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Interventions for improving communication with children and adolescents about their cancer (Review)

Ranmal R, Prictor M, Scott JT

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[Intervention Review]

Interventions for improving communication with children and adolescents about their cancer

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ABSTRACT

Background

Communication with children and adolescents with cancer about their disease and treatment and the implications of these is an important aspect of good quality care. It is often poorly performed in practice. Various interventions have been developed that aim to enhance communication involving children or adolescents with cancer.

Objectives

To assess the effects of interventions for improving communication with children and/or adolescents about their cancer, its treatment and their implications, updating the 2003 version of this review.

Search methods

In April 2006 we updated searches of the following sources: CENTRAL (*The Cochrane Library*, issue 1 2006); MEDLINE (Ovid), (2003 to March week 5 2006); EMBASE (Ovid) (2003 to 2006 week 13); PsycINFO (Ovid) (2003 to March week 5 2006); CINAHL (Ovid) (2003 to March week 5 2006); ERIC (CSA) (earliest to 2006); Sociological Abstracts (CSA) (earliest to 2006); Dissertation Abstracts: (2002 to 6 April 2006).

In 2003 we conducted searches of CENTRAL; MEDLINE, EMBASE, PsycINFO, CINAHL, ERIC, Sociological Abstracts and Dissertation Abstracts.

For the initial (2001) publication of this review we also searched the following databases: PsycLIT; Cancerlit; Sociofile; Health Management Information Consortium; ASSIA; LISA; PAIS; Information Science Abstracts; JICST; Pascal; Linguistics and Language Behavior Abstracts; Mental Health Abstracts; AMED; MANTIS.

We also searched the bibliographies of studies assessed for inclusion, and contacted experts in the field.

Selection criteria

Randomised and non-randomised controlled trials, and before and after studies, evaluating the effects of interventions for improving communication with children and/or adolescents about their cancer, treatment and related issues.

Data collection and analysis

Data relating to the interventions, populations and outcomes studied and the design and methodological quality of included studies were extracted by one review author and checked by another review author. We present a narrative summary of the results.

Main results

One new study met the criteria for inclusion; in total we have included ten studies involving 438 participants. Studies were diverse in terms of the interventions evaluated, study designs used, types of people who participated and the outcomes measured.

One study of a computer-assisted education programme reported improvements in knowledge and understanding about blood counts and cancer symptoms. One study of a CD-ROM about leukaemia reported an improvement in children's feelings of control over their health. One study of art therapy as support for children during painful procedures reported an increase in positive, collaborative behaviour. Two out of two studies of school reintegration programs reported improvements in some aspects of psychosocial wellbeing (one in anxiety and one in depression), social wellbeing (two in social competence and one in social support) and behavioural problems; and one reported improvements in physical competence. One newly-identified study of a multifaceted interactive intervention reported a reduction in distress (as measured by heart rate) related to radiation therapy.

Two studies of group therapy, one of planned play and story telling, and one of a self-care coping intervention, found no significant effects on the psychological or clinical outcomes measured.

Authors' conclusions

Interventions to enhance communication involving children and adolescents with cancer have not been widely or rigorously assessed. The weak evidence that exists suggests that some children and adolescents with cancer may derive some benefit from specific information-giving programs, from support before and during particular procedures, and from interventions that aim to facilitate their reintegration into school and social activities. More research is needed to investigate the effects of these and other related interventions.

PLAIN LANGUAGE SUMMARY

Ways of improving communication with children and adolescents about their cancer

Communicating about cancer may help some children and adolescents understand the disease and its treatment and help them cope better with their cancer.

Children and adolescents with cancer face many issues and may benefit from greater opportunities to talk to health professionals. Concerns about their illness and its treatment can result in psychological, behavioural and developmental problems. Various methods of communication have been designed to provide better access to the knowledge and understanding these children and adolescents require. The review of trials found that specific information-giving programs, support before and during particular procedures, and school reintegration programs may benefit children and adolescents with cancer when individual factors such as their age, level of understanding and medical condition have been considered. More research is needed.

BACKGROUND

A diagnosis of cancer in a child or adolescent can cause great suffering to patients and families. In addition to the effects of the disease itself, children and adolescents with cancer may undergo numerous medical examinations, tests, surgical operations, chemo- and/or radiotherapies, and other procedures, which can be painful, toxic and psychologically distressing. The disease and its treatment can cause disruption to schooling, and to other aspects of the child's and family's social life and relationships (Cavusoglu 2000).

Some experts argue that improved communication between health professionals and children and adolescents with cancer is needed (Claflin 1991; Eden 1994; Greenberg 1984; Harrington 1996; Hughes 1990; Hytten 1992; Kreuger 1981; Nathanson 1984). Im-

provements to routine communications with health professionals and/or additional communication-based interventions may help children and adolescents with cancer in several ways. They may help children and their families to better understand, prepare for, and cope with their illness, the medical or surgical procedures they may undergo, their discharge from hospital and return to school and community, any relapses that may occur, and, in some cases, their last weeks of life. Interventions that offer opportunities for children and adolescents with cancer to communicate their experience of their illness and treatment may be helpful to them and may also provide others with information relevant to caring for them and managing their illness.

Children and adolescents with cancer need honest communication that is appropriate to their needs and level of understanding (Diez 1997; Eden 1994; Foley 1989; Greenberg 1984; Horstman 2002; Last 1996; Nathanson 1984; Verri 1985). Communication needs will vary across patients of different ages, preferences, types and stages of disease and treatment (Levenson 1982), and care setting (Mercer 1997). Young children in particular may be unable to understand or remember adult explanations, so it may be necessary to find alternative approaches to communicating with them about their cancer and treatment (Eiser 1986). Teenagers' coping skills may be already stretched by their passage through adolescence, making coping with cancer especially hard.

Parents play an important role in meeting the communication needs of children with cancer. Parents are usually, though not always, gatekeepers or conduits for communication between health professionals and the ill child or adolescent. Communication with children and adolescents with cancer should be seen in the context of the family and other support systems. This can make communicating with them about their disease and its treatment a more sensitive and complex task than with adult patients (Foley 1993; Naber 1995; Ely 1997; Mulhern 1981).

Ways of communicating with children and adolescents with cancer have been studied for around thirty years. This review focuses on evaluative research that investigates the effects of interventions to improve communication.

A variety of different ways of enhancing communication with young cancer patients has been tried including play, art and storytelling, group therapy, and more formal education and rehabilitation techniques. Advances in technology provide new opportunities for support using interactive multimedia (Bradlyn 2003; Suzuki 2003). However, little is known about the effectiveness of the different methods used. This systematic review assesses the effects of interventions that aim to enhance communication with children and adolescents with cancer.

OBJECTIVES

To update an earlier Cochrane review (Scott 2001; Scott 2003) examining the effects of interventions to enhance communication with children or adolescents with cancer on the following: the child's or adolescent's knowledge and understanding of their cancer and its treatment, and psychological, social, behavioural and physical outcomes.

METHODS

Criteria for considering studies for this review

Types of studies

Randomised and non-randomised controlled trials, and before and after studies (studies that compare pre-intervention and post-intervention assessments), that evaluate the effects of interventions aimed at enhancing communication with children and/or adolescents about their cancer and its treatment.

Types of participants

Children and/or adolescents diagnosed with cancer. Childhood and adolescence are flexible categories and definitions vary. For the purposes of this review a child is defined as a person 2 to 12 years of age and an adolescent is defined as a person 13 to 21 years of age (Dark 1999). Studies were eligible for inclusion if the majority of participants had a diagnosis of cancer and were aged between 2 and 21 years.

Children and/or adolescents in long-term remission from cancer (ie. 'survivors' of cancer) are excluded.

Types of interventions

Any intervention designed to enhance communication between health professionals or others (for example parents or school teachers) and children and/or adolescents with cancer about their disease, its treatment and their implications. The interventions might aim to improve routine communication between health professionals and patients (for example by communication skills training, or by introducing new tools or techniques such as visual aids or puppets into routine discussions) or they might be communication-based interventions that are additions to routine care (for example additional discussion sessions, educational social programs, or access to informational resources).

Interventions featuring distraction techniques (e.g. during painful procedures) are excluded, unless there is a distinct information or education component to them.

Types of outcome measures

Data were extracted on any of the following types of outcomes that were reported in the studies:

1. Child's or adolescent's knowledge and understanding about cancer and its treatment;
2. Psychological, social and behavioural outcomes (for example anxiety, depression, participation in school and social activities, perceptions of coping, patterns of interaction within the family);
3. Physical health outcomes (for example cell counts, physical functioning, health related quality of life assessments, survival).

Search methods for identification of studies

Details of original (2001) and 2003 searches are presented in Appendix 1.

In April 2006 we conducted an updated search of the following databases:

- CENTRAL (*The Cochrane Library*) (issue 1 2006)
- MEDLINE (Ovid), (2003 to March week 5 2006)
- EMBASE (Ovid) (2003 to 2006 week 13)
- PsycINFO (Ovid) (2003 to March week 5 2006)
- CINAHL (Ovid) (2003 to March week 5 2006)
- ERIC (CSA) (earliest to 2006)
- Sociological Abstracts (CSA) (earliest to 2006)
- Dissertation Abstracts: (2002 to 6 April 2006)

The MEDLINE strategy is presented in Appendix 2; strategies were tailored to the other databases.

We also searched the bibliographies of studies assessed for inclusion, and contacted experts in the field.

Data collection and analysis

One review author pre-screened all identified titles and abstracts for relevance. Two review authors assessed potentially relevant studies for inclusion independently. Any disagreements were resolved by discussion.

A systematic approach to data extraction was used to produce a descriptive summary of evaluative studies of methods of enhancing communicating with children or adolescents about their cancer and/or its treatment. One review author extracted the relevant data from the included studies. A second review author checked the data extraction. Data extracted about participants included age, setting, diagnosis and stage of disease and treatment. Data extracted about interventions included aims, content, timing, duration and frequency. Outcome data extraction focused on timing, type of outcome and instruments. Authors were contacted for clarification where necessary.

The following aspects of methodological quality were assessed for all included studies: study design, numbers of patients, methods of recruitment of participants, method of allocation/randomisation, blinding of outcome assessor(s), participants' awareness of the study, proportion of participants followed up, method of analysis (whether or not intention to treat analyses were used). One review author assessed methodological quality and a second review author checked the assessments.

We prepared tabular summaries of extracted data (Table 1; Table 2; Table 3) and present a narrative overview of the findings.

For the original iteration of this review (Scott 2001), an advisory panel was set up to ensure the scientific validity and relevance of the review. To ensure that patient views and perspectives are represented in the review, the advisory panel included patient consumers of cancer care and consumer advocacy organisations in the United Kingdom, including Cancer BACUP, The National Cancer Alliance, the Consumers' Advisory Group for Clinical Trials (CAG-CT), and the Standing Advisory Group on Consumer Involvement in NHS Research. Review advisory panel members were invited to comment on both the protocol and the draft review.

RESULTS

Description of studies

See: Characteristics of included studies; Characteristics of excluded studies; Characteristics of studies awaiting classification.

In the initial (2001) review, of approximately 1,500 studies identified, 49 were judged potentially relevant and the full papers were assessed in detail. In the 2003 update, an additional ten studies were judged potentially relevant and the full papers were assessed in detail. In the 2006-07 update, 57 were judged potentially relevant and the full papers were assessed in detail.

Overall, ten studies were found to be eligible for inclusion in this review: four randomised controlled trials (Dragone 2002; Hinds 2000; Klosky 2004; Varni 1993), two non-randomised controlled trials (Frick 1987; Heiney 1988), one non-randomised trial with an historical control group (Favara-Scacco 2001), one before and after study with an historical control group (Katz 1988) and two uncontrolled before and after studies (Baider 1989; Petersen 1996). Klosky 2004 is newly included in the latest update of this review. Considerable heterogeneity is evident between the included studies in terms of the specific interventions evaluated, the interventions or forms of usual care given to the control groups, the age, diagnoses and stages of treatment of the participants, the types of outcomes assessed and the timing and methods of assessment.

One further study of a hospital-based behavioural intervention programme for families of children with newly diagnosed or relapsed Acute Lymphoblastic Leukaemia (Macner-Licht 1998) could not be definitively included or excluded without additional information from the study authors, who we have been unable to contact. This has been listed under Studies awaiting classification.

Interventions

Two studies evaluated group therapy that aimed to provide a forum for providing mutual support and to facilitate coping: one in comparison with usual care (Heiney 1988), the other using a before and after design (Baider 1989). Two studies evaluated programmes that aimed to help children and adolescents with reintegration at school: one compared social skills training in addition to school reintegration with school reintegration alone (Varni 1993), the other compared a school and social reintegration programme with usual care (Katz 1988). Two studies evaluated computer-based information programmes: one compared an interactive CD-ROM presenting information about all aspects of leukaemia and its treatment, aimed at children with leukaemia and their family, with a book about leukaemia (Dragone 2002); the other evaluated a computer-assisted instructional program that aimed to teach children about blood counts and to prepare them for the symptoms and treatment side effects they might experience (Petersen 1996). One non-randomised controlled study evaluated a planned play and story-telling intervention that aimed to help children cope with bone marrow aspirations by comparing it with routine diversional play (Frick 1987). One study evaluated art therapy, comprising clinical dialogue, visual imagination, medical play, structured and free drawing, redundant reading and dramatization, as support for children during painful procedures (Favara-Scacco 2001). One study evaluated a three-part educational intervention designed to facilitate self-care coping in adolescents with cancer (Hinds 2000). One newly-identified study compared a cognitive behavioural interactive package (comprising exposure to an interactive animatronic character, an educational video including filmed modelling and passive auditory distraction via narrated stories by a cartoon character) with a modified control group which comprised a cartoon video, non-interactive character and stories delivered via cassette tape (Klosky 2004).

Detailed information about the interventions used in each study is given in the table Characteristics of included studies.

Participants

The studies recruited children and/or adolescents, with ages ranging from 2 years to 25 years. Most recruited children and adolescents with a range of types of cancer, but three (Frick 1987; Favara-Scacco 2001; Dragone 2002) focused on children with leukaemia. The differences between studies in eligibility criteria and recruitment strategies meant that participants varied in the length of time since their cancer diagnosis and in the types of treatment they had or were going to receive. We present detailed information about the participants in each study in the table Characteristics of included studies.

Outcomes

One study assessed the impact of a computer-assisted instructional program focusing on blood counts, symptoms and treatment side-effects on knowledge and understanding of the program content (Petersen 1996). Another assessed the impact of a computer-assisted instructional program about all aspects of leukaemia and its treatment, versus a book about leukaemia, on knowledge about the disease, satisfaction with and use of the intervention, and health locus of control (Dragone 2002). Two studies evaluated the effects of group therapy programmes on psychological outcomes, including anxiety, depression, self-esteem and locus of control (Baider 1989; Heiney 1988). Two studies evaluated the effects of programmes to support children and adolescents returning to school after absences due to illness (school reintegration programmes) on psychological, social and behavioural outcomes, including anxiety, depression, behavioural and emotional problems, cognitive, social, behavioural and physical competence, self-esteem, perceived social support, school absences and grades (Katz 1988; Varni 1993). One study evaluated a directed play and story-telling intervention on psychological and physical health outcomes, including state anxiety and pulse rates (Frick 1987). One study evaluated an art therapy intervention on the child's behaviour (number of positive behaviours exhibited) before, during and after a painful procedure (Favara-Scacco 2001). One study assessed the impact of a three-part educational intervention designed to facilitate self-care coping on psychological outcomes including locus of control, hopefulness, hopelessness, self-esteem and self-efficacy, and physical outcomes including symptom distress and toxicity (Hinds 2000). One newly-identified study assessed the impact of a cognitive behavioural interactive package designed to reduce distress during radiation therapy, on the occurrence of sedation, observed behavioural distress, heart rate and parental anxiety (Klosky 2004). The outcomes assessed in the studies were not always closely related to the stated aims or theoretical basis of the interventions. The validity of the measures used to assess psychological, social and behavioural outcomes in particular often received little or no comment in the study reports. It is not clear how appropriate some of the psychological measures are for young people with cancer. Varni 1993 restricted the administration of self-report measures to children over the age of eight.

None of the included studies explicitly set out to measure harms or adverse effects as distinct outcomes. However, all the outcome measures were capable of showing negative as well as positive effects.

Risk of bias in included studies

The following aspects of methodological quality were assessed for all included studies: study design, numbers of patients involved in the studies, methods of recruitment of participants, method of allocation/randomisation, blinding of outcome assessor(s), participants' awareness of the study, proportion of participants followed up, and method of analysis (whether or not intention to treat analyses were used).

Study design

Four studies (Dragone 2002; Hinds 2000; Klosky 2004; Varni 1993) were randomised controlled trials. Dragone 2002 collected data longitudinally (ie. pre- and post-test) as well as cross-sectionally (ie. experimental and control conditions). Hinds 2000 collected data at four measurement points spanning the first six months of treatment. Klosky 2004 collected data from baseline until the end of a simulated radiation therapy procedure for both groups. Some of the results reported from Varni 1993 were presented as within-group differences before and after the intervention. These results are subject to the same problems of interpretation as those from uncontrolled before and after studies.

Four other studies had control groups but did not allocate participants to them on a random basis. Frick 1987 and Heiney 1988 were prospective studies. Katz 1988 used an historical control group but reported most results as within-group differences before and after the intervention. Favara-Scacco 2001 also used an historical control group.

Two other studies (Baider 1989; Petersen 1996) used uncontrolled before and after designs. One typical problem with these study designs is that it is hard to be confident that any differences in scores before and after the intervention are due to the effects of the intervention itself: the scores might have changed over time anyway, even if the intervention had not been used. This problem was minimised in one study that tested knowledge before and immediately after the use of a computer instruction program (Petersen 1996).

Number of patients involved in the studies

One of the studies was a five-centre trial (Dragone 2002). Two of the studies were two-centre trials (Hinds 2000; Varni 1993). The remaining seven were single-centre. The total number of participants ranged from eight to 85.

Two studies reported a sample size power calculation (Varni 1993; Klosky 2004).

Recruitment

Of the ten included studies, eight explained how they recruited participants (Baider 1989; Dragone 2002; Frick 1987; Heiney 1988; Hinds 2000; Klosky 2004; Petersen 1996; Varni 1993).

Patients' awareness of study

Informed consent was formally obtained and reported in eight studies but specific practices varied. Frick 1987 (participant age range: 3 years, 9 months to 12 years, 11 months), Varni 1993 (5 to 13 years), and Hinds 2000 (12 to 21 years) obtained consent both from participants and their parent(s). Heiney 1988 (14 to 19 years) obtained consent from the parent(s) of participants under 18 years of age and from participants over 18. Dragone 2002 (4 to 11 years) obtained formal consent from parents, and from participants aged 7 and older; and all participants were told about the study at their developmental level and were told they did not have to participate. Baider 1989 (15 to 25 years) obtained consent from participants only. Katz 1988 (5 to 17 years) and Klosky 2004 (2 to 7 years) obtained consent from parent(s) only.

Method of allocation

In one randomised controlled trial (Varni 1993), randomisation was stratified by age and took place after a pre-treatment assessment. The process used to achieve random allocation was not clearly described so it is not clear whether the people making the allocation might have been influenced by the findings of the assessment. Similarly, in Klosky 2004 participants were randomly assigned after an observation period and collection of baseline data, but the randomisation process is not clearly described. In Dragone 2002 participants were allocated in a balanced 4-block randomization pattern by age group (4 to 6 year olds versus 7 to 11 year olds) and institution; the process was not clearly described although it took place at the time of trial registration rather than after the pre-test. Hinds 2000 used stratified randomisation by diagnosis (method not stated).

Frick 1987 matched children according to their age and number of previous exposures to the procedure of interest before allocating them to one of three groups. The method of allocation in Heiney 1988 was unclear. Katz 1988 and Favara-Scacco 2001 used historical controls.

Blinding of outcome assessors

Only Klosky 2004 addressed the issue of blinding of outcome assessors (noting that assessors were not blind to group allocation).

Methods of analysis

Two of the controlled studies explicitly adopted an intention to treat approach to statistical analysis (Katz 1988; Varni 1993) and four (Frick 1987; Hinds 2000; Favara-Scacco 2001; Klosky 2004) included all participants who received the intervention in the analysis. Dragone 2002 analysed only the participants who completed post-testing.

Proportion of patients followed up

Eight out of ten studies reported the proportion of participants followed up for outcome assessment. Proportions varied between 55% and 100%.

Effects of interventions

Four randomised controlled studies (Dragone 2002; Hinds 2000; Klosky 2004; Varni 1993), two prospective non-randomised controlled studies (Frick 1987; Heiney 1988), one non-randomised trial with an historical control group (Favara-Scacco 2001), one before and after study with an historical control group (Katz 1988) and two uncontrolled before and after studies (Baider 1989; Petersen 1996) were included in the review. They compared a variety of interventions among different populations and measured different types of effect. The results for each type of intervention are presented separately and a summary of statistical results is presented in the Additional tables (Table 1; Table 2; Table 3).

Computer-assisted educational programmes

Using a before and after design, Petersen 1996 assessed the effect of a computer-assisted instructional programme about blood counts, symptoms and side effects on participants' knowledge and understanding immediately after completing the programme. Fourteen out of fifteen (93.3%) participants who completed the programme answered more questions correctly about its content (mean scores: before = 4.9 (range = 3 to 6), after = 6.5 (5 to 8), mean difference = 1.7 (standard deviation (SD) 0.90), t = 7.174, P < 0.001). No assessment was made of the participants' retention of knowledge over time.

One randomised controlled study (Dragone 2002) compared the effect of a CD-ROM 'Kidz with Leukemia: A Space Adventure' with a book 'You and Leukemia' by Lynn Baker, on children's health locus of control, their understanding of leukemia, and their satisfaction with the intervention. The researchers found that in both age groups (4 to 6 year olds, and 7 to 11 year olds), compared with the book, the CD-ROM was associated with a significantly greater increase in children's feelings of control over their health (4 to 6 year olds: I = before: 8.25 (SD 2.38) vs after: 9.13 (SD 3.23); C = before: 8.33 (SD 2.07) versus after: 6.17 (SD 3.87); 7 to 11 year olds: I = before: (11.14 (SD 3.29) versus after: 13.40 (SD 3.46); C = before: 13.70 (SD 2.98) versus after: 13.70 (SD 3.53)). There was no significant difference in children's understanding of events associated with leukemia between the CD-ROM and book groups, although participants in the CD-ROM group had more detailed narratives about leukemia events than those in the book group. Finally, a higher proportion of the children assigned the CD-ROM were satisfied with their assigned resource, than were those assigned the book.

School reintegration programmes

Two studies evaluated programmes designed to help children and adolescents with cancer to reintegrate into school after absences due to their illness and treatment.

(a) Psychological outcomes

One randomised controlled study found that participants in the intervention group had statistically signficantly reduced state anxiety scores after receiving the prospective social skills training intervention in addition to normal school reintegration (I = before: 29.75 (SD 6.37) versus after: 24.69 (SD 7.96), t = 2.14, P < 0.05, ES = 0.79) (Varni 1993). Another non-randomised controlled study found that participants in the intervention group had significantly lower depression scores after a school reintegration programme (I = before: 10.00 (SD 7.02) versus after: 6.69 (SD 5.65), P < 0.01) but found no difference between those who received the intervention and those who received usual care (Katz 1988). The same study found significant within group improvements in participants' perceived cognitive competence (I = before: 2.62 (SD 0.75) versus after: 2.87 (SD 0.72), P < 0.05) and perceived social competence (I = before: 2.85 (SD 0.79) versus after: 3.23 (SD 0.60), P < 0.05). It also reported significant between group differences for perceived social competence (I = after: 3.23 (SD 0.60) versus C = 2.96 (SD 0.62), P < 0.05), and perceived general competence (I = after: 3.34 (SD 0.49) versus C = 2.96 (SD 0.56), P < 0.01). There was a significant improvement in the perceived physical competence of participants who received school reintegration (I = before: 2.43 (SD 0.74) versus after: 2.82 (SD 0.67), P < 0.01) but no significant difference between the intervention and control groups.

(b) Social outcomes

Varni 1993 found that participants in the intervention group perceived signficantly greater parental social support six months after the intervention (I = before: 3.38 (SD 0.50) versus after: 3.69 (SD 0.30), t = -1.88, P < 0.05, ES = 0.62) but the difference was no longer significant at nine months. The same study found that participants in the intervention group perceived signficantly greater teacher social support at the nine month follow-up (I = before: 3.29 (SD 0.62) versus after: 3.58 (SD 0.45), t = -2.18, P < 0.05, ES = 0.47) and significantly greater classmate social support (I = before: 3.27 (SD 0.55) versus after: 3.51 (SD 0.40), t = -2.26, P < 0.05, ES = 0.44), whilst parents reported significant improvements in social competence on the School Subscale (I = before: 46.90 (SD 8.99) versus after: 49.79 (SD 4.43), t = -1.94, P < 0.05, ES = 0.32). The same study found no difference between those who received social skills training and those who received normal school reintegration alone at either six or nine months follow-up.

(c) Behavioural outcomes

Katz 1988 found that, according to parents, participants in the intervention group had statistically significantly fewer behaviour problems after a school reintegration programme (I = before: 57.14 (SD 9.47) versus after: 50.28 (SD 13.99), P < 0.001) but there were

no differences between those who received the school reintegration intervention and those who received usual care. The same study found no significant differences in absences or grades between the intervention and control groups.

Varni 1993 found that parents of intervention group participants who had received prospective social skills training in addition to normal school reintegration reported significantly fewer behaviour problems at the six month follow-up (I = before: 55.87 (SD 12.07) versus after: 50.87 (SD 9.62), t = 2.89, P < 0.005, ES = 0.41), and at the nine month follow-up (I = before: 56.61 (SD 11.28) versus after: 50.30 (SD 10.63), t = 3.22, P < 0.005, ES = 0.56) but no difference was found between the intervention group and the control group who received normal school reintegration.

Group therapy

Of two studies that assessed the effects of group therapy, one non-randomised controlled study found no differences in anxiety, depression, self-esteem or locus of control between participants in group therapy and those who received usual care (Heiney 1988). The other, a before-and-after study, found that group therapy had no significant effect on the psychological symptoms of participants (Baider 1989). It is important to note that in Baider 1989 only half of the young people accepted the invitation to participate in the group therapy.

Art therapy

One non-randomised study with an historical control found that children undergoing a lumbar puncture or bone marrow aspiration, supported by various art therapy modalities, exhibited a larger number of positive behaviours before, during and after the painful procedures, than those not supported by art therapy (Favara-Scacco 2001). Fifteen 'positive behaviours' such as 'Dialogues and/or questions doctors' and 'Shows no extreme emotional alterations' were selected as indicators that children had developed a better compliance with the painful procedures. Children who adopted eight or more positive behaviours were considered 'good responders'. In the experimental group, 23 of the total 32 children (72%) were considered 'good responders', compared with 3 of 17 children (18%) in the control group. These results were not analysed statistically.

Planned play and story-telling

One non-randomised controlled study evaluated the effects of a planned play and story-telling intervention for children undergoing a scheduled bone marrow aspiration on the state anxiety of participants, and the pulse rates of participants and their parents (Frick 1987). No significant differences in state anxiety or pulse rates were found between participants in the planned play and story-telling intervention and those who received usual care. It is important to note that more than two thirds of the participants had had at least six bone marrow aspirations before participating in this study.

Self-care coping intervention

One randomised controlled trial (Hinds 2000) found no sigificant effects of a self-care coping intervention compared with control, on psychological (hopefulness, hopelessness, self-esteem, self-efficacy and symptom distress) and clinical outcomes (toxicity) among adolescents newly diagnosed with cancer.

Cognitive behavioural interactive package

One newly-identified randomised controlled study (Klosky 2004) compared an interactive package (including an interactive animatronic character, an educational video including filmed modelling, and passive auditory distraction via narrated stories by a cartoon character) with a less interactive package on the child's distress during radiation therapy. The researchers found participants in the intervention group had lower mean heart rates from baseline to simulated radiation therapy during the total treatment (I = 112.3 (SD 3.0) to 106.2 (SD 3.2) versus C = 105.1 (SD 2.3) to 108.4 (SD 2.8), F = 4.11, P < 0.05). No statistically-significant difference was found between the groups in the proportion of children who needed sedation to complete the procedure and on the modified Observation Scale of Behavioural Distress.

DISCUSSION

Only ten studies were found that satisfied the inclusion criteria of this review. Their findings are difficult to interpret and summarise due to (a) inherent problems with the design of individual studies, and (b) the heterogeneity of their aims, study designs, interventions and controls, patient populations, outcomes, assessment instruments, and methods of analysis. The available evidence about the effects of different ways of enhancing communication with children and adolescents about their cancer and its treatment is weak and inconclusive.

Problems with study designs and methods

The interventions studied were complex in that they often had multiple components, could be tailored to individual circumstances and/or could vary according to the characteristics of the individuals who delivered them. In the Katz 1988 study of a school and social reintegration program, for example, psychologists intervened at different stages, in different ways and with different groups (patients, family, medical staff and school personnel), and it is difficult to discern which components, or combination of components had an effect. This was also the case in the study of

art therapy for painful procedures (Favara-Scacco 2001). Comparison groups sometimes also received a modified form of the intervention, rather than usual care (e.g. Klosky 2004).

The improved outcomes reported in uncontrolled before and after studies may be due to the passage of time and unrelated to the interventions tested. Some of the controlled studies reported within-group rather than (or as well as) between-group changes. These analyses have similar weaknesses to uncontrolled before and after studies. They may, however, usefully complement data from between group comparisons if the groups were not comparable at baseline. In Katz 1988, those receiving the intervention were newly diagnosed with cancer, whereas those in the control group had been diagnosed within 36 months before the study was initiated. It is possible that any between-group differences in outcomes may have been caused by systematic differences between the two groups. It is also possible that the intervention accelerated a process of adaptation, so that the intervention group adapted more rapidly than the control group.

Some studies assessed a large number of outcomes at several points in time and undertook many tests of statistical significance. As only a small proportion of the effects were statistically significant, it is possible that at least some of these were due to chance. Some studies were had small sample sizes (the number of participants ranged from 8 to 85) making it unlikely they could detect statistically significant treatment effects.

It is difficult to interpret the results of controlled studies which do not adequately describe the usual care with which interventions are compared.

Other factors affecting interpretation of findings

All the studies except Heiney 1988 and Klosky 2004 recruited participants with relatively wide age ranges. Some studies (e.g. Petersen 1996) applied the same intervention to different age-groups. If an intervention is more suitable for children or adolescents of certain ages than for others, then the age composition of the study groups could influence the effects reported. Other studies (e.g. Katz 1988; Favara-Scacco 2001) probably tailored interventions to suit participants of different ages or who varied in other characteristics. This makes it difficult to know exactly what kind of intervention is most effective for whom.

Some of the interventions studied might have had a greater or lesser impact among different participant groups. For example, the directed play and story telling intervention evaluated by Frick 1987 might have had more effect among children who were less accustomed to the bone marrow aspiration it focused on. The group therapy evaluated by Baider 1989 might have had a differential impact on the psychological wellbeing of young adults who were and were not receiving active treatment at the time. Young people's preferences for particular interventions might also moderate their effectiveness. For example, not all young people will be willing to participate in group therapy or other interventions.

The interventions studied might also have varying effects in different healthcare systems and cultural contexts. There is extremely limited evidence for the effects of these interventions beyond well-resourced, western healthcare settings. Eight of the ten studies were set in the USA. Some studies excluded participants who did not primarily speak English (e.g. Dragone 2002).

Range and appropriateness of outcomes assessed

The interventions assessed in this review might impact on a range of processes and outcomes by a variety of mechanisms. The included studies assessed various outcomes, but did not always attempt to assess the extent to which all the stated aims of the interventions were achieved. Only two studies looked at knowledge and understanding. Most studies investigated the effects of communication interventions on psychological, social and behavioural outcomes. Other outcomes which could have been affected include perceptions of coping, patterns and perceptions of interaction with peers, family and health professionals, general quality of life, physical health status, and even survival, although large trials with long-term follow up periods would probably be required to test the latter.

Cost considerations

None of the reviewed studies contained economic evaluations.

AUTHORS' CONCLUSIONS

Implications for practice

There have been few reported studies which have evaluated the effects of interventions to enhance communication with children and adolescents about their cancer. Those that have reported findings that are difficult to interpret and summarise due to differences in their design, methodology and outcomes. Overall there is weak evidence to suggest that interventions, such as computer-assisted learning, art therapy and multifaceted interactive interventions offering support before and during particular procedures, and school and social reintegration programmes, may lead to improvements in knowledge and understanding and in psychological, social and behavioural outcomes.

In the absence of more robust empirical evidence about the effects of particular interventions, health professionals must use their own individual judgement about how better communication with these patient groups might be achieved. A wide range of approaches, using techniques derived from formal education and the expressive arts, have been developed with the intention of enhancing communication to secure a range of other benefits, but few have been rigorously evaluated.

The selection of strategies for improving or supplementing routine communication between health practitioners and children or adolescents with cancer should take into account a range of factors. These include the young person's medical condition, physical health, stage of cognitive, emotional and physical development, perceived needs and concerns, readiness and ability to communicate, and with whom they prefer to discuss concerns about their cancer and treatment. The child or adolescent needs to be considered in the context of their family, and family members may need to be included in interventions aimed at enhancing communication with children and adolescents with cancer.

Implications for research

More rigorous research is needed to investigate the effects of interventions that aim to enhance communication with children and/or adolescents about their cancer, its treatment and their prognosis.

Interventions developed for testing should be underpinned by research that determines the needs and preferences of the children and adolescents with cancer who are supposed to benefit from them.

The outcomes assessed should reflect the aims of the intervention and the perceptions of children and adolescents with cancer about what is most important for the interventions to achieve and avoid.

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REFERENCES

References to studies included in this review

Baider 1989 ***{published data only}***
Baider L, De-Nour AK. Group therapy with adolescent cancer patients. *Journal of Adolescent Health Care* 1989;**10**(1):35–8.

Dragone 2002 ***{published data only}***
Dragone MA, Bush PJ, Joneds JK, Bearison DJ, Kamani S. Development and evaluation of an interactive CD-ROM for children with leukemia and their families. *Patient Education and Counseling* 2002;**46**:297–307.

Favara-Scacco 2001 ***{published data only}***
Favara-Scacco C, Smirne G, Schiliro G, Di Cataldo A. Art therapy as support for children with leukemia during painful procedures. *Medical and Pediatric Oncology* 2001;**36**(4):474–80.

Frick 1987 ***{published data only}***
Frick SB, DelPo EG. Play behaviors of children undergoing bone marrow aspiration. *Journal of Psychosocial Oncology* 1986;**4**(4):69–77.

Heiney 1988 ***{published data only}***
Heiney SP, Ruffin J, Ettinger RS, Ettinger S. The effects of group therapy on adolescents with cancer. *Journal of the Association of Pediatric Oncology Nurses* 1988;**5**(3):20–4.

Hinds 2000 ***{published and unpublished data}***
Hinds PS. Fostering coping by adolescents with newly diagnosed cancer. *Seminars in Oncology Nursing* 2000;**16**(4):317–27.
* Hinds PS, Quargnenti A, Bush AJ, Pratt C, Fairclough D, Rissmiller G, et al.An evaluation of the impact of a self-care coping intervention on psychological and clinical outcomes in adolescents with newly diagnosed cancer. *European Journal of Oncology Nursing* 2000;**4**(1):6–17.

Katz 1988 ***{published data only}***
Katz ER, Rubinstein CL, Hubert NC, Blew A. School and social reintegration of children with cancer. *Journal of Psychosocial Oncology* 1988;**6**(3-4):123–40.

Klosky 2004 ***{published and unpublished data}***
* Klosky JL. *Evaluation of an interactive-educational Barney (R) intervention for reducing distress in pediatric cancer patients experiencing radiation therapy treatment planning [thesis]*. Memphis, TN: University of Memphis, 2004.
Klosky JL, Tyc VL, Srivastava DK, Tong X, Kronenberg M, Booker ZJ, et al.Brief report: evaluation of an interactive intervention designed to reduce pediatric distress during radiation therapy procedures. *Journal of Pediatric Psychology* 2004;**29**(8):621–6.

Petersen 1996 *{published data only}*
Petersen M. What are blood counts? A computer-assisted program for pediatric patients. *Pediatric Nursing* 1996;**22** (1):21-5; quiz 26-7.

Varni 1993 *{published data only}*
Varni JW, Katz ER, Colegrove R, Dolgin M. The impact of social skills training on the adjustment of children with newly diagnosed cancer. *Journal of Pediatric Psychology* 1993;**16**(6):751–67.

References to studies excluded from this review

Allen 1997 *{published data only}*
Allen R, Newman SP, Souhami RL. Anxiety and depression in adolescent cancer: findings in patients and parents at the time of diagnosis. *European Journal of Cancer* 1997;**33**(8): 1250–5.

Antonov 2004 *{published data only}*
Antonov G, Konstantinov D, Georgieva I. Projective methodologies in the context of psychological study of patients and recuperated from non-Hodgkin lymphoma in childhood [Bulgarian]. *Pediatriya* 2004;**44**:31–3.

Askey 1982 *{published data only}*
Askey DG, White JE. Structuring information given to children about cancer. *Progress in Clinical & Biological Research* 1982;**83**:349–59.

Barakat 2003 *{published data only}*
Barakat LP, Hetzke JD, Foley B, Carey ME, Gyato K, Phillips PC. Evaluation of a social-skills training group intervention with children treated for brain tumors: a pilot study. *Journal of Pediatric Psychology* 2003;**28**(5):299–307.

Barlow 2004 *{published data only}*
Barlow JH, Ellard DR. Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child: Care, Health & Development* 2004;**30**(6):637–45.

Barrera 2002 *{published data only}*
Barrera ME, Rykov MH, Doyle SL. The effects of interactive music therapy on hospitalized chidlren with cancer: a pilot study. *Psycho-Oncology* 2002;**11**:379–88.

Baruch 2003 *{published data only}*
Baruch JM. Use of writing to strengthen coping in adolescents with cancer. *Communicating Nursing Research* 2003;**36**:295.

Basch 2005 *{published data only}*
Basch E, Artz D, Dulko D, Scher K, Sabbatini P, Hensley M, et al.Patient online self-reporting of toxicity symptoms during chemotherapy. *Journal of Clinical Oncology* 2005; **23**:3552–61.

Baysinger 1993 *{published data only}*
Baysinger M, Heiney SP, Creed JM, Ettinger RS. A trajectory approach for education of the child/adolescent with cancer. *Journal of Pediatric Oncology Nursing* 1993;**10** (4):133–8.

Beale 2003 *{published data only}*
Beale IL, Bradlyn AS, Kato PM. Psychoeducational interventions with pediatric cancer patients: Part II. Effects of information and skills training on health-related outcomes. *Journal of Child and Family Studies* 2003;**12**(4): 385–97.

Benner 1991 *{published data only}*
Benner AE, Marlow LS. The effect of a workshop on childhood cancer on students' knowledge, concerns, and desire to interact with a classmate with cancer. *Children's Health Care* 1991;**20**(2):101–7.

BluebondLangner 1990 *{published data only}*
Bluebond-Langner M, Perkel D, Goertzel T. Pediatric cancer patients' peer relationships: the impact of an oncology camp experience. *Journal of Psychosocial Oncology* 1991;**9**(2):67–80.
* Bluebond-Langner M, Perkel D, Goertzel T, Nelson K, McGeary J. Children's knowledge of cancer and its treatment: impact of an oncology camp experience. *Journal of Pediatrics* 1990;**116**(2):207–13.

Bradlyn 2003 *{published data only}*
Bradlyn AS, Beale IL, Kato PM. Psychoeducational interventions with pediatric cancer patients: part 1. Patient information and knowledge. *Journal of Child and Family Studies* 2003;**12**(3):257–77.

Carr-Gregg 1986 *{published data only}*
Carr-Gregg M, Hampson R. A new approach to the psychological care of adolescents with cancer. *Medical Journal of Australia* 1986;**145**(11-12):580, 582-3.

Claflin 1991 *{published data only}*
Claflin CJ, Barbarin OA. Does 'telling' less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology* 1991;**16**(2):169–91.

Cohen 1989 *{published data only}*
Cohen DS, Friedrich WN, Copeland DR, Pendergrass TW. Instruments to measure parent-child communication regarding pediatric cancer. *Children's Health Care* 1989;**18** (3):142–5.

Conway 1996 *{published data only}*
Conway C, Thompson E, Caldwell C. Peer support group for adolescents. *Paediatric Nursing* 1996;**8**(1):13–16.

Cooper 1985 *{published data only}*
Cooper SE, Blitz JT. A therapeutic play group for hospitalized children with cancer. *Journal of Psychosocial Oncology* 1985;**3**(2):23–37.

Cotanch 1985 *{published data only}*
Cotanch P, Hockenberry M, Herman S. Self-hypnosis as antiemetic therapy in children receiving chemotherapy. *Oncology Nursing Forum* 1985;**12**(4):41–6.

Councill 1993 *{published data only}*
Councill T. Art therapy with pediatric cancer patients: Helping normal children cope with abnormal circumstances. *Art Therapy* 1993;**10**(2):78–87.

de Gonzalez 1997 *{published data only}*
de Gonzalez Victorica MI, Bertolino L, Pavlovsky S. Argentina: telling the truth to cancer patients in a multicultural society. In: Surbone A, Zwitter M editor

(s). *Communication with the Cancer Patient: Information and Truth*. Vol. **809**, New York: New York Academy of Sciences, 1997:152–62.

De Trill 1997 ***{published data only}***
De Trill M, Kovalcik R. The child with cancer. Influence of culture on truth-telling and patient care. In: Surbone A, Zwitter M editor(s). *Communication with the Cancer Patient: Information and Truth*. Vol. **809**, New York: New York Academy of Sciences, 1997:197–210.

Diez 1997 ***{published data only}***
Diez B, Lascar E, Alizade A. Talking to a child with cancer. A valuable experience. In: Surbone A, Zwitter M editor (s). *Communication with the Cancer Patient: Information and Truth*. Vol. **809**, New York: New York Academy of Sciences, 1997:142–51.

Di Giulio 2004 ***{published data only}***
Di Giulio P, Cotta R, Bastianello D, Garaventa A, Jankovic M, Perilongo G, et al.Doctors-nurses integration in paediatric onco-hematology: a cornerstone for quality of care. Report on a three years experience [Italian]. *Assistenza Infermieristica e Ricerca* 2004;**23**(3):142–8.

Dobish 2003 ***{published data only}***
Dobish RB, Tulloch KJ, Chambers CR. Implementation of a telephone callback service for ambulatory oncology patients. *Journal of Oncology Pharmacy Practice* 2003;**9**(1): 21–8.

Doorenbos 2005 ***{published data only}***
Doorenbos A, Given B, Given C, Verbitsky N, Cimprich B, McCorkle R. Reducing symptom limitations: a cognitive behavioral intervention randomized trial. *Psycho-Oncology* 2005;**14**:574–84.

Dorn 1995 ***{published data only}***
Dorn LD, Susman EJ, Fletcher JC. Informed consent in children and adolescents: Age, maturation and psychological state. *Journal of Adolescent Health* 1995;**16**(3):185–90.

Eiser 1986 ***{published data only}***
Eiser C, Eiser JR, Hunt J. Comprehension of metaphorical explanations of illness. *Early Child Development and Care* 1986;**26**(1-2):79–87.

Fahrenheim 1993 ***{published data only}***
Fahrenheim E, Wintergerst U, Belohradsky BH. Reduction of pain perception of chronically ill children by intermittent infusion therapy [Minderung von Schmerserlebnissen chronisch kranker Kinder bei intermittierender Infusionstherapie]. *Monatsschrift Kinderheilkunde* 1993;**141** (4):330–2. [MEDLINE: 93254475]

Ford 2005 ***{published data only}***
Ford JG, Howerton MW, Bolen S, Gary TL, Lai GY, Tilbert J, et al.*Knowledge and access to information on recruitment of underrepresented populations to cancer clinical trials [Evidence Report/Technology Assessment Number 122]*. Rockville, MD: Agency for Healthcare Research and Quality, June 2005.

Freeman 1991 ***{published data only}***
Freeman M. Therapeutic use of storytelling for older children who are critically ill. *Children's Health Care* 1991; **20**(4):208–15.

Gariépy 2003 ***{published data only}***
Gariépy N, Howe N. The therapeutic power of play: examining the play of young children with leukaemia. *Child: Care, Health & Development* 2003;**29**(6):523–37.

Gershon 2004 ***{published data only}***
Gershon J, Zimand E, Pickering M, Olasov Rothbaum B, Hodges L. A pilot and feasibility study of virtual reality as a distraction for children with cancer. *Journal of the American Academy of Child and Adolescent Psychiatry* 2004;**43**(10): 1243–9.

Gibbons 1986 ***{published data only}***
Gibbons MB. Coping with childhood cancer: A family perspective. In: Power PW, Dell Orto AE, Gibbons M editor(s). *Family interventions throughout chronic illnss and disability*. New York: Springer, 1988:74–103.

Glazer 1997 ***{published data only}***
Glazer JP. Psychiatric aspects of cancer in childhood and adolescence. In: Lewis M editor(s). *Child and adolescent psychiatry: A comprehensive textbook*. Baltimore: Williams & Wilkins, 1991:956–68.

Haberle 1997 ***{published data only}***
Haberle H, Schwarz R, Mathes L. [Family-oriented management of children and adolescents with cancer] [German]. *Praxis der Kinderpsychologie und Kinderpsychiatrie* 1997;**46**(6):405–19.

Hanna 1993 ***{published data only}***
Hanna KM, Jacobs P. The use of photography to explore the meaning of health among adolescents with cancer. *Issues in Comprehensive Pediatric Nursing* 1993;**16**:155–64.

Hartwich 1979 ***{published data only}***
Hartwich P. The question of disclosing the diagnosis to terminally ill patients. *Archiv fur Psychiatrie und Nervenkrankheiten* 1979;**227**(1):23–32.

Heiney 1990 ***{published data only}***
Heiney SP, Wells LM, Coleman B, Swygert E, Ruffin J. Lasting Impressions: a psychosocial support program for adolescents with cancer and their parents. *Cancer Nursing* 1990;**13**(1):13–20.

Heiney 1991 ***{published data only}***
Heiney SP, Wells LM, Coleman B, Swygert E. 'Lasting Impressions: adolescents with cancer share how to cope' - a videotape program. *Journal of Pediatric Oncology Nursing* 1991;**8**(1):18–23.

Hinds 2001 ***{published data only}***
Hinds PS, Oakes L, Furman W, Quargnenti A, Olson MS, Foppiano P, et al.End-of-life decision making by adolescents, parents and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nursing* 2001;**24**(2):122–34.

Hooker 1996 ***{published data only}***
Hooker L, Williams J. Parent-held shared care records: bridging the communication gaps. *British Journal of Nursing* 1996;**5**(12):738–41.

Jankovic 1994 ***{published data only}***
Jankovic M, Loiacono NB, Spinetta JJ, Riva L, Conter V, Masera G. Telling young children with leukemia

their diagnosis: the flower garden as analogy. *Pediatric Hematology & Oncology* 1994;**11**(1):75–81.

Jay 1985 ***{published data only}***
Jay SM, Elliot CH. Behavioral management of chidren's distress during painful medical procedures. *Behavior Research and Therapy* 1985;**23**:513–20.

Jay 1991 ***{published data only}***
Jay SM, Elliott CH, Woody PD, Siegel S. An investigation of cognitive-behavior therapy combined with oral valium for children undergoing painful medical procedures. *Health Psychology* 1991;**10**:317–22.

Kameny 2002 ***{published data only}***
Kameny RR, Bearison DJ. Cancer narratives of adolescents and young adults: a quantitative and qualitative analysis. *Children's Health Care* 2002;**31**(2):143–73.

Kapelaki 2003 ***{published data only}***
Kapelaki U, Fovakis H, Dimitriou H, Perdikogianni C, Stiakaki E, Kalmanti M. A novel idea for an organized hospital/school program for children with malignancies: issues in implementation. *Pediatric Hematology and Oncology* 2003;**20**:79–87.

Kodish 2004 ***{published data only}***
Angiolillo AL, Simon C, Kodish E, Lange B, Noll RB, Ruccione K, et al.Staged informed consent for a randomized clinical trial in childhood leukemia: impact on the consent process. *Pediatric Blood and Cancer* 2004;**42**:433–7.
Drotar D, Millar V, Willard V, Anthony K, Kodish E. Correlates of parental participation during informed consent for randomized clinical trials in the treatment of childhood leukemia. *Ethics and Behavior* 2004;**14**(1):1–15.
Fisher CB. Commentary: SES, ethnicity and goodness-of-fit in clinician-parent communication during pediatric cancer trials. *Journal of Pediatric Psychology* 2005;**30**(3): 231–4.
Kodish E, Eder M, Noll RB, Ruccione K, Lange B, Angiolillo A, et al.Communication of randomization in childhood leukemia trials. *JAMA* 2004;**291**:470–5.
Miller VA, Drotar D, Burant C, Kodish E. Clinician-parent communication during informed consent for pediatric leukemia trials. *Journal of Pediatric Psychology* 2005;**30**(3): 219–29.

Konsler 1993 ***{published data only}***
Konsler GK, Jones GR. Transition issues for survivors of childhood cancer and their healthcare providers. *Cancer Practice* 1993;**1**(4):319–24.

Kravitz 1996 ***{published data only}***
Kravitz RL, Delafield JP, Hays RD, Drazin R, Conolly M. Bedside charting of pain levels in hospitalized patients with cancer: a randomized controlled trial. *Journal of Pain & Symptom Management* 1996;**11**(2):81–7.

Kreuter 2004 ***{published data only}***
Kreuter MW, Sugg Skinner C, Steger-May K, Holt CL, Bucholtz DC, Clark EM, et al.Responses to behaviorally vs culturally tailored cancer communication among African American women. *American Journal of Health Behavior* 2004;**28**(3):195–207.

Kupst 1983 ***{published data only}***
Kupst M, Tylke L, Thomas L, Mudd M, Richardson C, Schulman J. Strategies of intervention with pediatric cancer patients. *Social Work in Health Care* 1983;**8**:31–47.

Last 1995 ***{published data only}***
Last BF, van Veldhuizen AM. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. *European Journal of Cancer* 1996;**32A**(2):290–4.

Levenson 1982 ***{published data only}***
Levenson PM, Pfefferbaum BJ, Copeland DR, Silberberg Y. Information preferences of cancer patients ages 11-20 years. *Journal of Adolescent Health Care* 1982;**3**(1):9–13.

Marchese 2004 ***{published data only}***
Marchese VG, Chiarello LA, Lange BJ. Effects of physical therapy intervention for chidlren with acute lymphoblastic leukemia. *Pediatric Blood Cancer* 2004;**42**:127–33.

Maung 1993 ***{published data only}***
Maung ZT, Taylor PR, Robinson P, Moore J, Lucraft HH, Evans RG, et al.Patient education for self-referral and on-demand treatment for herpes zoster in lymphoma patients. *Leukemia & Lymphoma* 1993;**11**(5-6):447–52.

McCarthy 1998 ***{published data only}***
McCarthy AM, Williams J, Plumer C. Evaluation of a school re-entry nursing intervention for children with cancer. *Journal of Pediatric Oncology Nursing* 1998;**15**(3): 143–52.

McEvoy 1985 ***{published data only}***
McEvoy M, Duchon D, Schaefer DS. Therapeutic play group for patients and siblings in a pediatric oncology ambulatory care unit. *Topics in Clinical Nursing* 1985;**7**(1): 10–18.

McMillan 2005 ***{published data only}***
McMillan G. What do researchers say? What do subjects hear? Not what they would like to hear. What do subjects need? More information. *Protecting Human Subjects* 2005: 10–1.

Miller 2005a ***{published data only}***
Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *Journal of Palliative Medicine* 2005;**8**(2):333–43.

Mulcahey 1995 ***{published data only}***
Mulcahey AL, Young MA. A bereavement support group for children: fostering communication about grief and healing. *Cancer Practice* 1995;**3**(3):150–6.

Nielsen 2003 ***{published data only}***
Nielsen JD, Palshof T, Mainz J, Jensen AB, Olesen F. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Quality and Safety in Health Care* 2003;**12**(4):263–72.

Nolan 1987 ***{published data only}***
Nolan T, Zvagulis I, Pless B. Controlled trial of social work in childhood chronic illness. *Lancet* 1987;**2**(8556):411–5.

Olechnowicz 2002 *{published data only}*
Olechnowicz JQ, Eder M, Zyzanski S, Simon C, Kodish E. Assent observed: children's involvement in leukemia treatment and research discussions. *Pediatrics* 2002;**109**(5): 806–14.

Oliveria 2004 *{published data only}*
Oliveria SA, Dusza SW, Phelan DL, Ostroff JS, Berwick M, Halpern AC. Patient adherence to skin self-examination: effect of nurse intervention with photographs. *American Journal of Preventive Medicine* 2004;**26**(2):152–5.

Orr 1984 *{published data only}*
Orr DP, Hoffmans MA, Bennetts G. Adolescents with cancer report their psychosocial needs. *Journal of Psychosocial Oncology* 1984;**2**(2):47–59.

Pangher Manzini 2003 *{published data only}*
Pangher Manzini V, Fabbroni G, Manzin F, Silli P, Todsco M. The global approach to the needs of the cancer patient: results of a prospective study [L'approccio globale alle necessita del paziente oncologico: risultati di uno studio prospettico]. *European Journal of Oncology* 2003;**8**(3): 205–9.

Petermann 1987 *{published data only}*
Petermann F. Psychosocial sequelae of cancer in children and adolescents: Retrospective and prospective studies [Psychosoziale Folgen der Krebserkrankung im Kindes– und Jugendalter: Retro– und prospektive Studien]. *Zeitschrift fuer Klinische Psychologie, Psychopathologie und Psychotherapie* 1987;**35**(1):16–25.

Powers 1993 *{published data only}*
Powers SW, Blount RL, Bachanas PJ, Cotter MW, Swan SC. Helping preschool leukemia patients and their parents cope during injections. *Journal of Pediatric Psychology* 1993; **18**(6):681–95.

Robb 2003 *{published data only}*
* Robb SL, Ebberts AG. Songwriting and digital video production interventions for pediatric patients undergoing bone marrow transplantation, Part I: an analysis of depression and anxiety levels according to phase of treatment. *Journal of Pediatric Oncology Nursing* 2003;**20** (1):2–15.
Robb SL, Ebberts AG. Songwriting and digital video production interventions for pediatric patients undergoing bone marrow transplantation, part II: an analysis of patient-generated songs and patient perceptions regarding intervention efficacy. *Journal of Pediatric Oncology Nursing* 2003;**20**(1):16–25.

Robinson 1994 *{published data only}*
Robinson JW, Scott CB, Faris PD. Sexual rehabilitation for women with gynecological cancer: Information is not sufficient. *Canadian Journal of Human Sexuality* 1994;**3**(2): 131–142.

Rollins 2005 *{published data only}*
Rollins JA. Tell me about it: drawing as a communication tool for children with cancer. *Journal of Pediatric Oncology Nursing* 2005;**22**(4):203–21.

Ruffin 1997 *{published data only}*
Ruffin JE, Creed JM, Jarvis C. A retreat for families of children recently diagnosed with cancer. *Cancer Practice* 1997;**5**(2):99–104.

Sahler 2002 *{published data only}*
Sahler OJZ, Varni JW, Fairclough DL, Butler RW, Noll RB, Dolgin MJ, et al.Problem-solving skills training for mothers of children with newly diagnosed cancer: a randomized trial. *Journal of Developmental and Behavioral Pediatrics* 2002;**23**(2):77–86.

Sahler 2005 *{published data only}*
Sahler OJZ, Fairclough DL, Phipps S, Mulhern RK, Dolgin MJ, Noll RB, et al.Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial. *Journal of Consulting and Clinical Psychology* 2005;**73**: 272–83.

Sanden 2002 *{published data only}*
Sandén I. The Swenoteca medical care program as a resource for patients and physicians. *Vård i Norden [Nursing Science and Research in the Nordic Countries]* 2002;**22**:33–7.

Silber 1986 *{published data only}*
Silber TJ, Rosenthal JL. Usefulness of a review of systems questionnaire in the assessment of the hospitalized adolescent. *Journal of Adolescent Health Care* 1986;**7**(1): 49–52.

Smith 1987 *{published data only}*
Smith KE, Gotlieb S, Gurvitch RH, Blotcky AD. Impact of a summer camp experience on daily activity and family interactions among children with cancer. *Journal of Pediatric Psychology* 1987;**12**(4):533–542.

Sobo 2004 *{published data only}*
Sobo EJ. Good communication in pediatric cancer care: a culturally-informed research agenda. *Journal of Pediatric Oncology Nursing* 2004;**21**(3):150–4.

Sourkes 1991 *{published data only}*
Sourkes BM. Truth to life: art therapy with pediatric oncology patients and their siblings. *Journal of Psychosocial Oncology* 1991;**9**(2):81–96.

Standley 1995 *{published data only}*
Standley JM, Hanser SB. Music therapy research and applications in pediatric oncology treatment. *Journal of Pediatric Oncology Nursing* 1995;**12**(1):3–10.

Stevens 1992 *{published data only}*
Stevens MM. 'Shuttle sheet': a patient-held medical record for pediatric oncology families. *Medical & Pediatric Oncology* 1992;**20**(4):330–5.

Stiegelis 2004 *{published data only}*
Stiegelis HE, Hagedoorn M, Sanderman R, Bennenbroek F, Buunk BP, Van Den Bergh ACM, et al.The impact of an informational self-management intervention on the association between control and illness uncertainty before and psychological distress after radiotherapy. *Psycho-Oncology* 2004;**13**:248–59.

Suzuki 2003 *{published data only}*
Suzuki LK, Kato PM. Psychosocial support for patients in pediatric oncology: the influences of parents, schools, peers and technology. *Journal of Pediatric Oncology Nursing* 2003; **20**(4):159–74.

Svavarsdottir 2005 *{published data only}*
Svavarsdottir EK, Sigurdardottir A. The feasibility of offering a family level intervention to parents of children with cancer. *Scandinavian Journal of Caring Sciences* 2005; **19**:368–72.

Tomamichel 1995 *{published data only}*
Tomamichel M, Sessa C, Herzig S, de Jong J, Pagani O, Willems Y, et al.Informed consent for phase I studies: evaluation of quantity and quality of information provided to patients. *Annals of Oncology* 1995;**6**(4):363–9.

Van Cleve 2002 *{published data only}*
Van Cleve L, Bossert EA, Savedra MC. Children with leukemia: pain, management and outcomes. *Communicating Nursing Research* 2002;**35**:292.

Wells 2003 *{published data only}*
Wells N, Hepworth JT, Murphy BA, Wujcik D, Johnson R. Improving cancer pain management through patient and family education. *Journal of Pain and Symptom Management* 2003;**25**(4):344–56.

Young 2003 *{published data only}*
Rogers M. Research and commentary: communication in cancer care. *Paediatric Nursing* 2004;**16**(1):12.
* Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ* 2003;**326**:305.

Zahr 1998 *{published data only}*
Zahr LK. Therapeutic play for hospitalized preschoolers in Lebanon. *Pediatric Nursing* 1998;**24**(5):449–54. [MEDLINE: 99050098]

Zappa 1991 *{published data only}*
Zappa SC. Education program for hematology-oncology patients and siblings. *Journal of Pediatric Oncology Nursing* 1991;**8**(2):88.

Zeltzer 1984 *{published data only}*
Zeltzer L, LeBaron S, Zeltzer PM. The effectiveness of behavioral intervention for reduction of nausea and vomiting in children and adolescents receiving chemotherapy. *Journal of Clinical Oncology* 1984;**2**(6): 683–90.

Zeltzer 1991 *{published data only}*
Zeltzer LK, Dolgin MJ, LeBaron S, LeBaron C. A randomized, controlled study of behavioral interventions for chemotherapy distress in children with cancer. *Pediatrics* 1991;**88**:34–42.

References to studies awaiting assessment

Macner-Licht 1998 *{published data only}*
Macner-Licht B, Rajalingram V, Bernard-Opitz V. Childhood leukemia: towards an integrated psychosocial intervention programme in Singapore. *Annals of the Academy of Medicine, Singapore* 1998;**27**(4):485–90.

Additional references

Axline 1947
Axline V. *Play therapy: The inner dynamics of childhood*. Boston, Mass.: Houghton Mifflin, 1947.

Cavusoglu 2000
Cavusoglu H. Problems related to the diagnosis and treatment of adolescents with leukemia. *Issues in Comprehensive Pediatric Nursing* 2000;**23**:15–26.

Dark 1999
Dark G. CancerWEB on-line medical dictionary. http://www.graylab.ac.uk/omd/index.html. Academic Medical Publishing & Cancer WEB, 1999.

Eden 1994
Eden OB, Black I, MacKinlay GA, Emery AE. Communication with parents of children with cancer. *Palliative Medicine* 1994;**8**:105–14.

Ely 1997
Ely EA. Collaborative practice with children and parents. Enhancing preparation for and management of cancer treatment. *Cancer Practice* 1997;**5**:387–90.

Foley 1989
Foley MK. Children with cancer: ethical dilemmas. *Seminars in Oncology Nursing* 1989;**5**:109–13.

Foley 1993
Foley GV. Enhancing child-family-health team communication. *Cancer* 1993;**71**:3281–9.

Freud 1946
Freud A. *The psychoanalitic treatment of children*. London: Imago, 1946.

Greenberg 1984
Greenberg LW, Jewett LS, Gluck RS, et al.Giving information for a life-threatening diagnosis. Parents' and oncologists' perceptions. *American Journal of Diseases of Children* 1984;**138**:649–53.

Harrington 1996
Harrington V, Lackey NR, Gates MF. Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing* 1996;**19**: 118–25.

Harter 1982
Harter S. The Perceived Competence Scale for Children. *Child Development* 1982;**53**:87–97.

Horstman 2002
Horstman M, Bradding A. Helping children speak up in the health service. *European Journal of Oncology Nursing* 2002;**6** (2):75–84.

Hughes 1990
Hughes PM, Lieberman S. Troubled parents: vulnerability and stress in childhood cancer. *British Journal of Medical Psychology* 1990;**63**:53–64.

Hytten 1992
Hytten K, Kaasa S. [Information and support to cancer patients. Experience from a course for young cancer patients

at the Montebello Center (see comments)]. [Norwegian]. *Tidsskrift for Den Norske Laegeforening* 1992;**112**:1839–40.

Kovacs 1983
Kovacs M (1983). The Children's Depression Inventory: A self-rated depression scale for school-aged youngsters. Unpublished manuscript, University of Pittsburgh.

Kreuger 1981
Kreuger A, Gyllenskold K, Pehrsson G, Sjolin S. Parent reactions to childhood malignant diseases: experience in Sweden. *American Journal of Pediatric Hematology-Oncology* 1981;**3**:233–8.

Last 1996
Last BF, van Veldhuizen AM. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8-16 years. *European Journal of Cancer* 1996;**32A**:290–4.

Mercer 1997
Mercer M, Ritchie JA. Home community cancer care: parents' perspectives. *Journal of Pediatric Nursing* 1997;**12**: 133–41.

Mulhern 1981
Mulhern RK, Crisco JJ, Camitta BM. Patterns of communication among pediatric patients with leukemia, parents, and physicians: prognostic disagreements and misunderstandings. *Journal of Pediatrics* 1981;**99**:480–3.

Naber 1995
Naber SJ, Halstead LK, Broome ME, Rehwaldt M. Communication and control: parent, child, and health care professional interactions during painful procedures. *Issues in Comprehensive Pediatric Nursing* 1995;**18**:79–90.

Nathanson 1984
Nathanson MN, Monaco GP. Meeting the educational and psychosocial needs produced by a diagnosis of pediatric/ adolescent cancer. *Health Education Quarterly* 1984;**10 Suppl**:67–75.

Peller 1954
Peller L. Libidinal phases of ego development and play. In: R Eissler, A Freud, H Hartmann, & E Kris editor(s). *The psychoanalytic study of the child*. Vol. **9**, New York: International Universities Press, 1954:178–198.

Rosenberg 1979
Rosenberg M. *Conceiving the Self*. New York: Basic Books Inc., 1979.

Spielberger 1973
Spielberger CD. *STAIC preliminary manual*. Palo Alto, CA: Consulting Psychologists Press, 1973.

Spielberger 1983
Spielberger CD. *Manual for the Stait-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press, 1983.

Verri 1985
Verri AP, Scattolin O, Nespoli L, Burgio GR. [The leukemic child after therapy. Psychological aspects]. [Italian]. *Pediatria Medica e Chirurgica* 1985;**7**:545–8.

Wallston 1976
Wallston K. Development and validation of the health locus of control scale. *Journal of Consulting and Clinical Psychology* 1976;**44**(4):580–5.

Yalom 1975
Yalom I. *The Theory and Practice of Group Psychotherapy*. New York: Basic Books Inc., 1975.

Zung 1965
Zung W. A self-rating depression scale. *Archives of General Psychiatry* 1965;**12**:63–70.

References to other published versions of this review

Scott 2001
Scott JT, Entwistle VA, Sowden AJ, Watt I. Communicating with children and adolescents about their cancer. *Cochrane Database of Systematic Reviews* 2001, Issue 1.

Scott 2003
Scott JT, Harmsen M, Prictor MJ, Sowden AJ, Watt I. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database of Systematic Reviews* 2003, Issue 3. [DOI: 10.1002/ 14651858.CD002969]

* *Indicates the major publication for the study*

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Baider 1989

Methods	Objective: to evaluate the effectiveness of a group therapy intervention on the psychological status and communication behaviour of adolescent and young adult cancer patients Study design: Before and after study (uncontrolled). Recruitment: not stated. Allocation: N/A Assessor blind: N/A Informed consent: yes. Total number approached: 16. Number agreed to participate: 8. Method of analysis: Fisher's exact probability test; Pearson correlation coefficient Follow up: 100%.
Participants	Country: Israel. Clinical setting: oncology department of teaching hospital. Inclusions: young adults suffering from neoplastic disease and either in remission or receiving ambulatory treatment Exclusions: none stated. Diagnosis: neoplastic disease (Hodgkin's, disease stages IIA, IIB, and IIIB, Ewing's sarcoma, nasopharyngeal, rhabdomyosarcomas) Stage of illness/treatment: half of those who participated were in remission at the time of the study. All patients who refused group therapy had signs of active disease, and all but 1 were in active treatment Age: 15 to 25. Gender: not stated. Ethnicity: Jewish.
Interventions	Aims: the group therapy had a two-fold purpose: to prepare the participants for a support role in helping other patients in coping with cancer; and to provide a forum for the sharing and discussing of concerns arising from participants' experiences of their illness and their patterns of coping with it Participants attended weekly group therapy sessions of 1.5 hours each (number of sessions not stated). The group therapy sessions were dynamic in responding to participants' needs, as opposed to following a thematic structure imposed by the therapists N = 8. Theoretical basis: coping theory.
Outcomes	Timing of outcome assessment: 3 months. Psychological, social and behavioural outcomes: (1) a range of psychologic symptoms was measured by the Brief Symptom Inventory (BSI), (Derogatis and Melisaratos 1983); (2) degree of distress was measured by the Global Severity Index (GSI)
Notes	Power calculation: not stated. All 8 patients who refused to participate in the group had been diagnosed within the previous 6 months, and all those who agreed to participate had been diagnosed for more

	than 18 months (P < 0.01)

Risk of bias

Bias	Authors' judgement	Support for judgement
Allocation concealment (selection bias)	Unclear risk	D - Not used

Dragone 2002

Methods	Objective: to evaluate the effectiveness of an interactive CD-ROM for children with leukemia and their family, on the child's health locus of control, their understanding of leukemia, and satisfaction with the CD-ROM Study design: RCT with pre- and post-tests. Recruitment: convenience sample. Allocation: participants were randomly assigned to either the CD-ROM or comparison group at the time of registration, in a balanced 4-block randomisation pattern by age-group and institution Assessor blind: no. Informed consent: yes, for parents, and for children aged seven and over Total number approached: 137. Number agreed to participate: 41. Method of analysis: KR-20 tests for internal reliability, analysis of variance (ANOVA) using the general linear models (GLM) Intention-to-treat: not stated. Follow up: 31 out of 41 (76%).
Participants	Country: USA. Clinical setting: hospital. Inclusions: age 4 to 11 years; a diagnoses of Acute Lymphoblastic Leukemia (ALL) or Acute Myelogenous Leukemia (AML) in first remission, currently undergoing treatment or less than three years since the end of treatment; ability to understand spoken English; absence of a severe learning disability; lack of participation in any earlier focus groups about the CD-ROM development; and consent to participate for children 7 years of age and older. Additionally, parents had to understand spoken English and either the child or the parent had to be able to read materials written in English, in case the child was randomly assigned to the control group receiving printed text Exclusions: not stated. Diagnoses: Acute Lymphoblastic Leukemia (ALL) or Acute Myelogenous Leukemia (AML) State of illness/treatment: in first remission, or undergoing treatment or less than three years since the end of treatment Age: 4 to 11 years. Gender: not stated. Ethnicity: Caucasian, Latino, African American, Asian, other
Interventions	Aims: to educate children about their cancer and to give them greater feelings of control I (n = 15): received the CD-ROM 'Kidz with Leukemia: A Space Adventure' to use for approximately three months. The CD-ROM is tailored to three age groups: 4 to 6 year

	olds, 7 years and older, or adult. A 'Space Buddy' is the user's guide. Before users explore the planet 'Leukator' they are presented with three main facts about leukemia. The contents of the program include: 'The Get Better Place' (research studies, medicines, treatment, health care team), 'Help Yourself' (areas in which children can exert some control, including nutrition, preventing infections, pain control, creative arts, and relaxation techniques) , 'The Testing Centre' (bone marrow tests and spinal taps, blood tests, radiology tests, heart testing, and vital signs), 'The Fill and Fly' (red blood cells, white blood cells, and platelets), 'The Space Mall' (changes in appearance, central venous catheters, anatomy and physiology, and resource/reference section), and 'The Movies' (video hospital tour, living with leukemia, expert explanation of leukemia, and siblings' views of leukemia). The contents are presented interactively using video, animation, puzzles and games. Some sections of the program are designed for children 7 years and older, and adults, such as (7 years plus) 'Taking Part in Research', and (adults) 'Frequently Asked Questions for Parents', NCI's 'Physician Data Query', and the 'Resource Section' with hyperlinks to selected sites for those with internet access. Four commonly used multisyllabic words (leukemia, medicine, chemotherapy, infection) are defined via print and audio in the 'Book of Big Words' section, available to all users C (n=16): received a book 'You and Leukemia' (Baker, 1988), to use for approximately three months N=31. Theoretical basis: (1) Social Learning Theory, (2) theory that there is a dynamic relationship between how children cognitively represent and organise their experiences and how they adjust to these experiences
Outcomes	Timing of outcome assessment: pre- and post-test. Psychological, social and behavioural outcomes: (1) health locus of control was measured by the Leukemia Children's Health Locus of Control (LCHLC) scale; (2) knowledge about leukemia was measured by the Leukemia Event Knowledge Interview (LEKI); satisfaction with and use of the CD-ROM was measured by questionnaire
Notes	Power calculation: not stated. The small sample size and relatively high educational level of the children's primary care-givers are the study's greatest limitations to generalisability Participating children were given the option of receiving either US$25 or a copy of the completed CD-ROM as compensation

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	High risk	C - Inadequate

Favara-Scacco 2001

Methods	Objective: to evaluate the effects of an art therapy intervention to support patients during lumbar puncture (LP) or bone marrow aspiration (BMA) Study design: non-randomised controlled trial with an historical control Recruitment: not stated. Allocation: historic. Assessor blind: unclear. Informed consent: not stated. Total number approached: not stated. Number agreed to participate: 49. Method of analysis: statistical analysis not carried out. Intention-to-treat: yes Follow up: 100%.
Participants	Country: Italy Clinical setting: University Department of Pediatric Hematology and Oncology Inclusions: leukemic children who were candidates for LP or BMA Exclusions: none stated. Diagnosis: leukemia. Stage of illness/treatment: not stated. Age: 2 to 14 years (age 2 to 5: n=14; age 6 to 10: n=22; age 11 to 14: n=13) Gender: not stated. Ethnicity: not stated.
Interventions	Aims: to support children with leukemia during LP or BMA. To prepare them for the intervention, comfort them during the intervention and help them regain control and a sense of calm and self-assurance after the intervention I (n=32): Art Therapy (AT) offered by a psychologist-art therapist, consisting of: clinical dialogue to calm children and help them cope with painful procedures; visual imagination to activate alternative thought processes and decrease the attention towards overwhelming reality and raise the peripheral sensitivity gate; medical play to clarify illness, eliminate doubts and offer control over threatening reality; structured drawing to contain anxiety by offering a structured, predictable reality (the drawing) that was controllable by children; redundant reading; free drawing to allow children to externalize confusion and fears; and dramatization to help children accept and reconcile themselves to body changes C (n=17): no art therapeutic support. The accompanying parent was present during the intervention. N=49. Theoretical basis: not stated.
Outcomes	Timing of outcome assessment: before, during and after LP or BMA Psychological, social and behavioural outcomes: adoption of 'positive behaviours'
Notes	Power calculation: not stated. A pilot study.

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**

Allocation concealment (selection bias)	Unclear risk	D - Not used

Frick 1987

Methods	Objective: to evaluate the effectiveness of a directed play and story telling intervention, on the anxiety of children with cancer attending a bone marrow aspiration (BMA) Study design: non-randomised controlled trial. Recruitment: all eligible children in study period were invited to participate Allocation: children matched by age and number of BMAs before allocation to 3 groups - precise method not stated Assessor blind: no - researcher present during play sessions Informed consent: yes (parents and child). Total number approached: not stated Number agreed to participate: 15 (26 recruited but 11 lost prior to start of study) Method of analysis: not stated. Intention-to-treat: not stated. Follow up: not stated.
Participants	Country: USA. Clinical setting: paediatric oncology clinic in teaching hospital Inclusions: (1) aged 3 years to 14 years; (2) medical diagnosis of cancer; (3) scheduled for a BMA during the study Exclusions: none stated. Diagnosis: all participants had leukaemia. Stage of illness/treatment: stage of illness not stated but 6/15 participants had received more than 15 BMAs, 5/15 had received 6 to 15 and 4/15 had received fewer than 6 Age: 3 years, 9 months to 12 years, 11 months (mean: 6 years, 4 months) Gender: male: n = 8, female: n = 7. Ethnicity: not stated.
Interventions	Aims: to help children cope with the psychological upset associated with the various injections used in BMAs I1 (n = 6): diversional play + planned BMA play intervention based on mutual story-telling format (using actual medical equipment and anatomically correct dolls with removable hair) before and after the BMA. The children played out a BMA and constructed a story about the situation with the researcher I2 (n = 5): diversional play + planned BMA play intervention before the BMA only C (n = 4): routinely available diversional play only. The accompanying parent was present during the intervention. N = 15. Theoretical basis: psychoanalytical theory of child stress, play and communication (Axline 1947; Erickson 1936, 1972; Freud 1946, Peller 1954).
Outcomes	Timing of outcome assessment: before and after the play intervention and BMA (I1 & I2) ; before and after the BMA (C) Psychological, social and behavioural outcomes: state anxiety was measured by the State Anxiety Inventories (SAI) for adults and children (applied to children aged 8 years or older) , (Spielberger 1973, 1983).

Frick 1987 (*Continued*)

	Physical outcomes: the pulse rates of each child and parent.
Notes	Power calculation: not stated. The researcher observed a lack of verbal interactions between 'patient' and 'provider' during the dramatised play, in contrast to what happened in the actual BMA. In response to the researcher's questions, most of the children denied that the fictional child, doctor or nurse said or felt anything during the BMA The children often played out the BMA incorrectly, although they accurately reproduced in fine detail other procedures commonly carried out during a typical BMA A number of interpretations of these process variables are discussed

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	Unclear risk	B - Unclear

Heiney 1988

Methods	Objective: to evaluate the effectiveness of participation in a support group on aspects of psychosocial functioning of adolescents with cancer Study design: non-randomised controlled trial. Recruitment: convenience sample. Allocation: unclear Assessor blind: not stated. Informed consent: obtained from parents of minors and from participants over 18 years of age Total number approached: not stated. Number agreed to participate: not stated. Method of analysis: The mean difference between before and after scores was calculated for each group. An independent samples t-test was used to compare the two groups Intention-to-treat: not stated. Follow up: not stated.
Participants	Country: USA. Clinical setting: paediatric oncology centre. Inclusions: ages 15 to 19 years, being followed at the paediatric oncology centre Exclusions: none stated. Diagnosis: participants in both groups had a variety of cancer diagnoses Stage of illness/treatment: stage of illness not stated but individuals both on and off therapy participated Age: 14 to 19 years. Gender: 9 males; 7 females; (I) male: n = 4, female: n = 3; (C) male n = 5, female: n = 2 Ethnicity: not stated.
Interventions	Aims: to: (1) support and assist adolescents through peer interaction, (2) stimulate new ways of dealing with situations, (3) decrease a sense of isolation I (n = 7): 6 weekly 1-hour structured group therapy sessions focused on topics reflecting

Heiney 1988 (*Continued*)

	problems that adolescents with cancer must face: diagnosis, treatment, school and peer relations, parents and the future, including death C (n = 7): usual supportive care. N = 14. Theoretical basis: coping theory; group psychotherapy (Yalom 1975).
Outcomes	Timing of outcome assessment: baseline assessment prior to the beginning of the group. Follow-up assessment at the end of six 1-hour sessions Psychological, social and behavioural outcomes: (1) belief about the self was measured by the Rosenberg Self-Esteem Scale (Rosenberg 1979); (2) perceived control over one's health was measured by the Wallston Health Locus of Control Scale (Wallston 1976); (3) the presence of depression was measured by the Zung Depression Scale (Zung 1965); (4) state anxiety was measured by the Spielberger State Anxiety Scale (Spielberger 1983).
Notes	Power calculation: not stated.

Risk of bias

Bias	Authors' judgement	Support for judgement
Allocation concealment (selection bias)	Unclear risk	B - Unclear

Hinds 2000

Methods	Objective: to evaluate the effects of a three-part educational intervention designed to facilitate self-care coping on psychological and clinical outcomes among adolescents newly diagnosed with cancer Study design: a randomised, longitudinal, experimental two-group design Recruitment: all adolescents with newly diagnosed cancer who were receiving in-patient or out-patient treatment at a 48-bed pediatric cancer centre in the mid-south and those who were admitted to the pediatric oncology service in a large academic medical centre in the mid-west (who met the study criteria) were invited to participate Allocation: randomisation included stratification by diagnosis Assessor blind: Not stated. Informed consent: Potential participants and their parents were given a standardized explanation of the study. Written consent from both patients and parents was obtained Total number approached: 93. Number agreed to participate: 78. Method of analysis: Non-parametric statistical techniques, Spearman's correlational statistic, Wilcoxon rank-sum test, Wilcoxon signed ranks test Intention-to-treat: yes. Follow up: 78 adolescents completed the study instruments at baseline, 62 at the second data point and 55 at the third and fourth data points
Participants	Country: USA. Clinical setting: paediatric cancer centre; paediatric oncology service in a large academic medical center Inclusions: patients aged 12 to 21 years; English-speaking; with a newly diagnosed malig-

	nancy; enrolled on an institutional or co-operative group treament protocol for osteosarcoma, Ewing's sarcoma, acute lymphocytic leukemia, Hodgkin's disease or rhabdomyosarcoma; and scheduled to receive treatment for at least six months Exclusions: not stated. Diagnoses: osteosarcoma, Ewing's sarcoma, acute lymphocytic leukemia, Hodgkin's disease, primitive neuroectodermal tumour, rhabdomyosarcoma Stage of illness/treatment: newly diagnosed. Age: range from 12 to 21 years, with an average of 16.0 years (SD 2.1 years) Gender: Male (n = 32) and female (n = 46). Ethnicity: white (n = 68) and black (n = 10).
Interventions	Aims: to facilitate self care-coping. I (n = 40): the study intervention was based on metacognition principles and lasted about 40 minutes. The three components of the intervention comprised 1) information on self-care coping provided verbally by one of two nurse researchers or one social worker, 2) a 25-minute video in which four adolescents demonstrated or described behavioural and coping strategies that they had found helpful and 3) a rehearsal of those strategies which the study particpant selected as most likely to help him or her cope with the demands of treatment. Each of the adolescents in the intervention group worked individually with one of the researchers. Patients were instructed to use their chosen strategies during treatment and to monitor the effectiveness of these strategies C (n = 38): patients spent an amount of time with one of the researchers equivalent to the intervention, discussing topics of their choosing. They were given the opportunity to learn the self-care coping strategies after T4 N = 78. Theoretical basis: The Adolescent Self-Sustaining Model (Hinds & Haase 1998, Hinds & Martin 1988)
Outcomes	Timing of outcome assessment: four measurement points spanning the first six months of treatment: T1: pre-intervention, soon after chemotherapy had begun (1 to 12 days after diagnosis); T2: post-intervention, 5 to 7 weeks after diagnosis; T3: post-intervention, 3 months after diagnosis; T4: post-intervention, 6 months after diagnosis Psychological, social and behavioural outcomes: Nowick-Strickland Locus of Control Scale (NSLC) to measure the perceptions of children and adolescents regarding the relationship between their actions and the consequences; Hopefulness Scale for Adolescents (HAS); The Hopelessness Scale (HPLS) to measure negative expectations of the future in children aged 7 and older; The Rosenberg Self-Esteen Scale (RSE) to measure self-esteem in adolescents; The Self-Efficacy Scale (SES) to measure general belief in one's competence Physical outcomes: Symptom Distress Scale (SDS) to measure an individual's perceived degree of discomfort from specific symptoms; The NCI Common Toxicity Criteria (CTC) to measure toxicity secondary to treatment or disease
Notes	Power calculation: not stated. Several of the study instruments would not be used in the next testing of the intervention because of inadequate internal consistency, inabilty to capture changes and because of the burden on patients in terms of time needed to complete the entire battery of instruments The lack of statistically significant differences between the two groups on outcome measures could reflect an insufficiently powerful or mistimed intervention, or a mismatch between patient and intervention

Hinds 2000 (*Continued*)

Risk of bias		
Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	Unclear risk	B - Unclear

Katz 1988

Methods	Objective: to evaluate the effectiveness of an intervention to facilitate the successful school and social reintegration of children and adolescents newly diagnosed with cancer Study design: before and after study with retrospective control Recruitment: I - consecutive sample, C - retrospective sample Allocation: historic. Assessor blind: not stated. Informed consent: yes (parents'). Total number approached: not stated. Number recruited: I = 49, C = 36. Method of analysis: The impact of the intervention package on the school reintegration process was evaluated by comparing (1) the intervention group's before and after data and (2) the intervention group's post-intervention data and data obtained from the control group. The t test was used to assess differences Intention-to-treat: yes, but see Follow up. Follow up: percentages varied with different instruments: Child Behavior Checklist: 27/49 (55%); Child Depression Inventory and Perceived Competence Scale for Children: 35/49 (71%); Deasy-Spinetta Behavioral Questionnaire and Teacher's Rating of Child's Actual Competencies: 32/49 (65%)
Participants	Country: USA. Clinical setting: Children's Hospital. Inclusions (I): children newly diagnosed with cancer between November 1982 and April 1984; (C) children diagnosed within 36 months before the project began Exclusions: children with brain tumours. Diagnosis: acute leukaemia (37), solid tumour (31), lymphoma (17) Stage of illness/treatment: not stated. For a minority of patients who were in an acute medical crisis informed consent was usually obtained within 4 to 6 weeks after the diagnosis, when their condition had stabilised Age: 5 to 17 years. Gender: male: n = 43, female: n = 42. Ethnicity: White 43, Hispanic 29, Other 2.
Interventions	Aims: to faciliate the successful school and social reintegration of children and adolescents newly diagnosed with cancer I (n = 49): School Intervention Package including the following components: 1. Preliminary intervention activities. The psychologists discussed the importance of school reintegration with family, medical staff, and school personnel. They also helped to arrange interim educational programmes and maintained regular contact with schools. Parents and patients received direct counselling about the emotional impact of returning to school and the possibility that classmates would ask the patients questions or tease them about the

	visible side effects of treatment. The psychologists counselled school personnel and assisted with special educational services. They also helped school personnel to plan for predictable problems such as absenteeism, learning disabilities, physical disabilities, social isolation, anxiety, and fear. 2. Conferences with school personnel. The psychologists held conferences with school personnel to help them to understand basic issues about the patient's illness and treatment. They presented specific information about the scheduling of medical treatments and their side effects, and helped review plans for absences. They also discussed psychosocial issues such as the ability of children with cancer to participate in school and the reactions of teachers and other school staff to seriously ill children being in school. The patient's special educational needs were reviewed and an Individualized Educational Plan was developed. 3. Classroom presentations. During presentations to the patient's classmates, with the patient present, the psychologists countered the children's tendency to believe the patient to be unique owing to his or her medical condition, by exploring the natural differences in populations. The psychologists then provided age-appropriate information about the patient's illness and the medical procedures and treatment he or she had received. They continually tried to dispel common myths about cancer being contagious, hopeless or a punishment. They also reviewed the common side effects of treatment - e.g., nausea, hair loss, weight gain, immunosuppression. They led a discussion on the importance of social support to anyone with medical needs and disabilities. They also pointed out the negative consequences of teasing and the positive consequences of friendship. Finally, to facilitate communication between patients and their classmates, the psychologists established the patient as the resident expert on his or her disease and treatment. 4. Follow-up. After the patient had returned to school, the psychologists contacted the patient, parents, and teachers periodically to insure that the process of reintegration continued throughout the course of the patient's illness. Complications of the disease were addressed as they occurred. If the patient's health deteriorated, they prepared teachers and other school personnel for the patient's impending death, offered guidelines and suggestions for preparing classmates, and, when necessary, helped school personnel and classmates with their grief and bereavement C (n = 36): did not receive the School Intervention Package. No further information given N = 85. Theoretical basis: not stated.
Outcomes	Timing of outcome assessment: the intervention group was assessed twice: within 30 days after diagnosis, before receiving the school intervention package; and again at the end of the study. The interval between before and after assessments ranged from 1.2 months to 15 months (mean, 8.87 months). The control group was assessed once, with the time between diagnosis and testing ranging from 3.7 months to 37.1 months (mean, 21 months) Psychological, social and behavioural outcomes: Cognitive, social, physical and general competence were measured by the Patients' Perceived Competence Scale for Children (Harter 1982). Depression was measured by the Children's Depression Inventory (Kovacs 1983). Behaviour problems and social competency were measured by the Child Behavior Checklist (Achenbach & Edelbrock 1983), completed by parents Teachers completed two instruments. Cognitive, social and physical competency were measured by the Teacher's Rating of Child's Actual Competencies (Harter 1982). Total adjustment was measured by the Deasy-Spinetta behavioral Questionnaire (Deasy-Spinetta &

Katz 1988 (*Continued*)

	Spinetta 1980) Teachers also supplied data on patients' absences from school and their grades	
Notes	Power calculation: no.	
Risk of bias		
Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	Unclear risk	D - Not used

Klosky 2004

Methods	Objective: to evaluate the efficacy of an interactive intervention designed to reduce distress related to radiation therapy among paediatric cancer participants Study design: randomised controlled trial. Recruitment: Children receiving radiation therapy at St. Jude's Children's Research Hospital research aged 2 to 7 years Allocation: participants were randomly allocated after baseline observation and data collection to the intervention group or a modified control group - precise method not stated Assessor blind: No. Informed consent: yes, for parents. Total number approached: 80 families. Number agreed to participate: 79 families. Method of analysis: Fisher's exact tests, ANOVAs. Intention to treat: yes. Follow up: 100%
Participants	Country: USA Clinical setting: Children's research hospital. Inclusions: Children aged 2 to 7 years whose primary language was English, who had a primary diagnosis of malignancy, had no experience with external beam irradiation, and were functioning at a level at which they could tolerate radiation therapy intervention (Eastern Cooperative Oncology Group (ECOG) score of 0 to 3) Exclusions: Patients who were physically debilitated (i.e. functional impairment; ECOG score of 4) Diagnosis: Malignancy (Central nervous system; leukemia; solid tumor) Stage of illness/treatment: functioning at a level at which they could tolerate radiation therapy intervention (ECOG functional status: 81% no impairment; 13% minimal impairment; 6% mild impairment) Age: mean 4.2 years (SD 1.6). Gender: 37 female, 42 male. Ethnicity: 58 Caucasian, 17 African American, 4 Hispanic.
Interventions	Aims: to reduce distress among children with malignancy undergoing non-invasive medical procedures Barney intervention group: n = 41. Children received a cognitive behavioural package which included a 7-minute educational video with filmed modelling, exposure to an animated

	interactive character (Barney) and passive auditory distraction using Barney-narrated stories during the radiation therapy designed to calm and distract the child Modified control group: n = 38. Children received exposure to an animated non-interactive character, a cartoon video (selected by the child) but no filmed modelling, stories delivered via cassette during RT simulation but not Barney-narrated stories. The author noted that these components did not form part of standard treatment for children at the hospital Theoretical basis: psychological intervention using cognitive behavioural therapy
Outcomes	Timing of outcome assessment: data collection began as soon as the child entered the simulation room until the procedure was completed or until sedation was administered Psychological, social and behavioural outcomes: 1) Sedation was assessed by whether any type of pharmacotherapy was delivered at the time of the simulation initiation for the purpose of ensuring compliance with the procedure; 2) behavioural distress was measured using a version of the Observation Scale of Behavioural Distress (Jay, Ozolins, Elliott and Caldwell 1983), modified for use within the radiation therapy setting. In addition the parents rated their own state anxiety using the Spielberger State-Trait Anxiety Inventory (STAI) but these results were not reported Physical health outcomes: Distress and anxiety were measured using mean heart rate per minute
Notes	Power calculation: yes

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	Unclear risk	B - Unclear

Petersen 1996

Methods	Objective: to evaluate the effectiveness of a computer-assisted instructional program on blood counts for paediatric patients Study design: before and after (uncontrolled). Recruitment: convenience sample. Allocation: N/A Assessor blind: N/A Informed consent: not stated. Total number approached: not stated. Number agreed to participate: 15. Method of analysis: dependent t test. Intention-to-treat: not stated. Follow up: not stated.
Participants	Country: USA. Clinical setting: tertiary care facility. Inclusions: not stated. Exclusions: not stated. Diagnosis: haematological or oncological disease.

Petersen 1996 (*Continued*)

	Stage of illness/treatment: not stated but variable lengths of time since diagnosis Age: 9 to 16 years (mean 13 years). Gender: not stated. Ethnicity: Caucasian.
Interventions	Aims: to prepare children with cancer about the possible side-effects and symptoms they would experience as a result of the myelosuppression from their chemotherapy Participants used a computer program entitled "What Are Blood Counts?" containing information about the function of the red blood cells, white blood cells and platelets, normal values of each, and the signs and symptoms of low levels of each type of blood cell. Computer text, graphics and sound were used to provide the information in an entertaining way. The program was interactive and required the learner to mouse-click the correct answers to proceed. The children could choose to print out summary information sheets at the end of the program. The author was with the child as they used the program to answer questions about it but not to assist with questions about the content. All participants had prior experience with a computer through their school N = 15. Theoretical basis: not stated.
Outcomes	Timing of outcome assessment: at the completion of the program Knowledge and understanding: the before and after assessments were identical, consisting of 8 multiple-choice questions relating to information presented in the program
Notes	Power calculation: N/A. An ability to answer multiple choice questions correctly may not correlate with being better prepared for side-effects and symptoms: it is only one possible dimension of such preparation The children reported that the program was an entertaining method of learning about blood counts and four used the information sheets printed at the conclusion of the program for school projects In most cases the children used the program while their parents observed and the parents reported that they too found the program informative. The program also stimulated discussion between parents and children about the content and how some of the children had experienced some of the symptoms mentioned in the program

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation concealment (selection bias)	Unclear risk	D - Not used

Varni 1993

Methods	Objective: to evaluate the effectiveness of prospective social skills training on psychological, social and behavioural outcomes in children with newly diagnosed cancer (compared to standard school reintegration) Study design: randomised controlled trial. Recruitment: consecutive sample. Allocation: after T1 assessment, participants were assigned through stratified randomisation, stratifying for age Assessor blind: not stated. Informed consent: written informed consent from parents and written assent from the child were required for study participation Total number approached: not stated. Number agreed to participate: 77 (13 dropped out prior to randomisation) Method of analysis: ANCOVA, chi-square, t tests, and one-way analysis of variance Intention to treat: yes. Follow up: 54/64 (84.4%).
Participants	Country: USA. Clinical setting: two paediatric cancer centres. Inclusions: English-speaking school-aged children with newly diagnosed cancer in Grades K through 8 receiving medical treatment Exclusions: none stated. Diagnosis: Acute lymphocytic leukaemia (19), Hodgkin's lymphoma (5), non-Hodgkin's lymphoma (2), Wilm's tumour (1), Neuroblastoma (1), Rhabdomyosarcoma (1), brain tumour (2), other (2) Stage of illness/treatment: newly diagnosed and receiving medical treatment. Gender: 5 to 13 (mean=8) Sex: male: n=38, female: n=36. Ethnicity: White (17), Hispanic (11), Asian (4), American Indian (1), Black (0)
Interventions	Aims: to provide explicit social skills training to enhance adjustment and perceived social support above and beyond the effects of standard school reintegration I (n=33): received social skills training in addition to routine school reintegration services provided at each centre. Social skills training comprised 3 individual 60-minute sessions with a research assistant who guided the participants through a structured curriculum. Each session was devoted to one of the following areas: 1. Social Cognitive Problem-Solving. The children were taught to problem-solve cancer-related interpersonal difficulties with peers, teachers, parents, and siblings as they occurred. 2. Assertiveness Training. The children were taught how to effectively express their thoughts, wishes, and concerns to others. 3. Handling Teasing and Name-Calling. The children were taught how to cope with verbal and physical teasing associated with changes in their physical appearance (e.g., hair loss, weight gain or loss, surgical disfigurement). Detailed handouts were given to the children and their parents to facilitate generalisation of the skills taught to the child's home and school environment. Two 15-minute videotapes were developed, one for children aged 5 to 8 years, and one for children aged 9 to 13 years. Actual school situations were modelled that demonstrated the coping strategies taught.

	The children were also instructed in an abbreviated cue-controlled relaxation procedure to counteract social anxiety associated with physiological arousal that might inhibit social skill performance. The children were given specific homework assignments at the end of each session. Parents were given one training session and encouraged to support their child's social cognitive problem solving efforts at home and school throughout the intervention phase. The children were seen for two follow-up social skills training booster sessions at 3 weeks and 6 weeks following their return to school. These sessions reviewed the child's actual school and home experiences, offered suggestions as to how children could most effectively utilise the skills that were taught, and the children were once again shown the social skills videotapes C (n=31): received the routine school reintegration services provided at each centre. Children were provided basic assistance in their reintegration into school by hospital-based paediatric psychologists. They received a minimum of 2 hours of individual intervention as part of their routine school reintegration services, as well as approximately equal time with a research assistant linked to the time spent with the intervention group. This consisted of 5 sessions of play interaction with the research assistant as an attention-control condition linked temporally with the intervention sessions The routine school reintegration intervention for both intervention and control groups consisted of the following components: (a) early preventive education and support for patients, parents, medical and school staffs about the importance of rapid return to school when medically feasible; (b) school conferences and classroom presentations to demystify the cancer experience for classmates and teachers, with direct patient participation whenever possible; (c) regular follow-up with all concerned to ensure that progress was maintained N = 64. Theoretical basis: not explicit.
Outcomes	Timing of outcome assessment: Time 1 (T1, pre-intervention) within 1 month of diagnosis; Time 2 (T2, posttreatment follow-up) at 6 months postdiagnosis; and Time 3 (T3, follow-up) at 9 months postdiagnosis. These assessment intervals were selected in order to acquire data on the children prior to return to school (T1), following intervention and return to school (T2), and a subsequent longer follow-up period (T3) Psychological, social and behavioural outcomes: Child Self-Report (administered to children 8 years of age and older), including: (1) Child's Depression Inventory (CDI; Kovacs, 1983). (2) Stait-Trait Anxiety Inventory for Children (STAIC; Spielberger, 1973). (3) General self-esteem was measured by the Self-Perception Profile for Children (SPPC; Harter, 1985a). (4) Perceived social support was measured by the Social Support Scale for Children (SSSC; Harter, 1985b) Parent Report (completed for children 5 to 13 years of age), including: (1) Behaviour and emotional problems, measured by the Child Behavior Checklist-Parent Report Form (CBCL; Achenbach, 1991). (2) Social competence, measured by the CBCL social competence scale (Achenbach, 1991)
Notes	Power calculation: yes, but a sample size needed to avoid a Type II error was not achieved. To compensate for this a priori planned t tests were conducted within groups to test pretreatment to follow-up statistical significance on all outcome measures The study authors state that "it became quite evident as the present study progressed that

	not all children who were entered into the study required explicit social skills training, while other children were clearly at greater risk for social skills deficits and problematic peer interactions". This has implications for identifying subgroups of children who are at greatest risk and most likely to benefit from interventions tailored to their individual needs The outcomes for which statistically significant before/after differences were found tended to differ between T2 and T3

Risk of bias

Bias	Authors' judgement	Support for judgement
Allocation concealment (selection bias)	Unclear risk	B - Unclear

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Allen 1997	Not an intervention study.
Antonov 2004	Does not address a cancer population; case study.
Askey 1982	Does not address a cancer population.
Barakat 2003	Population is comprised of survivors of cancer.
Barlow 2004	Not an intervention study.
Barrera 2002	Not an information/communication intervention.
Baruch 2003	Not an intervention study.
Basch 2005	Does not address children/adolescents.
Baysinger 1993	Not a controlled or before and after study.
Beale 2003	Not an intervention study.
Benner 1991	Intervention does not target child about his/her cancer.
BluebondLangner 1990	Not an information/communication intervention.
Bradlyn 2003	Not an intervention study.
Carr-Gregg 1986	Not an intervention study.

(*Continued*)

Claflin 1991	Not an intervention study.
Cohen 1989	Not an intervention study.
Conway 1996	Not a controlled or before and after study.
Cooper 1985	Not a controlled or before and after study.
Cotanch 1985	Not an information/communication intervention.
Councill 1993	Not a controlled or before and after study.
de Gonzalez 1997	Not an intervention study.
De Trill 1997	Not an intervention study.
Di Giulio 2004	Not an intervention study.
Diez 1997	Not an intervention study.
Dobish 2003	Does not address a majority of children/adolescents.
Doorenbos 2005	Does not address children/adolescents.
Dorn 1995	Not an information/communication intervention.
Eiser 1986	Does not address a cancer population.
Fahrenheim 1993	Does not address a cancer population.
Ford 2005	Not an intervention study.
Freeman 1991	Not a controlled or before and after study.
Gariépy 2003	Not an information/communication intervention.
Gershon 2004	Not an information/communication intervention.
Gibbons 1986	Not an intervention study.
Glazer 1997	Not an intervention study
Haberle 1997	Not an information/communication intervention.
Hanna 1993	Not a controlled or before and after study.
Hartwich 1979	Not a controlled or before and after study.

(*Continued*)

Heiney 1990	Not a controlled or before and after study.
Heiney 1991	Not a controlled or before and after study.
Hinds 2001	Not a controlled or before and after study; not an intervention study
Hooker 1996	Not an information/communication intervention
Jankovic 1994	Not a controlled or before and after study.
Jay 1985	Not an information/communication intervention.
Jay 1991	Not an information/communication intervention.
Kameny 2002	Not an intervention study.
Kapelaki 2003	No evaluation of intervention.
Kodish 2004	Not an intervention study.
Konsler 1993	Not an intervention study.
Kravitz 1996	Does not address a cancer population.
Kreuter 2004	Does not address children/adolescents.
Kupst 1983	Not an information/communication intervention
Last 1995	Not an intervention study.
Levenson 1982	Not an intervention study.
Marchese 2004	Not an information/communication intervention.
Maung 1993	Does not address children/adolescents.
McCarthy 1998	Not a controlled or before and after study.
McEvoy 1985	Not a controlled or before and after study.
McMillan 2005	Not an intervention study.
Miller 2005a	Does not address children/adolescents.
Mulcahey 1995	Not a controlled or before and after study.
Nielsen 2003	Does not address children/adolescents.

(*Continued*)

Nolan 1987	Does not address a cancer population.
Olechnowicz 2002	Not an intervention study.
Oliveria 2004	Does not address children/adolescents.
Orr 1984	Not an information/communication intervention.
Pangher Manzini 2003	Does not address children/adolescents.
Petermann 1987	Not an intervention study.
Powers 1993	Not an information/communication intervention.
Robb 2003	Not a controlled or before and after study.
Robinson 1994	Does not address children/adolescents.
Rollins 2005	Not an intervention study.
Ruffin 1997	Not a controlled or before and after study.
Sahler 2002	Does not address children/adolescents.
Sahler 2005	Does not address children/adolescents.
Sanden 2002	Does not address children/adolescents.
Silber 1986	Not a controlled or before and after study.
Smith 1987	Not an information/communication intervention.
Sobo 2004	Not an intervention study.
Sourkes 1991	Not a controlled or before and after study.
Standley 1995	Not a controlled or before and after study.
Stevens 1992	Not a controlled or before and after study.
Stiegelis 2004	Does not address children/adolescents.
Suzuki 2003	Not an intervention study.
Svavarsdottir 2005	Does not address children/adolescents.
Tomamichel 1995	Not a controlled or before and after study.

(*Continued*)

Van Cleve 2002	Not an intervention study.
Wells 2003	Does not address children/adolescents.
Young 2003	Not an intervention study.
Zahr 1998	Does not address a cancer population.
Zappa 1991	Not a controlled or before and after study.
Zeltzer 1984	Not an information/communication intervention.
Zeltzer 1991	Not an information/communication intervention.

Characteristics of studies awaiting assessment *[ordered by study ID]*

Macner-Licht 1998

Methods	
Participants	
Interventions	
Outcomes	
Notes	This study could not be definitively included or excluded without additional information from the study authors, who we have been unable to contact

DATA AND ANALYSES

This review has no analyses.

ADDITIONAL TABLES

Table 1. Psychological, social and behavioural outcomes

Study ID	Description	Results					
Baider 1989	Group therapy, before versus after	No significant differences were found between participants' before and after scores on the Brief Symptom Inventory (no details given). Global Severity Index scores were reported separately for the participants who were on active treatment (mean increase from 0.39 to 0.58) and those not in active treatment (decreased from 0.84 to 0.65). No statistical signifiance was reported					
Dragone 2002	CD-ROM versus book, before versus after	Patients' mean scores on the Leukemia Children's Health Locus of Control (LCHLC) scale: Age 4 to 6: CD-ROM	Satisfaction: Children: of children in the CD-ROM group, 86.7% used their assigned intervention to learn about	Use: Children: more children in the CD-ROM group (93.3%) reported using their intervention indepen-			

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		= before: 8. 25 (SD 2. 38); after: 9. 13 (SD 3. 23); Book = before: 8.33 (SD 2.07) ; after: 6.17 (SD 3.87). Age 7 to 11: CD-ROM = before: 11. 14 (SD 3.29) ; after: 13.40 (SD 3.46); Book = before 13.70 (SD 2.98); after: 13.70 (SD 3. 53).Analysis of variance (ANOVA) using the general linear models (GLM) procedure in SAS on the LCHLC change scores (post-test less pre-test), with main effects treatment group and age group, found a significant change with model F = 6. 38, R2 = 0.33, P = 0.004 and no significant interaction effects. For treatment group, F = 9.24, P = 0. 005; for age group, F = 5.	leukemia compared with 56.3% in the book group (P = 0. 06). In the CD-ROM group, 93.3% found their intervention 'easy to use', compared to 68.8% in the book group (P = 0.08). Only three of the eight 4 to 6 year olds reported they needed help to use the CD-ROM. The groups were similar in their willingness to advise other children with leukemia to use the CD-ROM or read the book. Parents: parents were asked to respond on a 4-point Likert scale to questions about use of their assigned intervention. ANOVA using the GLM procedure found no differences	dently at least once than did children in the book group (37.5%, P = 0.001). In the CD-ROM group, only one child, a 4 to 6 year olds, did not report using the CD-ROM at least once by himself. None of the six children in the book group who reported using the book independently did so 'many times' compared with six of the 14 in the CD-ROM group. In the CD-ROM group, 73.3% of the children used their assigned intervention for 'a long time' each time they used it, compared with 12. 5% in the book group (P = 0.0006)			

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		45, P = 0.027. The analyses indicated that in both age groups, compared with the book, the CD-ROM was associated with an increase in LCHLC scores, indicating relatively increased feelings of control over health	between the CD-ROM and book groups in ease of use for parents, use to get specific information about leukemia, or willingness to recommend their assigned intervention to other parents of children with leukemia. Parents in the book group were more likely to feel that their intervention was not easy for their children to use, compared to parents in the CD-ROM group (P = 0.01)				
Favara-Scacco 2001	Art therapy intervention versus control	Fifteen positive behaviours were selected by the trialists as indicators that children had developed a better compliance with the painful procedures. Children who adopted eight or more posi-					

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		tive behaviours were considered 'good responders'. In the control group (n = 17) the number and percent of good responders were as follows: Age 2 to 5 years: 0/3 (0%); age 6 to 10 years: 2/8 (25%); age 11 to 14 years: 1/6 (17%). In the intervention group (n = 32) the number and percent of good responders were as follows: Age 2 to 5 years: 7/11 (64%); age 6 to 10 years: 10/14 (71%); age 11 to 14 years: 6/7 (86%)					
Frick 1987	Directed play and storytelling versus control	All participants answered more questions correctly after the program, except 1 child who achieved the same score on both tests. Mean scores: before = 4.9 (range = 3 to 6), after = 6.5 (5 to 8), mean					

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		difference = 1.7(SD 0.90), t = 7.174, P < 0.001					
Heiney 1988	Group therapy versus control	No significant before and after differences were found between the groups on any of the measures used					
Hinds 2000	Coping skills intervention versus control	Patients' mean scores on the Nowick-Strickland Locus of Control Scale (NSLC), in both groups decreased from T1 to T4 (I: 11.97 (SD 4.8) to 10.9 (SD 4.7); C: 12.3 (SD 4.7) to 11.04 (SD4.4)), indicating the adolescents became more internally oriented during the 6-month study period	Patients' mean scores on the Hopefulness Scale for Adolescents (HSA), in both groups were highest at T4 (six months after diagnosis): I = T1: 1902.8 (SD 297.3); T2: 1906.3 (SD 358.9); T3: 1875.0 (SD 363.0); T4: 1992.8 (SD 338.0).C = T1: 1788.7 (SD 431.4); T2: 1913.2 (SD 336.6); T3: 1930.2 (SD 304.3); T4: 2072.2 (SD 226.6). T4 was the point at which the 39 patients diagnosed with Hodgkin's disease were completing treatment	Patients' mean scores on the Hopelessness Scale (HPLS), in both groups were highest soon after diagnosis and initiation of treatment (T1): I = T1: 2.71 (SD 2.4); T2: 2.0 (SD 1.8); T3: 2.41 (SD 2.5); T4: 2.21 (SD 2.0); C = T1: 3.11 (SD 2.5); T2: 2.16 (SD 2.2); T3: 2.62 (SD 2.1); T4: 2.33 (SD 2.1)	Patients' mean scores on the Rosenberg Self-Esteem Scale (RSE) and the Self-Efficacy Scale (SES): both groups consistently reported moderate to high levels of self-esteem (T4: I= 32.32, SD 3.9; C=32.69, SD 4.4) and self-efficacy (T4: I=89.17, SD 10.8; C= 88.21, SD 13.9) with the highest mean scores at T4		

Table 1. Psychological, social and behavioural outcomes (*Continued*)

Katz 1988	School reintegration, before versus after versus control	Patients' Mean Scores on the Children's Depression Inventory. I = before: 10.00 (SD 7.02) versus after: 6.69 (SD 5.65), P < 0.01. I = after: 6.69 (SD 5.65) versus C = 7.75 (SD 6.47), P = not significant	Parents' Mean Ratings of the Patients' Adjustment on the Child Behavior Checklist. Behavior Problems (total): I = before: 57.14 (SD 9.47) versus after: 50.28 (SD 13.99), P < 0.001. I = after: 50.28 (SD 13.99) versus C = 55.79 (SD 8.96), P = not significant. Social Competence (total): I = before: 45.22 (SD 11.59) versus after: 54.74 (SD 7.47), P < 0.01. I = after: 54.74 (SD 7.47) versus C = 41.52 (SD 13.16), P < 0.01	Patients' mean Scores on the Deasy-Spinetta Behavioral Questionnaire (Teachers' ratings) I = before: 23.42 (SD 6.81) versus after: 26.46 (SD 5.85), P < 0.01. I = after: 26.46 (SD 5.85) versus C = 18.87 (SD 8.33), P < 0.01	Patients' Mean Scores on the Perceived Competence Scale for Children. Cognitive: I = before: 2.62 (SD 0.75) versus after: 2.87 (SD 0.72), P < 0.05. I = after: 2.87 (SD 0.72) versus C = 2.66 (SD 0.63), P = not significant. Social: I = before: 2.85 (SD 0.79) versus after: 3.23 (SD 0.60), P < 0.05. I = after: 3.23 (SD 0.60) versus C = 2.96 (SD 0.62), P < 0.05. Physical: I = before: 2.43 (SD 0.74) versus after: 2.82 (SD 0.67), P < 0.01. I = after: 2.82 (SD 0.67) versus C = 2.84 (SD 0.66), P = not significant. General: I = before: 2.88 (SD 0.59) versus after: 3.34 (SD 0.49),	Teacher's Rating of Child's Actual Competencies Cognitive: I = before: 3.16 (SD 0.99) versus after: 3.22 (SD 0.89), P = not signficant. I = before: 3.16 (SD 0.99) versus C = 2.32 (SD 0.90), P < 0.01. I = after: 3.22 (SD 0.89) vs. C = 2.32 (SD 0.90), P < 0.01. Social: I = before: 3.33 (SD 0.66) versus after: 3.11 (SD 0.67), P = not signficant. I = after: 3.11 (SD 0.67) vs. C = 2.79 (SD 3.33), P < 0.01. Physical: I = before: 2.73 (SD 1.20) versus after: 2.78 (SD 0.74), P = not significant. I = after: 2.78 (SD 0.74) vs. C = 2.35 (SD 0.85), P < 0.05.	Absences and grades: No statistically significant differences were observed between groups on absences or grades. Mean Days absent* Year before diagnosis: I (n = 29) = 9.85 (SD 3.43, range 0 to 40) versus C = 11.57 (SD 10.08, range 0 to 38). Year of the diagnosis: I (n = 35) = 53.88 (SD 33.24, range 3 to 137) versus C = 46.00 (SD 17.92, range 4 to 72). Year after the diagnosis: I (n = 32) = 39.28 (SD 32.71, range 0 to 138) versus C = 33.33 (SD 19.37, range 6 to 86). *ANOVA, Group x Year. Signficant

Table 1. Psychological, social and behavioural outcomes (*Continued*)

					P = not significant. I = after: 3.34 (SD 0.49) versus C = 2.96 (SD 0.56), P < 0.01	General: I = before: 3.46 (SD 0.52) versus after: 3.48 (SD 0.49), P = not significant. I = after: 3.48 (SD 0.49) vs. C = 2.91 (SD 0.83), P < 0.01.	main effect for years: F (1,52) = 9.73, P < 0.05. Mean Grade point average** Year before diagnosis: I (n = 29) = 3.43 (SD 0.65, range 2.2 to 5.0 versus C = 3.46 (SD 0.65, range 1.0 to 4.6). Year of the diagnosis: I (n = 35) = 3.59 (SD 0.74, range 2.0-5.0 versus C = 3.57 (SD 0.64), range 2.0 to 4.7). Year after the diagnosis: I (n = 32) = 3.49 (SD 1.08, range 1.0 to 4.7) versus C = 3.48 (SD 0.83, range 1.0 to 5.0). **Nonsignificant ANOVA
Klosky 2004	Interactive intervention including filmed modelling versus control	Observed Behavioural Distress: There were no significant group differences in the increase in the total composite distress	Sedation: There was a non-significant difference between groups: 61% of the interactive intervention group and 63.2% of				

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		scores from base- line to simulated radiation therapy procedure	the modified control group participants required sedation to complete the simulated radiation therapy procedure (P < 0.50) . Of children aged 4 years and over, 25% of the intervention group and 48% of the modified control group were sedated, but this difference was not statistically significant (P < 0.16)				
Varni 1993	Social skills training plus school reintegration program versus school reintegration program alone	At 6 months (T2) 2 out of 8 subscales on the Child Self-Report yielded statistically significant before and after or between-group results: State Anxiety: I (n = 15) = before: 29.75 (SD 6.37) versus after: 24.69 (SD 7.96), t = 2.14, P < 0.05, ES = 0.79. Parent Social Support: I (n = 13) = before: 3.38 (SD 0.50) versus af-	At 9 months (T3) 2 out of 8 subscales on the Child Self-Report yielded statistically significant before/after or between-group results: Teacher Social Support: I (n = 15) = before: 3.29 (SD 0.62) versus after: 3.58 (SD 0.45), t = -2.18, P < 0.05, ES = 0.47. Classmate Social Support: I (n = 15)	At 6 months (T2) 2 out of 8 subscales on the Parent Report yielded statistically significant before/after or between-group results. Total Behaviour Problems: I (n = 23) = before: 55.87 (SD 12.07) versus after: 50.87 (SD 9.62), t = 2.89, P < 0.005, ES = 0.41. Social Subscale: C (n	At 9 months (T3) 4 out of 8 subscales on the Parent Report yielded statistically significant before/after or between-group results: Total Behavior Problems: I (n = 23) = before: 56.61 (SD 11.28) versus after: 50.30 (SD 10.63), t = 3.22, P < 0.005, ES = 0.56. Internalizing Behavior		

Table 1. Psychological, social and behavioural outcomes (*Continued*)

		ter: 3.69 (SD 0.30), t = -1.88, P < 0.05, ES = 0.62. C (n = 11) = before: 3.61 (SD 0.41) versus after: 3.85 (SD 0.22), t = -2.02, P < 0.05, ES = 0.59. At 6 months (T2) 2 out of 8 subscales on the Child Self-Report yielded statistically significant before and after or between-group results: State Anxiety: I (n = 15) = before: 29.75 (SD 6.37) versus after: 24.69 (SD 7.96), t = 2.14, P < 0.05, ES = 0.79. Parent Social Support: I (n = 13) = before: 3.38 (SD 0.50) versus after: 3.69 (SD 0.30), t = -1.88, P < 0.05, ES = 0.62. C (n = 11) = before: 3.61 (SD 0.41) versus after: 3.85 (SD 0.22), t = -2.02, P < 0.05, ES = 0.59	= before: 3.27 (SD 0.55) versus after: 3.51 (SD 0.40), t = -2.26, P < 0.05, ES = 0.44	= 18) = before: 42.22 (SD 8.33) versus after: 39 (SD 11.23), t = 2.24, P < 0.05, ES = -0.39	Problems: I (n = 23) = before: 55.96 (SD 12.81) versus after: 51.87 (SD 10.13), t = 1.85, P < 0.01, ES = 0.32. Externalizing Behavior Problems: I (n = 23) = before: 54. 30 (SD. 11.01) versus after: 48.30 (SD 11.13), t = 3.44, P < 0.005, ES = 0.55. School Subscale: I (n = 19) = before: 46.90 (SD 8.99) versus after: 49.79 (SD 4.43), t = -1.94, P < 0.05, ES = 0.32		

Table 2. Knowledge and understanding

Study ID	Description	Results
Dragone 2002	CD-ROM versus book, before versus after	Leukemia Event Knowledge Interview (LEKI): The were no differences between the CD-ROM and book groups on the pre- to post-test change scores based on : (1) number of events stated, (2) number of superordinate event categories, and (3) the number of basic level events, erroneous events, spontaneously stated events, and elaborated events. However, for 7 to 11 year olds, the changes between pre- and post-test scores were in the expected direction for all variables listed above except the total number of events. In these analyses (ANOVAs with main effects treatment group and age group) both generally and specifically elicited events were entered as data. With only generally elicited events in the model, F = 2.66, R2 = 0.219, P = 0.096; for treatment group, F = 4.93, P = 0.039. For both age groups, participants in the CD-ROM group had a greater increase in the proportion of basic level events on the post-test than pre-test, compared to participants in the book group. This finding supported the comparative efficacy of the CD-ROM by showing that the CD-ROM group had more detailed narratives about leukemia events than the more superordinate, less articulated narratives among the book group
Petersen 1996	Computer asisted instruction, before versus after	All participants answered more questions correctly after the program, except 1 child who achieved the same score on both tests. Mean scores: before = 4.9 (range = 3 to 6), after = 6.5 (5 to 8), mean difference = 1.7(SD 0.90), t = 7.174, P < 0.001

Table 3. Physical health outcomes

Study ID	Description	Results	
Frick 1987	Directed play and storytelilng versus control	No significant between-group differences in pulse rate found at any stage (no further details given)	
Hinds 2000	Coping skills intervention versus control	Symptom distress: both groups at T1 reported moderate symptom distress scores (I = 20.5 (SD 6.9); C = 21.45 (SD 6.7)); scores decreased over time and were lowest at T4 (I = 18.14 (SD 8.6); C = 17.21 (SD 6.1)) with the greatest decrease (though not statistically significant) occuring between T1 and T2 (I: 20.5 to 18.43; C: 21.45 to 19.58). The symptoms rated as most distressing were the same at all four	Toxicity: staff ratings of treatment- and disease-related toxicity in the HCI Common Toxicity Criteria Scale (CTC) were lowest at T1 and highest at T3 and T4 for both groups. The actual scores indicated low to moderate toxicity grades: I = T1: 7.54 (SD 6.4); T2: 7.16 (SD 3.9); T3 10.96 (SD 5.6); T4 9.79 (SD 4.9); C = T1: 5.84 (SD 4.9); T2: 8.22 (SD

Table 3. Physical health outcomes (*Continued*)

		time-points: tiredness, altered sleep, and change in either appetite or appearance	5.3); T3: 9.13 (SD 4.0); T4: 11.07 (SD 7.0)
Klosky 2004	Interactive intervention including filmed modelling versus control	Heart rate: Intervention group participants had significantly lower mean heart rates (beats per minute) from baseline to simulated radiation therapy during the total treatment than modified control group participants: I = 112.3 (SD 3.0) to 106.2 (SD 3.2) versus C = 105.1 (SD 2.3) to 108.4 (SD 2.8), F = 4.11, P < 0.05)	

APPENDICES

Appendix 1. 2001 and 2003 searches

For the original (2001) review we searched:

- Cochrane Controlled Trials Register, *The Cochrane Library,* issue 1 1999
- MEDLINE (1966 to December 1998), using Ovid CD-ROM
- EMBASE (1985 to 1999), Dialog
- PsycLIT (1887 to December 1998) using WinSPIRS
- CINAHL (1982 to December 1998), using Ovid CD-ROM
- Cancerlit (1975 to January 1999), Dialog
- Health Management Information Consortium (1979 to 1998), WinSPIRS
- British Nursing Index (1985 to 1999), Silverplatter
- Sociological Abstracts (1963 to 1998), WinSPIRS
- Dissertation Abstracts (1861 to 1999), Dialog
- IAC Health & Wellness (1976 to January 1999), Dialog
- JICSTE-Plus (1985 to November 1999), Dialog
- Pascal (1973 to December 1998), Dialog
- ERIC (1966 to December 1998), Dialog
- Linguistics and Language Behavior Abstracts (1973 to 1998), Dialog
- Mental Health Abstracts (1969 to January 1999), Dialog
- AMED (1985 to February 1999), Datastar
- HUMN (1973 to December 1998), Datastar
- MANTIS (1997 to November 1998), Datastar
- ASSIA (1987 to February 1999), Datastar

On the advice of peer reviewers, we subsequently searched MEDLINE and the Cochrane Controlled Clinical Trials Register for studies that evaluated the use of 'puppets' in interventions designed to help prepare children for hospitalisation or unpleasant medical interventions.

We conducted an updated search in January 2003. The following databases were searched:

- Cochrane Central Register of Controlled Trials (CENTRAL), (*The Cochrane Library*, issue 1 2003)
- MEDLINE (1996 to January week 2 2003)

- EMBASE (1996 to 2003 week 4)
- CINAHL (1982 to December week 4 2002)
- Dissertation Abstracts (1998 to January 2003)
- ERIC (1998 to January 2003)
- PsycINFO (1985 to January week 4 2003)
- Sociological Abstracts (1998 to January 2003)

Strategies for the searches conducted in 2001 and 2003, which were tailored to each database, are available from the Review Group Editorial Base.

Appendix 2. 2006 MEDLINE (Ovid) search strategy

1. exp neoplasms/
2. (cancer$ or neoplasm$ or leuk?emia$ or sarcoma$ or carcinoma$ or oncolog$ or radiotherapy or chemotherapy).tw.
3. 1 or 2
4. (child$ or adolescen$ or teen$ or young).tw.
5. exp child/ or adolescent/
6. 4 or 5
7. 3 and 6
8. (communicat$ or inform$ or advis$ or instruct$ or educat$ or discuss$).tw.
9. case conference.tw.
10. counsel$.tw.
11. counseling/
12. group therap$.tw.
13. psychotherapy, group/
14. patient education/
15. self-help groups/
16. ((self help or support) adj3 group$).tw.
17. (tell$ or disclos$ or bad news).tw.
18. (helpline$ or help line$ or hotline$).tw.
19. informed consent.tw. or informed consent/
20. decision making.tw. or decision making/
21. group intervention.tw.
22. therapeutic play.tw.
23. play therapy.tw. or play therapy/
24. (imagery or rehearsal or imagination).tw.
25. art therap$.tw. or art therapy/
26. music therap$.tw. or music therapy/
27. (puppet$ or doll$ or maniken$).tw. or manikens/
28. (story$ or stories or picture$ or novel$ or narrative$).tw.
29. ((child$ or adolescen$ or teen$ or young) adj4 (allay$ or reliev$ or alleviate$)).tw.
30. (internet or video$ or audio$ or computer$).tw.
31. (book$1 or booklet$).tw. or books/
32. or/8-31
33. 7 and 32
34. randomized controlled trial.pt.
35. controlled clinical trial.pt.
36. randomized controlled trials.sh.
37. random allocation.sh.
38. double blind method.sh.
39. single blind method.sh.
40. or/34-39
41. animal/ not (human/ and animal/)

42. 40 not 41
43. clinical trial.pt.
44. exp clinical trials/
45. (clin$ adj25 trial$).ti,ab.
46. ((singl$ or doubl$ or trebl$ or tripl$) adj25 (blind$ or mask$)).ti,ab.
47. placebos.sh.
48. placebo$.ti,ab.
49. random$.ti,ab.
50. research design.sh.
51. or/43-50
52. 51 not 41
53. 42 or 52
54. 33 and 53
55. (pre test or pretest or post test or posttest).tw.
56. 33 and 55
57. 54 or 56
58. limit 57 to yr=2003-2006

WHAT'S NEW

Last assessed as up-to-date: 31 March 2006.

Date	Event	Description
6 March 2012	Amended	Additional tables linked to text.

HISTORY

Protocol first published: Issue 1, 2001

Review first published: Issue 1, 2001

Date	Event	Description
30 May 2008	New citation required but conclusions have not changed	The new citation reflects new authorship of the updated review (Ranmal R, Prictor MJ, Scott JT)
29 May 2008	Amended	Converted to new review format.
29 October 2007	New search has been performed	The 2007 update of the review includes one new study, Klosky 2004 which evaluated a cognitive behavioural interactive package for reducing distress related to radiation therapy among children with cancer. The inclusion of this study did not result in any substantial change to the review's conclusions

(*Continued*)

29 January 2003	New search has been performed	The 2003 update of the review included three new studies: Hinds 2000 which assessed a three-part educational intervention designed to facilitate self-care coping for adolescents with cancer; Dragone 2002 which evaluated an interactive CD-ROM for children with leukaemia and their family; and Favara-Scacco 2001 which evaluated art therapy for children with leukaemia undergoing painful procedures. The inclusion of these studies did not result in any substantial change to the review's conclusions
29 January 2003	New citation required but conclusions have not changed	The citation of the updated review was amended to reflect new authorship: Scott JT, Harmsen M, Prictor MJ, Sowden AJ, Watt I The original title of this review was "Communicating with children and adolescents about their cancer." The title was amended in 2003 to meet standard Cochrane review format

CONTRIBUTIONS OF AUTHORS

For the 2001 review:

J. Tim Scott (JTS), Vikki Entwistle (VAE), Amanda Sowden (AJS) and Ian Watt (IW) contributed to the preparation of the protocol and the final manuscript and assessed the relevance and methodological quality of retrieved reports. JTS prepared the first drafts of the protocol and the completed review, assessed the studies for inclusion and extracted data from the selected studies. VAE, AJS and IW co-assessed the studies for inclusion and checked the extracted data against the original reports.

For the 2003 update:

Mirjam Harmsen (MH) ran the search strategies; MH and Megan Prictor (MP) assessed the retrieved studies for relevance and inclusion. MH collected data from the selected studies, MP checked the collected data against the original reports. MP revised the 2001 review, JTS, IW and AJS checked and approved the revised review.

For the 2007 update:

Megan Prictor (MP) ran the search strategies; MP assessed the abstracts for relevance. Rita Ranmal (RR) and Megan Prictor (MP) assessed the selected studies for inclusion and extracted data. J. Tim Scott (JTS) co-assessed the studies for inclusion. RR and MP revised the 2003 review text and tables.

DECLARATIONS OF INTEREST

None known

SOURCES OF SUPPORT

Internal sources

- Cochrane Consumers and Communication Review Group, Australian Institute for Primary Care, La Trobe University, Australia.

External sources

- NHS National Cancer Research & Development Programme, UK.

INDEX TERMS

Medical Subject Headings (MeSH)

*Communication; *Neoplasms [psychology; therapy]; *Patient Education as Topic; Clinical Trials as Topic; Family; Professional-Patient Relations

MeSH check words

Adolescent; Child; Humans