

Anticipatory Guidance and Psychoeducation as a Standard of Care in Pediatric Oncology

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The aim of this review was to critically evaluate the literature on anticipatory guidance and psychoeducation for youth with cancer and their caregivers. Twenty-one publications were identified. Overall, psychoeducation efforts and interventions were well-liked and accepted by patients and caregivers, improved patient and family knowledge about childhood cancer, and increased patient's health

locus of control. A number of modalities are effective in giving families anticipatory guidance, provided the content and delivery are matched to the needs and preferences of individual patients and caregivers. Evidence supports a strong recommendation for psychoeducation for youth with cancer and their families. *Pediatr Blood Cancer* 2015;62:S684–S693. © 2015 Wiley Periodicals, Inc.

Key words: anticipatory guidance; childhood cancer; psychoeducation; psychosocial

INTRODUCTION

When a child or adolescent is diagnosed with cancer, patients, parents, and other family members are challenged to learn about evolving diagnostic data, treatment and treatment-related side effects, prolonged hospitalizations, tests and procedures, navigating the hospital system, and overall uncertainty about prognosis and outcome.[1] Because the unfamiliar nature of the hospital can be distressing,[2] providing patients and families with anticipatory guidance, information, or psychoeducation about what to expect at points along the disease trajectory (e.g., diagnosis, throughout treatment, during survivorship, at end-of-life) is believed to be an important aspect of care.[3–5] It has been argued that educating children and their parents about the diagnosis and treatment plan helps to reduce uncertainty and decrease associated distress,[6] establish trust with health care providers, and enhance adjustment to illness.[7,8]

Although it was standard practice in the 1960s to withhold information about disease and treatment from children with cancer, it is now widely accepted that patients should be offered a developmentally appropriate education about their disease in a timely fashion, as this understanding contributes to better psychological outcomes.[7–10] Evidence supports that children and adolescents want more information about their bodies, their illnesses, and their treatment.[11,12] and that without such information, they may form beliefs and attitudes that are inaccurate, provoke fear and anxiety, and/or adversely affect compliance.[7,13] Alternatively, children who know more about their illness may feel more in control of their health overall, which can lead to reduced distress and better outcomes.[7,14,15]

Although clinicians agree that providing guidance to and educating patients and families is important, pediatric patients and caregivers continue to report unmet informational needs along the cancer trajectory, i.e., from diagnosis,[16,17] through to end of treatment,[18–20] and into survivorship[21,22] or end-of-life.[23] Retrospectively, caregivers and pediatric patients indicate that they needed additional guidance and information regarding illness and treatment; treatment decisions; side effects; late effects; tests and procedures; fertility; diet/nutrition; caring for their child; physical and emotional impact; available services and resources for support; appropriate follow-up care; and impact on the family.[1–22,24–26] As such, a standard of care for providing guidance and education to patients with cancer and their families is overdue.

Psychosocial Standard of Care

Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.

The scope of this work is focused on youth ages 0–18 diagnosed with any malignancy and their caregivers and includes both anticipatory guidance and psychoeducation. Anticipatory guidance, a longstanding practice in general pediatrics literature,[27–30] is a proactive, developmentally based education approach that prepares parents for what they should expect in the coming months and years and focuses on the needs of a child at each developmental stage. Psychoeducation is a related concept, used in the context of chronic illnesses to refer to the process of providing information to patients and/or family members in order to empower them, assist with day-to-day management of the disease and decision-making, relieve uncertainty, and enhance psychosocial adaptation to the illness.[31] Guidance and psychoeducation can take many forms, including formal or informal, individual, dyadic, or group models where a

Abbreviations: QoL, quality-of-life; RCT, randomized control trial

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provider gives information to the patient and/or family members via verbal instructions/consultation, written/printed materials, or computer-mediated methods such as video, computer programs, video games, the Internet, and tutorial CD-ROMS.[32]

METHODS

To develop this standard, we used methods described by Wiener et al.[33] in this special issue for the Standards for Psychosocial Care of Children with Cancer and Their Families project. Computerized literature searches of PubMed, PsychInfo, and CINHALL were performed. Search inclusion criteria included English-language literature published from March 1, 1995 to March 1, 2015 in peer-reviewed journals with participants aged 0–18 years and with a history of any malignancy. Exclusion criteria included non-cancer diagnoses, patients over age 18, foreign language publications, and literature that was not empirical research. Specific search terms included “psychoeducation,” “anticipatory guidance,” “information intervention,” “didactic intervention,” “patient education (as topic)” OR “family education” AND cancer-related terms AND “Child” OR “Adolescent” OR “Pediatric” OR “Pediatric” OR “Youth” OR “Children” (using indexed MeSH terms). Results of database searches were supplemented with hand-searching of the reference lists of all included studies. Searches revealed a total of 1,168 citations. Authors followed PRISMA guidelines for systematic reviews[34] and excluded 1,147 articles for the following reasons: 1)

duplicate articles, 2) articles not related to childhood cancer, 3) articles not about patients or parents of patients age 0–18, and 4) articles not related to the topic of anticipatory guidance/psychoeducation. Articles were restricted to informational interventions, excluding skills-based interventions (i.e., cognitive-behavioral), except in cases where informational interventions were included with skills-based interventions and study designs precluded teasing apart unique effects of intervention components. Articles specific to siblings and to providing procedural support were excluded, as they are more relevant to and are covered in separate standards.[35,36] Finally, articles describing education about research were excluded. These exclusions left 21 articles for inclusion in the synthesis of evidence.

External reviews were conducted by representatives of child life and nursing education, as well as physicians, several parents of children with cancer and childhood cancer survivors. Revisions were made according to feedback received from these reviewers. No members of the study team had any conflicts of interest with the development of this standard.

RESULTS

The search strategy identified 21 peer-reviewed articles, including four systematic reviews, one meta-analysis, and three randomized controlled trials (RCTs). A summary of the evidence is provided in Table I. Supplemental Table I briefly summarizes each

TABLE I. Anticipatory Guidance and Psychoeducation Standard Summary of Evidence Table

Standard	Evidence summary ¹	Methodology ²	Quality of evidence ³	Strength of recommendation ⁴
Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.	<p>Patients and caregivers report unmet informational needs along the cancer trajectory. Psychoeducation appears to have the most consistent effects on improving patient/caregiver knowledge about disease and treatment and on increasing health locus of control. A number of modalities are effective in providing families anticipatory guidance, provided the content and delivery is matched to the needs and preferences of the particular patient and caregiver.</p> <p>Existing studies had methodological and conceptual weaknesses, including lack of an organizational model, lack of support for the ideal type of education, and inconsistent assessment of health-related or psychological outcomes.</p>	<p>Systematic reviews, RCTS, Pre/post-test designs, and individual qualitative and quantitative studies. Consistent findings evident, although literature is quite scattered.</p>	<p>Moderate quality given consistent findings from moderate-level evidence studies.</p>	<p>Strong recommendation given risk-benefit ratio (i.e., minimal risk to patients and caregivers and potential benefits of meeting unmet informational needs, improving disease-related knowledge, and increasing health locus of control).</p>

¹Based on summary of evidence table for that standard. ²Types of studies: e.g., RCT, cross-sectional, longitudinal; consensus; systematic review articles. ³Quality of evidence: high, moderate, low, and very low. ⁴Strength of recommendation: strong or weak (based on GRADE quality criteria).

of the 21 studies with regard to study design, sample characteristics, main findings related to this standard, study rigor, and level of evidence.[37] In general, multiple reports support psychoeducation efforts as helpful to, well accepted, and appreciated by patient and family stakeholders.[38–44]

Five articles, including one systematic review and two RCTs, indicated that psychoeducational interventions improve patient and caregiver knowledge about disease and treatment.[45–49] Bradlyn et al.[45] concluded that acquisition of health-related knowledge in children is best facilitated by modalities that are highly interactive and individualized. In a large, multi-site RCT of adolescents and young adults with cancer, a psychoeducational video game improved cancer knowledge and was found to be an effective method of delivery for disease education.[48,49] A small intervention study reported that parents participating in a four session intervention demonstrated better cancer knowledge compared to waitlist controls,[47] and an evaluation of a survivorship education program reported that adolescent and young adult survivors and their caregivers perceived an increase in knowledge of survivorship topics and resources after program attendance.[46]

Three articles found that psychoeducation increased patient's health locus of control.[38,39,42] Children with leukemia,[38] and solid tumors[42] randomized to receive an interactive CD-ROM about disease and treatment showed increased feelings of control over their health, compared to children who received written materials. Data on other health-related outcomes were less consistent, with some studies reporting improvements in outcomes like anxiety,[2,8] depression,[2] pain,[40] disease-related skills,[50] caregiver well-being,[44] self-efficacy,[48] and adherence.[48] Others reported no differences or changes in nausea,[51] stress,[47,48] psychological problems,[47] or quality of life (QoL).[48]

Of note, the systematic review of published research on psychoeducation by Bradlyn et al.[45] concluded that psychoeducation is most effective and impactful when it is tailored to the individual patient/family, rather than based on assumptions about the patient's needs or preferences. Factors suggested to influence the effectiveness of informational interventions include socio-demographics (e.g., education and literacy level of the patient or caregiver), coping styles/preferences (e.g., information seekers vs. information avoiders), learning styles (e.g., auditory, visual), and culture. Similarly, in a study of parents over the course of the first year of diagnosis, qualitative analysis supported that information should be adjusted to caregiver needs and that providers should consider what information is provided when and in what format, depending on family preferences.[52]

Several studies described development, feasibility, and acceptability of computer, video, or web-based formats for providing guidance and information to patients and families. [2,38,39,41,42,45,48,49,53,54] These formats appear to be well-received by families and may be promising, but additional research is needed, as some studies showed low utilization of information web-based resources[53] and no differences in knowledge gains, QoL, self-efficacy, or coping when compared to less technological/handbook formats.[38,42]

DISCUSSION

Overall, review of data from 21 studies indicates that psychoeducation appears to have the most consistent effects on improving

patient/caregiver knowledge about disease and treatment and increasing health locus of control. A number of modalities are potentially effective in providing families anticipatory guidance, provided the content and delivery is matched to the needs and preferences of the particular patient and caregiver. The benefits of anticipatory guidance as an intervention per se are limited in the literature; however, information needs at critical times during the cancer trajectory have been described[16,18,19,21,22] and, consistent with the adult cancer literature, patients and families want and benefit from information.[55] Although the Children's Oncology Group's Survivorship Guidelines are currently being used as an anticipatory guidance tool for patients and families,[56] standardized, evidence-based tools for other points along the trajectory are lacking or have not been widely disseminated.

The current evidence base is somewhat scattered and lacks an organizational or theoretical model. In general, studies were rated as moderate quality because of small sample sizes, lack of control groups, and limited RCTs. Many studies combine psychoeducational/informational interventions with skills-based interventions (e.g., cognitive behavioral therapy), making it difficult to tease apart unique effects of intervention components. Furthermore, the terminology used in the cancer literature to refer to psychoeducational efforts (e.g., information, knowledge, education, training, didactics) is inconsistent and frequently used without qualification or definition,[45] which makes it difficult to draw generalizable conclusions across studies.

Psychoeducational or informational interventions for increasing patients' knowledge, self-help skills, and attitudes are already well established for other chronic diseases of childhood such as asthma and diabetes.[57,58] Similarly, the adult cancer literature shows that such interventions can reduce distress, depression, anxiety, improve a variety of health-related outcomes, and increase satisfaction with care.[59,60] Comparatively, studies evaluating the impact of psychoeducation and anticipatory guidance on health outcomes in children with cancer and their families are relatively limited. As such, more research is needed to guide best practice. Important future directions include evaluating effects of informational interventions on health-related (e.g., adherence, illness-self management) or psychological outcomes (e.g., anxiety, depression), determining components of psychoeducation that are most helpful, the appropriate depth and timing of info to give children and families undergoing treatment, and preferred and most efficacious models and methods of delivery. Finally, little is known about how educational needs change at different points along the illness trajectory and across a patient's development or how to tailor education to families of different compositions, cultures, and learning styles.

Having sufficient personnel resources may be an organizational barrier to implementation of psychoeducation and anticipatory guidance for patients with families and their caregivers. This is especially true if providers make efforts to tailor education to the individual needs and preferences of specific patients and families, as the research recommends. Providing education in a group format or through the use of standard curriculum/platforms may assist with reaching multiple patients and families with less expenditure of personnel resources, but the consequence may be a lack of personalization to patient needs and preferences. Lack of role definition of providers may present additional challenges to effective education of patients and caregivers, as professionals across a wide-range of disciplines (e.g., nurses, physicians, social

workers, psychologists, child life specialists) have experience with and expertise in providing psychoeducation and anticipatory guidance to patients and families; this may result in duplication of effort and inefficient use of resources. Communication and coordination of services may be accomplished through clear documentation of efforts and through multidisciplinary rounds, where providers can discuss patient and family education needs and delineate what guidance will be provided by whom along the trajectory of cancer care.

With some consistent findings from moderate-level evidence studies, current evidence for this psychoeducation standard is of moderate quality overall; notably, there are no data regarding essential elements of services or consistent evidence for improved health-related outcomes. This standard is an overall strong recommendation given the minimal risk to patients and families and the potential benefits of meeting unmet informational needs, improving disease-related knowledge, and increasing health-locus of control (Table I).

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SUPPLEMENTARY INFORMATION
SUPPLEMENTAL TABLE I. Psychoeducation Standard Evidence Table.

Study	Design	Sample	Findings	Study rigor	Level of evidence
Barlow & Ellard, 2004 [1]	Systematic review of psycho-educational interventions for children with chronic disease, parents, and sibling	12 review papers found, including one intervention for childhood cancer	<ul style="list-style-type: none"> Main focus of interventions is disease management, with less attention being paid to the psychosocial aspects of living with a chronic condition No systematic reviews or meta-analyses of psychoeducational interventions for parents or siblings were identified 	Only pulled reviews, not individual studies; studies of small sample sizes; relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	5
Beale, Bradlyn, & Kato, 2003[2]	Systematic review of psychoeducational interventions with pediatric cancer patients focused on effects of information and skills training on health-related outcomes	N/A	<ul style="list-style-type: none"> Many types of psychoeducational interventions appear to be effective in improving a variety of health-related outcome, including distress, anxiety, and depression However, studies with children are sparse and mainly limited to interventions targeting distress about painful procedures and hospitalization Interventions that are training based generally appear to be more effective than those that are information based Development of digital-based training interventions may overcome resource barriers Knowledge scores in the psychoeducational group improved significantly more over the follow-up periods 	Correct types of papers included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	5
Beale, Kato, Marin-Browning, Guthrie, & Cole, 2007 [3]	Multi-site, RCT of a psychoeducational video game vs regular commercial game; baseline, 1 and 3 month timepoints	375 adolescent and young adult cancer patients	<ul style="list-style-type: none"> Self-report ratings indicate a significant increase in perceived knowledge of survivorship topics and resource awareness for AYA survivors and caregivers 	Sufficient sample size; control group, randomization, and blinding; correct analyses	2
Bingen & Kupst, 2010 [4]	Descriptive evaluation of a survivorship educational program for adolescents and young adult survivors of childhood cancer; pre- and post ratings	257 AYA and caregiver attendees to a speaker series and a conference, 11% adolescent	<ul style="list-style-type: none"> Self-report ratings indicate a significant increase in perceived knowledge of survivorship topics and resource awareness for AYA survivors and caregivers 	No control group, unstandardized measures; large sample (although small percentage were adolescents)	3

(Continued)

SUPPLEMENTAL TABLE I. (Continued)

Study	Design	Sample	Findings	Study rigor	Level of evidence
Bradlyn, Beale, & Kato, 2003[5]	Systematic review of published research on psychoeducational interventions for children with cancer, including effects on treatment expectations, treatment credibility and acceptability, treatment adherence, perceptions of internal states, pain management, participation in health care, decision making, risk judgments and risk behaviors	N/A	<ul style="list-style-type: none"> Young patients with cancer need information; common perceived information needs included severity and course and long-term effects of treatment Interventions that are individualized for each patient are more likely to be effective than interventions that make assumptions about patients' needs Few generalizable conclusions at this time, except that the development of health-related knowledge in children is best accomplished by information transfer methods that are highly interactive and individualized Interventions are more likely to increase knowledge if they are interactive and participative in a way that address differences in patients' preferences for information and changes in preferences across time Interactive multimedia formats such as video games are seen as having the best potential, but further research is required SBW is a vehicle for children and adolescents to pursue a range of issues on their own term, to process important issues in a manner consistent with their own coping styles SBW provides information and opportunities to communicate with others facing similar challenges, in a way that is familiar to patients Effect of relaxation and education in alleviating nausea was not supported statistically Descriptive data suggests that both interventions promoted the intake of antiemetics 	Correct types of papers included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered; included a significant amount of adult and non-cancer literature	5
Brokstein, Cohen, & Walco, 2002 [6]	Descriptive, non experimental, case review design; discusses implementation of STARBRIGHT World, a tool to facilitate adjustment to illness and treatment	N = 4 children over the age of 8		Case review but no clear qualitative method used in analyses	6
Chan, Lam, Cheung, Cheng, Chik, Chan, Winnie, & Tang, 2014 [7]	Pre- and post-test control group design	20 patients, age 4-11, all diagnoses and 20 matched controls from historical data		Low participation rate, small sample size; cannot tease apart unique effects of psychoeducation vs relaxation	3

(Continued)

SUPPLEMENTAL TABLE I. (Continued)

Study	Design	Sample	Findings	Study rigor	Level of evidence
Dragone, Bush, Jones, Bearison, & Kamani, 2002 [8]	Randomized controlled experimental design; participants randomized to receive either the CD-ROM or an educational book about leukemia. Outcomes included children's health locus of control, their understanding of leukemia, and satisfaction with the program	31 children 4-11 years old with ALL at five sites, average of 2.6 years from diagnosis	<ul style="list-style-type: none"> Children in the CD-ROM group, compared with those in the book group, showed increased feelings of control over their health No differences in children's understanding of events associated with leukemia Although there was a high level of satisfaction with the CD-ROM among all users, younger children and their parents were most satisfied CD-ROM was found to be a useful, engaging, and empowering tool for children with leukemia Utilization and satisfaction were lower than expected Most accessed sections of the site were the discussion group, common areas of concern, FAQs, and coping information Barriers include unfamiliarity with computers and being too busy Concluded that further research is warranted to examine whether the Internet is a viable method of delivering support to families 	Small sample size; included a control group; randomization occurred but not blinded	2
Ewing, Long, Rotondi, Howe, Bill, & Marsland, 2009 [9]	Development of a web based resource for families with cancer to assess viability of support Quantitative data on use of website (frequency) Qualitative data on satisfaction	21 children (8-17 years old) and their families (51 participants total) newly diagnosed with cancer	<ul style="list-style-type: none"> Most accessed sections of the site were the discussion group, common areas of concern, FAQs, and coping information Barriers include unfamiliarity with computers and being too busy Concluded that further research is warranted to examine whether the Internet is a viable method of delivering support to families 	Small sample size; correct analyses	6
Haeberli, Grotzer, Niggli, Landolt, Linsenmeier, Ammann, & Bodmer, 2008 [10]	Non experimental study of a psychoeducational intervention using retrospective data as comparison	223 pediatric cancer patients receiving radiotherapy	<ul style="list-style-type: none"> Only 8.9% of patients in the intervention group needed anesthesia for radiotherapy, compared to 21.4% in the retrospective cohort 	Good sample size; comparison group was a retrospective cohort; not an RCT of the intervention	4
Jones, Kamani, Bush, Hennessy, Marfatia, & Shad, 2010 [11]	Descriptive study of development and evaluation for can education interactive CD-ROM for teens with cancer; pre-post design, randomized to one of two treatment levels (CD-ROM or Handbook)	71 teenagers with solid tumors, no more than 3 years out of treatment, mean age 14.8 (12-18yrs)	<ul style="list-style-type: none"> Increase in feelings of control over health in the CD-ROM group No significant differences in QoL, self-efficacy, coping, or cancer knowledge CD-ROM was more acceptable and used more often than handbook Information provided enhanced but did not replace expert medical advice 	Small sample size, limited power	3
Kato, Cole, Bradlyn, & Pollock, 2008 [12]	RCT of a video game intervention; baseline, 1 and 3 month assessments	375 patients 13-29 years old, initial or relapsed malignancy; currently on treatment	<ul style="list-style-type: none"> Self-efficacy, knowledge, and adherence to 6MP and antibiotics increased in the intervention group compared to the control group Intervention did not affect self-report measures of adherence, stress, control, or quality-of-life 	Sufficient sample size; control group, randomization, and blinding used; correct analyses	2

(Continued)

SUPPLEMENTAL TABLE I. (Continued)

Study	Design	Sample	Findings	Study rigor	Level of evidence
Kibby, Tyc, & Mulhern, 1998 [13]	Meta-analysis of 42 studies of psychological interventions for children and adolescents with chronic medical conditions. Included "didactic" as a classification domain for intervention	42 studies	<ul style="list-style-type: none"> Overall effectiveness of psychological interventions, effect size of 1.12, as well as maintenance of treatment gains for at least 12 months post-treatment Number of studies classified as didactic was too small to conduct meaningful analysis of comparative effectiveness 	Studies analyzed had small sample sizes; Correct types of papers included; important, relevant studies included; appropriately assessed for quality of studies; reasonable to combine results in this way; important outcomes considered	5
Knijnenburg, Kremer, Versluis, Braam, Mud, van der Pal, Caron & Jaspers, 2013 [14]	Descriptive evaluation of a patient information website for childhood cancer survivors	55 survivors and 43 parents	<ul style="list-style-type: none"> Respondents were satisfied with useability and content of the website, given high ratings on standardized scales No significant relationships between useability or satisfaction scores and educational level, internet/computer use, type of tumor, decision style having received radiotherapy Qualitative analyses revealed respondents preference for more detailed and even scientific information on late effects 	Low response rate; use of standardized measures to evaluate website; correct analyses	6
Last & van Veldhuizen, 1996 [15]	Quantitative and qualitative study examining whether open information about diagnosis and prognosis benefits emotional well-being of children with cancer; included both structured interviews with families and use of standardized measures of depression and anxiety	56 children with cancer, aged 8-16	<ul style="list-style-type: none"> Open information about dx and prognosis found to be beneficial to child's emotional wellbeing Significantly less anxious and less depressed three months to 3 years later as compared to children who did not receive open information and/or information at later stage of illness 	Retrospectively interviewed; small sample size for quantitative portion but reasonable for qualitative. Correct analyses. No control group.	6
Lewis, Gunawardena, & Saadwai, 2005 [16]	Development and qualitative validation of information resources on the Caring Connection Website	17 family caregivers and 10 oncology healthcare providers	<ul style="list-style-type: none"> Design features identified as most important were easy navigation, search capabilities, and individualization of content Participants recommended additions of patient-provider communication, access to online health information, and online support resources Preliminary studies support the feasibility of a Web-based information and communication resources 	Minimal justification of qualitative method; formal qualitative approach not used; research questions not clearly stated; correct analyses	6

(Continued)

SUPPLEMENTAL TABLE I. (Continued)

Study	Design	Sample	Findings	Study rigor	Level of evidence
Maurice-Stam, Silberbusch, Last, & Grootenhuis, 2009 [17]	Descriptive evaluation of a psychoeducational group intervention for children treated for cancer; pre- and post- assessments of disease-related skills	11 children (8-12years, all malignancies) and their parents	<ul style="list-style-type: none"> Positive outcomes were found on most items concerning disease-related skills (e.g., information seeking, relaxation, social competence, and positive thinking). Most favorable outcomes were reported on the item "If I have a question about my disease I know different ways to get an answer" Both educational intervention studies were well-accepted, impacted outcomes such as locus of control and family hardness, and highlighted the feasibility of a web-based medium for provision of this type of support. 	Very small sample, no control group; based on cognitive theory so intervention was not purely psycho-educational and included some skills training	3
Meyler, Guerin, Kiernan, & Breatnach, 2010 [18]	Systematic review of family based psychosocial interventions	21 studies identified, with 2 focused on educational/informational support	<ul style="list-style-type: none"> Increased knowledge of cancer in the parents who were in the intervention State Trait used to assess anxiety did not show a reduction in anxiety in intervention; rather both groups showed decrease anxiety No significant differences in either groups for symptoms of stress or children's psychological problems before or after intervention 	Right types of papers included (but only 2 fit in the educational/informational category); appropriately assessed quality of studies; important outcomes considered	5
Othman, Blunden, Mohamad, Hussin, Azhar, & Jamil Osman, 2010 [19]	Convenience sample study; pre post assessment of intervention of a 4 session information and coping strategies for new cancer parents	41 parents in intervention and 38 waitlist controls	<ul style="list-style-type: none"> Intervention found to be important, helpful and supportive; but level of usefulness varied Parents' level of well-being increased after one month of the intervention 	Small sample size; convenience sample; correct analyses	3
Svavarsdottir & Sigurdardottir, 2006 [20]	Feasibility and effectiveness study of family level educational intervention of internet support and one on one support; interviews with parents of newly diagnosed children	10 families (19 parents) newly diagnosed children and adolescents	<ul style="list-style-type: none"> No significant differences in coping scores between groups Experimental group reported significantly lower scores on GI problems and pain Qualitative results reported that participants evaluated the intervention positively 	Small sample; no control group; correct analyses	3
Wu, Chiou, Sheen, Lin, Liao, Chen, & Hsiao, 2013 [21]	Quasi-experimental design; pre and post test one group RCT of a psycho-educational intervention designed to improve coping and reduce symptom severity in children with cancer	58 patients of any malignancy, older than age 9, treated in Taiwan; randomized to intervention or standard care (n = 29 in each group)	<ul style="list-style-type: none"> No significant differences in coping scores between groups Experimental group reported significantly lower scores on GI problems and pain Qualitative results reported that participants evaluated the intervention positively 	Small sample size; control group used; randomized but not blinded; intervention included education and cognitive-behavioral modification, so unable to tease apart which components of intervention were effective	2

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