development without being reported in the publicly available literature.

## Conclusion

This systematic review identified 11 manualized intervention programs designed to support parents of children with cancer. Most models include a sound theoretical framework, targeted outcomes, and strategies of implementation. However, findings show that programs' development phases are often not sufficiently detailed. For instance, the programs' description tends to apply only to a limited range of cultures and their implementation phase, in which feasibility and treatment fidelity are described, is rarely sufficiently documented. To improve help for families, further developments of manualized intervention programs should probably combine existing programs and components for which evidence is stronger. They could also focus on expanding how existing components and programs can be applied to other cultures or develop new ways to address parental distress in cultures where no components are available. From a methodological viewpoint, it would be very beneficial for intervention developers to follow standard steps and provide clearer information on initial development steps, as this type of information is necessary for both research reproducibility and clinical dissemination. Ultimately, this development research process should ensure better support for parents dealing with a child's cancer.

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## Compliance with Ethical Standards

**Conflict of interest** David Ogez, Katherine Péloquin, Laurence Bertout, Claude-Julie Bourque, Daniel Curnier, Simon Drouin, Caroline Laverdière, Valérie Marcil, Rebeca Ribeiro, Melissa Callaci, Emélie Rondeau, Daniel Sinnett, and Serge Sultan declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human participants or animals performed by any of the authors.

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