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A Swedish perspective on nursing and psychosocial research in paediatric oncology: A literature review

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A B S T R A C T

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Purpose: A dramatic improvement in outcomes of survival rates of childhood cancer has been seen. Caring science research is central in providing skills and knowledge to the health care sector, but few overviews of the content of published research have been carried out. The aim of this review was to investigate the content and methodology of published studies in paediatric oncology relevant to caring science, and also to compare possible differences in content and method of the published studies from the nursing and psychosocial perspectives.

Method: A systematic literature review was performed of 137 published articles on paediatric oncology relevant to caring science in Sweden.

Results: The results show that most of the studies were descriptive or comparative ones with a quantitative design. Most of them focused on parents (43%) or children (28%). Most of the studies investigated wellbeing (88%), using questionnaires (54%) or interviews (38%). Several different measurement instruments had been used. While the results were often clearly presented, the clinical implications were more diffuse. The most acknowledged research fund was the Swedish Childhood Foundation (75%).

Conclusions: To reflect the children's perspectives in paediatric oncology require that future researchers take on the challenge of including children (even young ones) in research. The use of a limited number of agreed measurement instruments is desirable. The biggest challenge for the future is to make a shift from explorative to intervention studies. There is an urgent need to transform research results into clinical practice.

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Introduction

Over the past 40 years, the five-year survival rates of children and adolescents with cancer have risen dramatically in Sweden (and other countries), with improvement largely attributed to more effective treatment (Gustafsson et al., 2007). However, further improvements in both survival rates and quality of survival can still be achieved (Reaman, 2004).

According to the Swedish government, caring sciences research is central to enhancing skills and knowledge to the health care

sector. In the latest government research bill (Regeringens proposition 2008/09:50), caring science research was presented as a strategic research area (SFO) with additional funding being allocated to the area. In 2010, the government commissioned the Swedish Research Council to conduct an evaluation into the field and submit recommendations for the future of Swedish caring science research. The international expert scientific panel concluded that the Swedish Government could be proud of much of the ongoing research activity in this field. The panel was impressed with the research staffing and infrastructure, research activities and outputs, and future plans and collaborations. However, areas for improvement were identified, such as; more clinically relevant research, research collected into fewer but larger clusters, and the establishment of interdisciplinary projects (Swedish Research Council, 2010).

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“Research in **Caring Sciences** emanates from a multiscientific and multiprofessional perspective which includes preventive, supportive, caring and rehabilitative actions” (Government Bill 2008/09:50 p.85). One area of caring sciences emphasizes social and behavioural science, and includes relevant theories and methods (**the Psychosocial perspective**) to be utilised. An important field of study is the interaction between staff, patients and their family/significant others. The individual’s resources for keeping and regaining optimal health, as well as his/hers ability to adjust to change in health status, is another important focus for research. Supportive resources for individuals and their families within the health care system are also of great interest, particularly in palliative care or when such resources are found to be lacking. Finally, research concerning quality of care, cultural aspects, health care organizing and education is also within the scope of the caring sciences (**the Nursing perspective**) (Department of Public Health and Caring Sciences (IFV), Uppsala University, 2013).

In early 1990’s, a survey to identify research priorities for paediatric oncology nursing, was carried out by the Association of Paediatric Oncology Nurses. The priorities were primarily about paediatric procedures and psychosocial care needs of patients and their families. The top priority was to; measure the quality of life and late effects of treatment in long-term survivors of childhood cancer (Hinds et al., 1994). Since the 1990s, the body of research-based knowledge in paediatric caring sciences has been increasing. Early work focused on symptom relief related to the side effects of chemotherapy, and pain management related to invasive medical procedures. As survival rates improved, the focus has shifted to examine the psychosocial impact of paediatric cancer and its treatment for children and their families, both during and after treatment. The success of survivorship highlights an even greater need for psychosocial research and improvement of quality nursing care (Noll et al., 2013). Earlier reviews have been carried out through interviews with qualitative analysis (e.g. Neil and Clarke, 2010) or by questionnaires analyzed with quantitative methods (e.g. Rosenberg et al., 2012) Also studies using a mix-method design have been carried out (e.g. Long and Marsland, 2011). Mattsson et al. (2008) review on the positive consequences of childhood cancer showed that different designs bring out different results when examining the same phenomena.

Aim

The aim of this systematic literature review was to investigate the content, processes and methodology used in published studies on paediatric oncology and which were related to caring sciences. A further aim was to compare the possible differences in the content and method of the published studies between nursing, psychosocial and medical perspectives.

Methods

Study design

This study presents a systematic review of the literature using database keyword searches. The selection of studies was performed in two steps. The first step was to identify articles by reading through titles and abstracts using an abstract protocol. The second step involved reviewing the entire article on a full text level using a mapping protocol.

Literature search

In the first step, studies with empirical data from Swedish participants, and which were relevant to caring sciences and including

nursing and psychosocial sciences (as defined in the background section), were identified through a search in the databases CINAHL, PsycINFO, and PubMed. Box. 1 presents the keywords used in the search.

Studies meeting the following inclusion-criteria were included: samples of persons diagnosed with cancer during childhood, on or off treatment, a caring sciences perspective (the definition presented in the background being used), in Sweden and articles written in English and published in a peer-reviewed journal between January 2000–June 2013. As a result of this, 325 studies were identified through this search. Of this 325, 140 were picked out by reading through the titles and abstracts. To identify further studies a basic search was carried out based on the author’s names using the same databases, as well as on the internet. First or last authors with >2 publications were included which yielded another 37 studies. Each of these 177 studies were read and reviewed at full-text level. During the review-process, 40 were subsequently excluded as they did not meet the inclusion-criteria. Reasons for exclusion included; not a paediatric patient (16 studies), did not include Swedish patients and/or their families (eight studies), review article (six studies), was not childhood cancer (five studies), was not researched from a caring science perspective (three studies) and description of instrument development (two studies). All of the remaining 137 studies are included in the analysis section and the final report.

Data analysis

A mapping protocol was developed, in part, using the MacMaster critical review form for qualitative and quantitative studies (Letts et al., 2007). The protocol examination of the full text level included description of: a) the target person of the research, b) the aim of the research, c) scientific tradition and theoretical aspects, d) data collection, e) study design, f) results, g) clinical implication(s), h) ethics, i) research funds, as well as, j) information about the publication such as journal and year. A summary of the results, conclusions and suggestions for clinical implications also was included in the analysis. As a result of this seven of the articles were reviewed by two of the authors and an interrater reliability was found to be 95%. The remaining articles were divided between and reviewed by each of the six authors. The first author collected and scrutinized all protocols and related articles, before entering them into the data file and revising any misunderstanding of the protocol.

SPSS Statistics 19[®] was used to analyse the quantitative data from the mapping protocol. Non-parametric statistics were used as the data were nominal and ordinal and not considered to be normally distributed. Chi² was used to compare the scientific perspectives (nursing versus psychosocial versus medical perspectives). The statistical significance was established at $p < .05$.

During the process of reviewing the articles, full text extract on; a), the results of the study and b), the clinical implications was collected and analysed. The result of those analysis will be reported elsewhere.

Results

The main results of the 137 reviewed studies are presented.

Research area

Half ($n = 69/50\%$) of the studies in this review ($n = 137$) involved a psychosocial perspective, with 55 (40%) a nursing perspective, and 13 (9%) more of a medical perspective, but still considered from a caring perspectives. The classification is based on the definition presented in the background and not on the profession of the authors.

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