

REVIEW

EVALUATING THE NEEDS OF CHILDREN WITH CANCER

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Received October 7, 2014
Accepted February 4, 2015

Abstract

Aim: The aim of the survey study was to analyze published studies assessing the needs of children with cancer. **Design:** Literature review. **Methods:** Freely available and licensed databases (MEDLINE, ProQuest, ScienceDirect, Scopus, EBSCO, Google Scholar, Web of Science, Wiley and CINAHL) were searched for necessary data. **Results:** The literature analysis revealed that needs assessment of children with cancer was described by several authors. Specifically, eight studies were found that were published between 1993 and 2011. The needs of children with cancer diagnosis were evaluated by both qualitative and quantitative research methods. Individual areas of bio-psycho-socio-spiritual needs of the study were investigated separately by the authors. None of the studies evaluated children's needs comprehensively in all the areas. **Conclusion:** The issue of assessing the needs of children with cancer is often discussed and examined. Studies cover different needs, from biological to spiritual needs. The greatest emphasis should be placed on biological needs due to many side effects of cancer treatment. In the future, it would be appropriate to develop and validate an evaluation tool that would map biological needs of children with cancer. The most effective way would be an assessment tool which would map the needs of children in a comprehensive way.

Keywords: assessment, need, child, cancer.

Introduction

Cancer in childhood ranks among the most severe and life-threatening diseases. In our population, about 1% of children are diagnosed with cancer (Jurga, 2010, p. 1255).

In the course of cancer, a child's needs are modified in a certain way, the child may begin to feel a sense of threat not only in physical needs but also in psychosocial and spiritual ones. Related anticancer treatment entails considerable concerns of the child and parents and serious medical complications, especially during highly intensive chemotherapy (Koutecký et al., 2002, p. 60).

McCaffrey (2006, p. 59–66) states that oncological treatment and especially chemotherapy is often considered as the biggest stress factor for both children and parents (Koutecký et al., 2002, p. 77–78). It may therefore be concluded that cancer treatment has a significant impact on a child's needs.

Symptoms of damage due to chemotherapy and radiotherapy depend on location (Koutecký et al., 2002, p. 61). Complications that may occur during cancer treatment are numerous. The most frequent ones are fever, vomiting, constipation, diarrhea, dysphagia, bleeding, pain, and also behavioral changes (Koutecký, Cháňová, 2003, p. 109–111).

To provide a child with comprehensive medical and nursing care and to prevent adverse effects that often accompany cancer treatment, attention should be paid to evaluating the child's needs which are closely related to the subsequent effectiveness of all medical and nursing interventions.

Aim

The aim was to analyze published studies assessing the needs of children with cancer. The information analysis focused on the problem areas of children's needs related to cancer diagnosis.

Methods

Selection criteria

For the literature analysis, both quantitative and qualitative studies of the needs of children with cancer in the bio-psycho-socio-spiritual context were

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collected, or studies evaluating only one selected area of needs. The exclusion criteria were: studies that dealt with quality of life in palliative care, needs assessment of hospitalized children with non-cancer illness, treatment of cancer and studies that evaluated the needs of adult patients.

Sources

Studies evaluating the needs of children were searched in the licensed and freely accessible databases MEDLINE, ProQuest, ScienceDirect, Scopus, EBSCO, Google Scholar, Web of Science, Wiley and CINAHL (period of 1980 to 2014).

Search

The following keywords were used for the search: need, identification, children and cancer.

Selection and analysis of studies

From a total of 52 studies found (excluded were duplicate studies, case studies and theoretical studies beyond the literature review), 5 empirical studies, 1 literature review and 2 validation studies (tool development and testing) were selected according to the above criteria and analyzed. Figure 1 shows the exclusion process as recommended by the PRISMA (Moher et al., 2009, p. 1009). The studies were evaluated based on the hierarchy of evidence defined by Fineout-Overholt and Johnston (2005, p. 37–39) that defines 7 levels of evidence. Levels IV and V were included in our study.

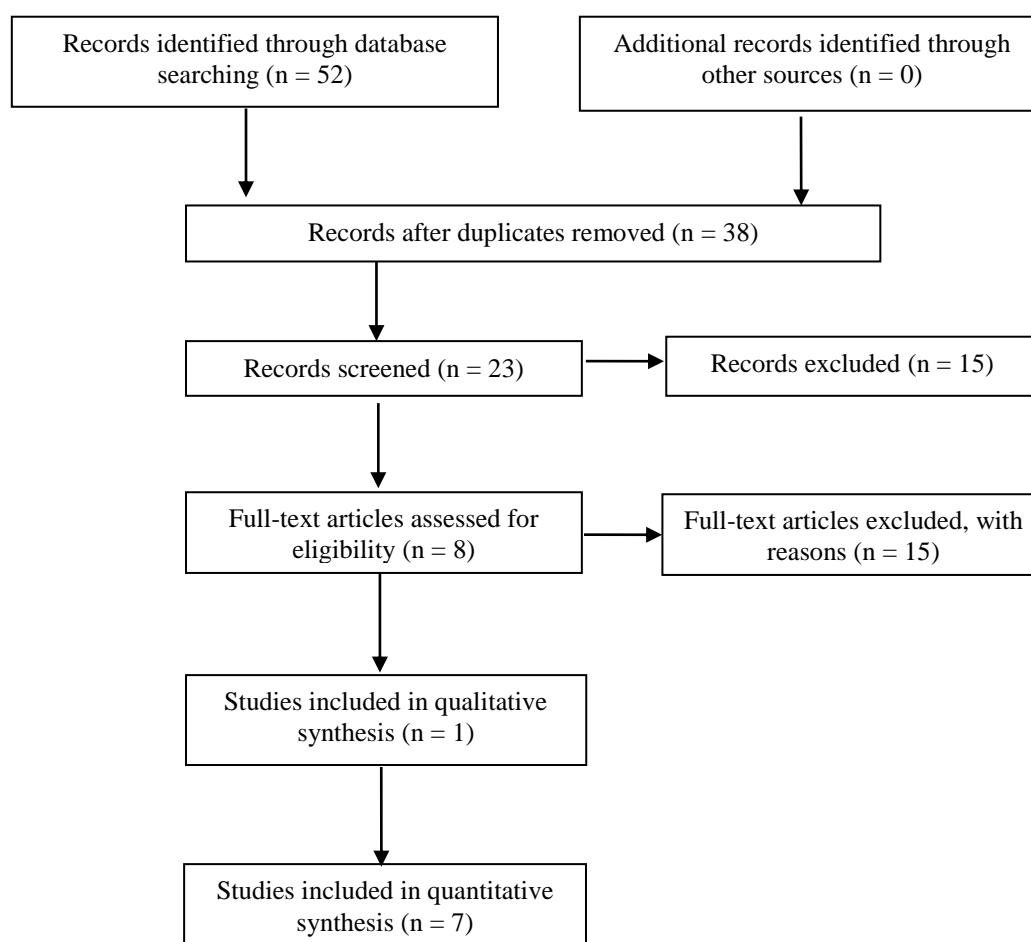


Figure 1 Flow diagram of the exclusion process recommended by the PRISMA

Results

The selection process yielded 6 quantitative studies (Table 1), 1 qualitative study and 1 literature review which evaluated the needs of children with cancer.

The selected studies always evaluated only some of the areas of needs; no study evaluated the needs comprehensively from the bio-psycho-socio-spiritual perspective.

Table 1 Summary of studies evaluating the needs of children with cancer

Author(s)	Evaluated area of needs	Method / type of study	Subjects	Results / needs assessment	Level of evidence
Ellis R, Leventhal B. (1993)	Psychosocial	Quantitative method/questionnaire survey	50 children 60 parents	Information needs – the presence of differences in perception and priorities in terms of information needs of sick children and their parents. Children always wanted to be informed about all aspects of prognosis and treatment of cancer, but their parents tried to protect them from this information.	IV
Hooker L. (1997)	Psychosocial	Quantitative method/validation study	7 children 10 health care workers	Information needs – perception of prior information needs from the perspective of teenagers and health care workers is significantly different. The highest priority evaluated by teenagers was recorded in information needs in the area of physical restriction of cancer itself and then the prognosis and treatment.	IV
Hockenberry MJ et al. (2003)	Biological	Quantitative method/validation study	149 children 147 parents 124 health care workers	Fatigue – higher intensity of fatigue was detected mainly in children after chemotherapy and in children in relapse. Children often do not verbalize fatigue; therefore, this area should be monitored regularly within nursing care.	IV
Mitchell W, Clarke S, Sloper P. (2006)	Psychosocial	Quantitative method/questionnaire survey	112 children 303 parents	Psychosocial care and support – children lack information concerning the disease demonstrated by various pictures; they would also appreciate assistance in finding information about the disease on the Internet and they would like to meet other children more often.	IV
Houlston A et al. (2009)	Biological	Quantitative method/questionnaire survey	39 families (1 child + 1 parent)	Nutrition – meeting a biological need of nutrition should not be a problem but only under strict monitoring of problem areas and early intervention.	IV
Galati PC et al. (2011)	Biological	Quantitative method/cross-sectional study	16 children with cancer 19 healthy children (controls)	Energy needs – there was no evidence of increased energy expenditure or changes in energy use in children with cancer compared with healthy children.	IV

In their questionnaire survey, Ellis and Leventhal (1993, p. 277–284) dealt with evaluation of information needs. Also Hooker (1997, p. 160–168) focused on information needs of teenagers.

Nutrition was another area for needs evaluation, with Houlston et al. (2009, p. 25–27) performing a questionnaire survey at Children's Hospital in Oxford which examined primarily suitability of food and satisfaction of respondents with catering. Also Galati et al. (2011, p. 306–313) focused on energy needs of children with cancer in her cross-sectional study.

The psychosocial area of needs was mapped by Björk et al. (2006, p. 210–219) in her observational study of children with cancer under seven years of age in interaction with their parents. Mitchell, Clarke and Sloper (2006, p. 805–816) used questionnaires to investigate psychosocial care and support in the context of needs of children.

Hockenberry et al. (2003, p. 319–328) aimed at developing and testing an instrument for measuring fatigue in children with cancer from the perspective of children, parents and staff.

In a literature review, Hart and Schneider (1997, p. 263–270) discussed spiritual interventions in pediatric cancer patients on the basis of theoretical frameworks by Erikson and Piaget and Fowler's stages of faith development.

Area of biological needs

In her study, Houlston et al. (2009, p. 25–27) evaluated nutritional needs of children with cancer. Any information concerning meals in hospitals was obtained through a questionnaire survey from both children and their parents. The survey was conducted at two pediatric wards of Children's Hospital in Oxford. A total of 85% of respondents were not satisfied with catering in a medical facility. Respondents identified the following issues: using a cart in a department – smell of food often causes nausea to cancer patients, poor presentation of food – inappropriately served food, insufficient offer, absence of favorite foods. Furthermore, due to the amount of examination and treatment interventions, patients have little time to eat – a lack of flexibility on the side of medical staff. The last area of concern was feeling of hunger out of timing meals. Ninety-five percent of families felt the need to bring food from the “outside” and 75% of families and children stated that it would be appropriate to have greater time flexibility of meals.

Children and parents could also label their favorite food and disliked food. The favorite foods included, for example, lasagne, broccoli, carrots, fruit salad or baked potato with cheese. The disliked foods involved rice pudding, cucumbers, cabbage, cake, etc.

After a thorough analysis and reflection of obtained data, changes were made to the hospital ward regime on the basis of the above requirements of parents and children. Re-survey after the implementation of changes showed that 100% of parents and children were satisfied with improvement of the catering system after the implemented interventions.

A cross-sectional study by Galati et al. (2011, p. 306–313) dealt with determination of energy needs of children and adolescents with cancer. The inclusion criteria were age from 6 to 15 years and diagnosis of malignancy regardless of cancer treatment stage. The criterion for inclusion in the control group was age 6 to 15 years. The following areas were evaluated: anthropometric data, food intake and body composition with bioelectric impedance analysis. Energy expenditure was measured by indirect calorimetry which failed to reveal significant differences between the two groups. There was no evidence of increased energy expenditure or changes

in energy use in children with cancer as compared with healthy controls.

In terms of biological needs, not only nutritional needs were studied, but attention was also paid to fatigue assessment in children with cancer, as in a validation study by Hockenberry et al. (2003, p. 319–328). Its aim was to develop and test tools for measuring fatigue in children with cancer from the perspective of children, parents and staff. The study consisted of three phases: development of tools, content validation and measurement of psychometric properties. The research sample consisted of 149 children aged 7 to 12 years receiving cancer treatment. Also involved in the research were 147 parents and 124 health care workers. Three evaluation tools were developed for measuring fatigue in children with cancer from different perspectives. The *Child Fatigue Scale* evaluates fatigue from the perspective of a child who has an opportunity to mark on the Likert scale (1 – not at all; 2 – little; 3 – sometimes; 4 – quite a lot; 5 – a lot) how much tired it has been during the last week, whether it felt tired in the morning and how “its body” physically feels. The *Parent Fatigue Scale* was created for parents of children with cancer. Once again, parents have an opportunity to express, on the Likert scale (1–5), whether their child is tired in the morning, if it is difficult to get it out of bed and whether it is also tired at meals. The *Staff Fatigue Scale*, developed for health care professionals, evaluates behavior and mood of a pediatric patient during the last week of hospitalization. Staff members assess whether the child is able to participate in daily nursing care, if it is refreshed after sleep and whether it has strength and will to participate in care.

The Likert scale (1–5) is used again. The tools showed strong initial validity and reliability. However, according to the authors, it will be necessary to keep testing the instruments in the future. Higher intensity of fatigue was detected mainly in children after chemotherapy due to decrease of white blood cells and in children in relapse. Although fatigue is present in the vast majority of children with cancer, it is very rarely verbalized by them. Continuous monitoring of needs in the area of physical activity should therefore become a part of daily nursing care.

Area of psychosocial needs

In studies that dealt with areas of psychosocial needs, the authors evaluated primarily information needs, a need for contact between a child and its parents and needs for psychosocial care and support.

The area of psychosocial needs of children with cancer is very often investigated. Hooker (1997, p. 160–168) developed and tested a tool that comprehensively assessed the information needs from the perspective of teenagers and then compared these with responses from medical staff. The aims were the design, development and pilot testing of a tool that would identify the information priorities of teenagers (13–17 years) with cancer, as well as description of these issues from the perspective of professionals (nurses, doctors, psychologists and social workers). Needs assessment was carried out using the method of Thurstone's law of comparative judgment, with a scale of values of 1.5 (most important) to -1.5 (least important). The findings were evaluated on the basis of priorities of teenagers. The highest priority in needs was found in *information about the chance that my illness can be cured, information about whether my treatment is working, information about my illness, information about my treatment plan, and information on cancer.*

Furthermore, the priority of needs of teenagers ranked in descending order was as follows: *information on the side effects of my treatment, information on how the disease and treatment may affect my future, information about how I take care of myself during treatment, information on how the disease can affect what I usually do, information on who I can contact to inquire, and information on how the disease can change my appearance.*

In experts, the emphasis was primarily on providing information about the physical problems, emotions and finance. The research suggests that the perception of priority of information needs from the perspective of teenagers and health care workers is significantly different.

Also Ellis and Leventhal (1993, p. 277–284), in a questionnaire survey, examined information needs and preferences of children with cancer. Their research was conducted in 50 cancer patients (8–17 years) and 60 parents who accompanied their children during hospitalization. The results were surprising and, once again, the responses of children and parents differed significantly. Children required information about their disease and its treatment in all aspects, especially information about prognosis. As many as 76% of children wished to know their chance of recovery, regardless of what it was. By contrast, only 38% of parents agreed that their children could know this information ($p < 0.01$). Ninety-five percent of patients wanted to know whether they were terminally ill. Most respondents indicated that treatment decisions depended more on the doctor. Patients felt that people aged 14 years and

more should be allowed to freely decide whether to participate in medical research, those aged 16 or more to decide on treatment of minor medical problems, and those over 17 years of age on refusing cancer treatment. Parents often want to protect their children from bad news, but most children want to be fully informed about their illness. They usually do not want to decide on their initial treatment, but many of them feel that they should have a chance to decide on palliative care.

Mitchell, Clarke and Sloper (2006, p. 805–816) conducted quantitative research to map satisfaction with care and support for children and adolescents with cancer. They also included parents of children with cancer in the research. The questionnaire examined satisfaction with hospital services, advice and information, needs for care and support, social and emotional support, support for other family members, support during transition into the home environment, adulthood and future, and return to school. Children identified plenty of toys suitable for their age as an unmet need and then they did not like food in the hospital. In the field of counseling and information, children would appreciate more information concerning the disease demonstrated by pictures, assistance in finding information on the Internet and more “verbal” information about the disease. Another problematic area was social and emotional support for children who wanted to meet several other children with cancer and friends.

An observational study by Björk et al. (2006, p. 210–219) focused on the needs of children with cancer at the beginning of their hospitalization. The aim was to describe behavior, body language and verbal expression of children under 7 years of age with newly diagnosed cancer during initial hospitalization (the first 10 months) to identify their needs. During the observation, children always had parents or at least other family members present. Field notes were transcribed into text and after content analysis, the following five categories of needs were established (needs were classified into semantic units in a broader sense, as to what the baby needed, searched, wanted, expressed, or what it was desperate for, etc.): need to be close to parents, need to play and experience joy, need to participate in the care and treatment, need of good relations with health workers, and need of physical and emotional satisfaction.

Physical and emotional contact of a child with parents was identified as the most significant need, with the child experienced a feeling of security and safety.

The results show that during hospitalization, it is essentials for children to have their parents with them, so that they can meet selected psychosocial needs.

Area of spiritual needs

Hart and Schneider (1997, p. 263–270) published a literature review the purpose of which was to discuss spiritual interventions in pediatric cancer patients on the basis of theoretical frameworks by Erikson and Piaget and Fowler's stages of faith development. Spiritual care should be primarily consistent with psychosocial needs. The article involves assessment and intervention within the spiritual care of children with cancer in various stages of development from childhood to adolescence.

When caring for children with cancer, nurses should remember some of the following recommendations:

- promote spirituality in the family of a sick child and perceive the family as a whole;
- nurses must be aware of various losses that the child experiences in connection with cancer and provide interventions that are aimed at regaining a sense of "normalcy";
- the child should be involved in decision-making processes relating to a care plan, in accordance with its religious orientation, faith and value system;
- nurses should provide care sensitively so as to give the child a sense of trust and equal "partnership"; and
- nurses should provide care that is focused not only on the disease but on the child as a whole.

Discussion

A comprehensive evaluation of needs of children with cancer is an integral part and a priority of nursing care. Quality needs assessment in turn leads to effective nursing interventions and especially to the prevention of complications of cancer treatment. In clinical nursing practice, nurses should focus not only on the evaluation of biological needs but also on the area of psychosocial and spiritual needs. High quality nursing care means that needs of children with cancer are assessed comprehensively.

The area of biological needs is a key element in the whole hierarchy of needs. Houlston et al. (2009, p. 25–27) identified shortcomings in the area of nutrition in children receiving chemotherapy. The biggest problem for hospitalized children and their parents was the smell of food in the department as a result of using carts, improper food service, insufficient offer and absence of favorite foods. Furthermore, respondents lacked time flexibility and

often felt hungry outside the schedule of meals. The identified deficiencies were eliminated and thus the children's needs in the field of nutrition were appropriately saturated. The study suggested that satisfying biological nutritional needs should not be a problem but only under strict monitoring of problem areas and early intervention.

Nutritional needs of cancer children patients were also evaluated in terms of energy expenditure. Galati et al. (2011, p. 306–313), based on their cross-sectional study, concluded that there was no evidence of increased energy expenditure or changes in energy use in pediatric cancer patients as compared with healthy children.

Also analyzed were the biological needs of rest and sleep. A validation study by Hockenberry et al. (2003, p. 319–328) presented highly valid and reliable tools for evaluating fatigue of children with cancer from the perspective of children themselves (*Child Fatigue Scale*), their parents (*Parent Fatigue Scale*) and medical staff (*Staff Fatigue Scale*). According to the authors, however, the tools need further testing. Higher levels of fatigue were detected mainly in children after chemotherapy and in those in relapse. As children often do not verbalize fatigue, this area should be monitored regularly within nursing care.

Studies that evaluated psychosocial needs were often directed at educating children as well as their parents and health care professionals on cancer diagnosis and treatment.

Hooker (1997, p. 160–168) identified especially priorities of information needs of teenagers from the perspective of teenagers themselves and also from the perspective of medical staff. The highest priority was assigned by teenagers to information needs in the areas of physical constraint, cancer itself and prognosis and treatment. From the perspective of medical staff, an emphasis was also placed on information that could be related to physical limitations and on information about mental condition and financial situation.

A similar study was carried out by Ellis and Leventhal (1993, p. 277–284) who examined information needs and preferences in children with cancer and their parents. Obvious differences were discovered by comparing results of the research groups of children and parents. A very important finding was that children wanted to be always informed about all aspects of prognosis and treatment of cancer, but their parents tried to protect them from this information. Therefore, it can be concluded that there are differences in perception and priorities in

terms of information needs of sick children, their parents and medical staff.

Mapping of care and support saturation of children and adolescents with cancer was another matter of concern. It was found that children lack information concerning their disease demonstrated by various pictures; they would also appreciate assistance in finding information about the disease on the Internet and would like to meet other children with cancer and friends (Mitchell, Clarke, Sloper, 2006, p. 805–816).

Also Björk et al. (2006, p. 210–219) dealt with psychosocial needs of children with cancer, concluding that most important was the need of physical and emotional contact of a child with its parents as the child experienced feelings of safety and security in their presence during hospitalization. It is obvious that in nursing practice, the problems of psychosocial needs are still underestimated.

The area of spiritual needs has proven to be least researched. There was no empirical study mapping spiritual needs of children with cancer. There are only a theoretical background and recommendations for high quality care for children with cancer (Hart, Schneider, 1997, p. 263–270).

Conclusion

Cancer treatment is often accompanied by numerous side effects. Assessment of the needs of children with cancer should be an integral part of nursing care. And it is desirable that the needs are evaluated comprehensively in the bio-psycho-social context. Although spiritual needs should not be neglected either, they have not received sufficient attention. Shortcomings were also found in biological needs. Due to the large amount of side effects of chemotherapy and radiotherapy, nursing care should be more focused on monitoring and saturation of biological needs. In the future, it would be appropriate to carry out a study that would focus on satisfying biological needs.

Ethical aspects and conflict of interest

All the bibliographic resources were properly cited. The authors are not aware of a conflict of interest.

Author contribution

Concept and design (AF, LS), data collection (AF), analysis and interpretation of data (AF, LS), drafting of the manuscript (AF), supervision (LS), critical correction of the manuscript (AF, LS).

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