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Review

School-aged and adolescent children's experience when a parent has non-terminal cancer: a systematic review and meta-synthesis of qualitative studies

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Abstract

***Objective*: The purpose of this study was to systematically review and synthesise qualitative studies pertinent to male and female school-aged and adolescent children's experience when a parent is diagnosed with non-terminal cancer.**

***Methods*: A rigorous systematic review and meta-synthesis process were conducted. Seven computerised databases were searched, and 2027 articles were retrieved. After screening the titles and abstracts, full texts of 24 articles were critically appraised, and finally, 16 articles were further analysed and synthesised with a thematic-synthesis approach.**

***Results*: Five themes were identified: being informed of parental cancer, emotional concerns, changes in daily life, seeking factual information and seeking emotional support. As indicated in the results, most children had been informed of the parent's diagnosis of cancer. They suffered from a wide range of concerns when facing the situation, and their lives had been interrupted to different degrees. In order to cope with the event, children adopted various strategies. Their information and support needs were reported to have been poorly met.**

***Conclusions*: This systematic review provides insight into the scenario of children living with a parent with non-terminal cancer and indicates some suggestions for future studies. The experience of children when the father has cancer should be further explored. Short-term and long-term impacts of parental cancer on children, especially young children within different cultural contexts, should be investigated to help health care professionals provide individualised assistance to those children.**

Introduction

Cancer is one of the most fatal diseases with a high incidence rate, and it is predicted to be more prevalent in the next few decades because of a variety of risk factors, such as smoking, being overweight, having unhealthy diets or having sedentary lifestyles [1]. Assuming that the incidence rate stays stable, the estimated new cases of cancer could increase from 12.7 million in 2008 [2] to 21.4 million by 2030 [1]. In 2008, 1 009 178 women aged 15–44 years were diagnosed with cancer, accounting for approximately 17% of all female cancers [3]. As the age period of 15–44 years is defined as the reproductive age for women [4], many cancer patients, especially those who are diagnosed before their 50s, may have dependent children.

A diagnosis of cancer is an event that affects not only patients themselves but also their whole families. Those who have dependent children living at home are most affected, even if the cancer is not advanced or terminal and has a positive prognosis [5,6]. Patients and their spouses struggle with maintaining a balance between the fight with cancer and fulfilling their responsibility of childrearing [7]. They are confronted with a wide range of long-term physical, psychological and social problems, which impact their quality of life [8,9]. The pervasive stressor of parental cancer may have detrimental effects on children who are still dependent on their parents [10,11].

Studies with children of terminal cancer patients indicated the importance of talking about death in an appropriate manner and dealing with bereavement of children [12]. In contrast, studies with children of non-terminal cancer patients paid more attention to children's difficulties during the survival period of parents [6,11,13–16]. The topic of non-terminal parental cancer has triggered interest among researchers since the late 1970s. Several literature reviews have focused on the topic [6,7,11,13–17], the majority of which addressed the impact of parental cancer on school-aged children and adolescents and its associated factors [6,11,13–16]. These reviews focused on quantitative studies [13,14] or included both quantitative and qualitative studies [6,11,15,16]. As indicated in existing reviews, qualitative and quantitative studies produced inconsistent findings, and qualitative research reported more issues encountered by children than quantitative research [15,16]. However, no previous research has systematically reviewed

the available qualitative studies on this topic. A systematic review of qualitative research, therefore, is needed to compare results with previous reviews [14]. Quantitative studies aim to explain the causes and results of social facts by using objective measurement and statistical analysis, whereas qualitative studies seek to understand phenomena from participants' perspectives through methods such as interview and observation, and mostly present the results in words rather than numbers [18,19].The purpose of this paper is to systematically analyse the existing qualitative literature, which explores the experience of school-aged and adolescent children whose parents have non-terminal cancer. This review will uncover the concerns that children experience from their own perspectives, and it aims to further our understanding of these children's concerns and needs. School-aged children refer to children between 6 and 12 years old, whereas adolescent children or adolescents refer to children who are 12–18 years old [20]. In this review, the term 'children' indicates children between ages 6 and 18 years.

Methods

The principles of systematic review of qualitative studies and a meta-synthesis process were adopted, including the development of a specific research aim and questions, application of full searching strategy, literature screening, quality appraisal, data analysis, extraction and synthesis [21,22]. Meta-synthesis is an umbrella term referring to various approaches, including grounded formal theory, meta-ethnography, meta-study, meta-summary, meta-aggregation and thematic synthesis, which are diverse in their specific data analysis and synthesis processes but similar in principle [23–26]. It is indicated that meta-synthesis of qualitative research plays a similar role to meta-analysis of quantitative research in the systematic review process [27]. Meta-analysis seeks to determine the relationship between causes and effects, whereas meta-synthesis aims to interpret the findings of original qualitative studies and thus further the understanding of the phenomenon under study [21]. Meta-synthesis is a technique that analyses individual studies, breaks down the findings, reveals key characteristics and then integrates them to generate a new entirety, which provides new interpretations of phenomena, variables and concepts [21,23,28]. This kind of interpretation serves the purpose of a specific meta-synthesis, looking for homogeneity and discordance of the original studies, creating a holistic perspective of the phenomenon and gaining new insights into the phenomenon, which goes beyond the primary studies but preserves the meaning of the original findings [21]. Meta-synthesis is now widely accepted as an analysis of a series of qualitative literature, with multiple theoretical frameworks and methodologies, but similar or related topics, in which the findings are usually demonstrated as concepts, themes or metaphors [23,24,29].

Search strategy

In March 2013, seven computerised English-based databases Cochrane Library, MEDLINE, EMBASE, CINAHL, ProQuest health & medical complete, AMED and PsycINFO were searched to find relevant literature. Search terms included a variety of relevant terms (e.g. 'neoplasms', 'parent–child relations', 'child', 'adolescent', 'adaptation, psychological' and 'stress, psychological'). Specific search strings, refined according to each database, were applied, and a subject heading search was combined with term search when available. The year of publication was limited to between 1990 and 2013, and the language was restricted to English. In addition, references from included articles and previous related literature reviews were checked. Full search strategies can be retrieved by contacting the first author.

Inclusion and exclusion criteria

Papers that met the following criteria were included if they were: (i) written in English; (ii) published in peer-review journals; (iii) focusing on male and female school-aged and adolescent children; (iv) focusing on children's own experience when a parent is diagnosed with cancer; and (v) qualitative studies or mixed-method studies. For mixed-method studies included in this review, only the qualitative parts were analysed. For studies that explored both parents' and children's experiences, only the studies emphasising children's perspectives or having a separate part of findings from children's point of views were included.

Papers were excluded if they were: (i) written in languages other than English; (ii) focusing on adult children; (iii) indicating that parent's cancer was advanced or terminal, or parents were receiving palliative care; (iv) focusing on parents' perspectives; or (v) non-peer-reviewed literature, such as tutorials, letters, comments, conference abstracts, posters, book reviews and dissertations.

Search outcome

Initially, 2027 articles were identified by searching the databases. Citations for all of the articles were imported into EndNote. Duplicates ($n = 273$) were filtered automatically by utilising EndNote (Thomson Reuters, New York, NY, USA) software. Titles of the remaining 1754 articles were checked to remove apparently irrelevant articles, and 533 articles that were potentially relevant were read based on titles and abstracts. Full texts of 198 articles related to studies focusing on the situation when a parent was diagnosed with cancer and who had school-aged and adolescent children were retrieved and read thoroughly by the researchers. Most of the studies were found to be quantitative studies and demonstrated

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findings from parents' perspectives rather than the children's perspectives. Finally, 24 English articles that potentially satisfied the inclusion criteria were reviewed in the quality appraisal process. No additional articles that had potential to be included were found via the reference lists of the 24 articles and previous reviews.

Quality appraisal

The full texts of the 24 articles were reviewed by the researchers to critically evaluate the quality using the Critical Appraisal Skills Programme (CASP) [30] checklist for qualitative studies. CASP, developed in Oxford in 1993, was created to assist researchers in acquiring skills in the process of evidence-based practice. Two screening questions are provided in the checklist pertaining to the purpose of the research and the appropriateness of undertaking a qualitative methodology according to the research aim. In addition, eight detailed questions are available regarding the research design, recruitment strategy, data collection methods, relationship between researcher and participants, ethical issues, data analysis process, research findings statement and value of the research. Prompts are offered in detail for each question, which can help researchers further understand the meaning and importance of the questions [30].

Sixteen articles were finally retained for the meta-synthesis. Among the eight articles that were excluded, one article [31] was not published as a peer-reviewed article because of the small sample size of only three participants; one article [32] did not report the research methods in detail; three studies [33–35] neither presented results from interviews of parents and children individually nor focused on the findings from children's perspectives; one study [36] mixed results from interviews of children and surveys of staff of an organisation; two studies [37,38] interviewed participants whose parents were diagnosed with terminal or non-terminal cancer with 38% [38] and 41% [37], respectively, of parents deceased when participants were interviewed, but the results of those participants of deceased parents were not revealed separately. The process of searching, screening and appraising the literature is illustrated in Figure 1.

Data extraction and synthesis

The full texts of 16 articles included in the meta-synthesis were imported into QSR NVivo 10 software [39]. Data on methodology, data collection and analysis methods, characteristics of participants, purpose and main findings of included studies were extracted and summarised in the data extraction form (Table 1).

During the data analysis and synthesis procedure, the principle of thematic synthesis developed by Thomas and Harden [26] was adopted. This was because the purpose of this review was to explore broadly the phenomena of children living with parental cancer rather than building a theory or explicating a single concept. For this reason, some popular meta-synthesis approaches aiming more for theory generation or concept analysis, such as grounded formal theory, meta-ethnography and meta-study [23,24], were considered unsuitable. Furthermore, the broad range of participants' age, the diversity of research questions used in the studies and inconsistency of methods rendered the building of theory impossible. A thematic analysis method similar to that used in qualitative studies was undertaken in the thematic-synthesis process [26], and several steps were conducted to integrate and interpret the studies. First, the findings of the studies, as well as original data that supported the findings were read and reread by the researchers in order to fully understand the meaning. The primary findings of the original articles were coded line by line according to meaning and content using NVivo 10 [39]. Phrases and sentences with similar meaning were coded into the same codes. The codes were then compared with seek the commonalities and differences and then grouped into a hierarchical structure with new codes to represent groups of original codes [26]. Then, the codes were divided into different descriptive themes on the basis of the similarity of meaning and relativity of contents. These descriptive themes remained close to the original studies [26]. Finally, these themes were integrated and interpreted into a set of synthesised findings in the form of analytical themes, which went beyond the original articles and produced additional understanding of children's experience within the context of parental cancer (Table 2).

Results

Characteristics of included studies

The 16 articles included in the meta-synthesis were generated from 15 studies, carried out in USA ($n = 6$), Canada ($n = 4$), UK ($n = 3$), Norway ($n = 1$) and Denmark ($n = 1$). The data collected by one study were interpreted from two different perspectives, so two articles [40,41] were published to fully illustrate the findings. Four studies collected data both from parents and children, among which one [40,41] reported findings only from children's interviews, whereas the other three [42–44] demonstrated findings mainly from the analysis of children's data. The majority of the studies ($n = 10$) recruited children of women with non-terminal breast cancer. The majority of participants were adolescents. In addition, the interval between diagnosis of parents and interview of children varied from study to study ranging from 64.7 days to 12 years, and some studies did not state the interval clearly [42,45,46].

Most of the studies ($n = 12$) did not indicate a specific theoretical framework, and around half ($n = 7$) did not

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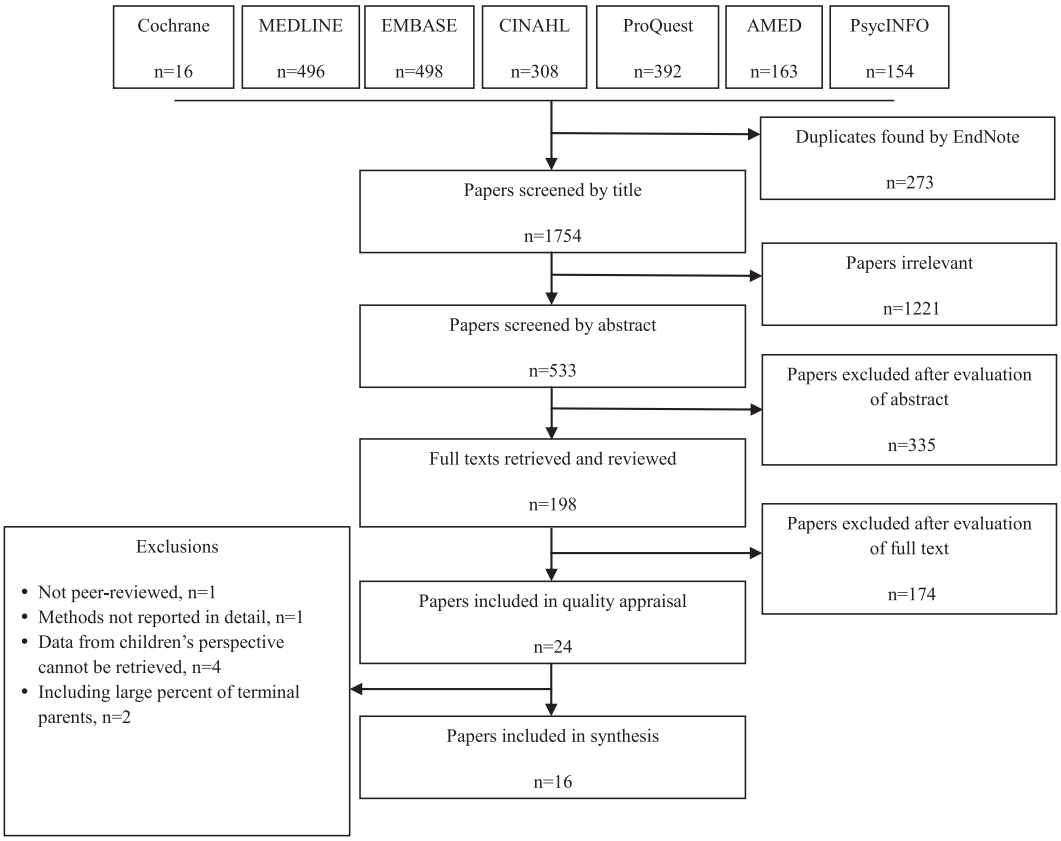

Figure 1. Flowchart of included studies in systematic review and meta-synthesis

state a specific qualitative methodology. Generally, semi-structured interviews and focus groups were conducted to collect data, and content analysis or thematic analysis methods were mainly adopted during the data analysis period. Most of the results ($n = 14$) were revealed in themes, whereas one study [47] categorised the findings according to the questions being asked. Statements of participants were quoted by most research ($n = 13$) to support the findings; however, one study [48] also reported percentage of responses of each theme, and another study [49] illustrated findings in number of expressions generalised to each theme without quotes.

Synthesised findings

Being informed of parental cancer

According to the studies included in this review, most of the children participating in the research had been informed of their parents' diagnosis of cancer. A substantial proportion of children received the information shortly after the diagnosis had been confirmed by test results [40,43–45,50], whereas some were told later [40,43–45]. A few children had been aware of the possibility of their parents having cancer before a precise diagnosis, when their parents discussed with them that a lump was found [50].

The amount and content of information provided about the illness and treatments by parents varied from person to person. Generally, older children tended to be given the truth in detail, whereas young children were provided with limited information [44,49]. Nevertheless, children were so sensitive that they often perceived bad news before they were informed and sometimes discovered the truth on their own [44]. Some of those who were only told that their parents had to go to hospital because of illness and a lump found could connect this immediately to cancer, and others could have been exposed by accident, such as through reading a poster when visiting the ward, or learning about the truth from talking to others who did not know that the child was protected from the information [40,44,49,50].

Emotional concerns

The reviewed studies revealed that children experienced a wide range of emotional responses following a parent's diagnosis of cancer. It has been indicated that no apparent differences were detected among children of varied ages in the aspect of emotional reactions [44]. Children reported various feelings, such as shock, upset, worry, fear, anxiety, depression, anger, sadness and uncertainty [40–42,44,45,50–52]. When first hearing about

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Table 1. Studies included in the meta-synthesis

Authors/year/country	Participants	Diagnosis of parent	Theoretical framework	Methodology	Method	Data analysis	Purpose	Themes/results
Davey *et al.*, 2011; USA [40]	(1) 12 African–American youth, *A* = 11–18, *MA* = 14.5; *M* = 3, *F* = 9 (2) Nine parents, *A* = 34–56, *MA* = 44	Parent: stage I, II or III breast cancer within the past 2 years (one ill parent is the father)	—	Qualitative	Focus groups	Content analysis	To explore how African–American youth cope with the diagnosis and treatment of parental breast cancer and to identify culturally sensitive ways to recruit and sustain participation of this vulnerable population in intervention programs	1.Coping with cancer 2.It affects us too 3.Changes in family functioning 4.Growth through pain
Kissil *et al.*, 2010; USA [41]	(1) 12 African–American youth, *A* = 11–18, *MA* = 14.5; *M* = 3, *F* = 9 (2) Nine parents, *A* = 34–56, *MA* = 44	Parent: stage I, II or III breast cancer within the past 2 years (one ill parent is the father)	—	Qualitative	Focus groups	Content analysis	To explore experiences of posttraumatic growth among African–American adolescents currently experiencing parental breast cancer	1.Parental cancer: a life changing experience 2.Greater appreciation for life 3.Increased intimacy in relationships 4.Sense of increased personal strength 5.Other domains of growth 6.Health-related attitudes and behaviours
Clemmens, 2009; USA [55]	11 adolescents, *A* = 13–19	Mother: stage I or II breast cancer within a year	—	Van Manen's phenomenologic interpretive paradigm	In-depth, semi-structured interviews	Content analysis	To describe adolescents' experiences of living with mothers with breast cancer	1.Life changed 2.Turning to self 3.Learning to be with my mother 4.Needing to normalise
Finch and Gibson, 2009; UK [50]	Seven adolescents D: *A* = 14-18	Parent: cancer within 4–12 months	—	Interpretative phenomenological approach	Semi-structured interviews	Interpretative phenomenological analysis	To explore how young people experience learning about their parent's cancer diagnosis	1.First hearing about parent's diagnosis 2.Vulnerability of self and others 3.Communication within the family 4.Feeling supported in experience 5.Experience and support of school
Stiffler *et al.*,2008, USA [51]	Eight adolescent daughters D: *A* = 10–15, *MA* = 13.5;	Mother: breast cancer (stage 0–III)	—	Empirical phenomenologic	Open-ended interview	Procedure adapted from Colaizzi (1978)	To examine the experiences of being parented when mothers are diagnosed and treated for breast cancer from the perspectives of adolescent daughters	1.A world turned upside down 2.Stop the intrusion, need to get away, reluctant to leave 3.Mom can't die 4.A hole where mom used to be

(Continues)

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Table 1. *(Continued)*

Authors/year/country	Participants	Diagnosis of parent	Theoretical framework	Methodology	Method	Data analysis	Purpose	Themes/results
	I: *A* = 13–24							5.Filling in the hole where mom used to be 6.Being there for mom, managing mom 7.Managing my reactions-being selfish or difficult 8.Guarded relief
Thastum *et al.*, 2008; Denmark [43]	(1) 21 children from 15 families, *A* = 8–15, *MA* = 11; *M* = 8, *F* = 13 (2) Parents from 12 families	Parent: various cancers; disease duration ranged from 2 to 153 months	—	Phenomenology	Semi-structured interviews	Phenomenological method	To explore ways of informing the child of the parent's illness, how the child perceives the parent's emotional state, how the child copes with the parent's illness and how this coping relates to the parent's coping and concerns for the child	1.Levels of information 2.Children's use of coping strategies 3.Advice to other children
Fitch and Abramson, 2007; Canada [45]	13 adolescents I: *A* = 16–25; D: *A* = 13–19, *MA* = 15.7; *M* = 3, *F* = 10	Mother: breast cancer within 10 years	—	Exploratory descriptive	In-depth semi-structured interviews	Standard content and theme analysis	To increase understanding of the information needs of adolescents when a mother is diagnosed with breast cancer	1.Learning about the diagnosis 2.Information needs
Forrest *et al.*, 2006; UK [44]	(1) 37 mothers (2) 31 children, *A* = 6–18	Mother: breast cancer (stage I–IIIa)	—	Qualitative	Semi-structured interviews	Qualitative thematic analysis	To explore how children of mothers newly diagnosed with breast cancer perceive their mother's illness and its initial treatment and to contrast their accounts with the mothers' perceptions of their children's knowledge	1.Awareness of cancer 2.Learning about the mother's diagnosis 3.Reactions to mother's treatment 4.What did children of different ages wish to know
Davey *et al.*, 2005; USA [47]	10 adolescents, *A* = 13–18; *M* = 5, *F* = 5	Mother: breast cancer within 2 years (stages 0, I, II and III)	—	Qualitative	Focus groups	Content analysis	To gain a deeper understanding of how adolescents are affected by their mothers' breast cancer and discover their opinions about how future intervention programs should be designed	Adolescents' lives had been complicated by their mothers' illness, as they often felt burdened with additional roles and responsibilities. Adolescents suggested that future intervention programs should have the following elements: Adolescent group comprised of boys and girls within 4 months of cancer diagnosis, psychoeducation, target coping skills sensitive to girls and boys of different ethnic and racial backgrounds and after the adolescent group, have multiple-family therapy groups that

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								promote shared family understanding and open communication between parents and adolescents
Kristjanson *et al.*, 2004; Canada [52]	31 adolescents I: $A = 12–20$; D: $A < 18$; $M = 9$, $F = 22$	Mother: breast cancer (31 in total, four advanced or terminal)	Family systems theory and symbolic interactionism	Exploratory, qualitative	(1) Semi-structured interviews (2) Focus groups	Constant comparison techniques	To elicit detailed descriptions of adolescents' information and support needs in response of their mothers' breast cancer	1.Information and support needs of adolescent children 2.Effects of stage of their mother's illness, gender and developmental stage 3.Perception of needs being met
Helseth and Ulfsæt, 2003; Norway [42]	(1) 11 children, $A = 7–12$; $M = 7$, $F = 4$ (2) 10 mothers and eight fathers	Parent: cancer, not terminal	—	Phenomenologic-hermeneutic frame	In-depth interviews	Open, explorative approach	To explore the well-being and coping of young children during a period of cancer illness in the family	1.Illness ruling in the family 2.Reactions over and under the surface 3.Many efforts to manage the situation 4.Feeling good most of the time
Hilton and Gustavson, 2002; Canada [53]	11 children, $A = 7–21$; $M = 4$, $F = 7$	Mother: breast cancer in the prior 2 years	—	Qualitative	Semi-structured interviews	Constant comparative analysis	To describe the children's perspectives and to suggest interventions to assist children to manage the experience with less stress	1.Knowing/understanding 2.Acknowleding/feeling 3.Sharing 4.Shifting/helping
Zahlis, 2001; USA [54]	16 children I: $A = 11–18$; D: $A = 8–12$; $M = 8$, $F = 8$	Mother: early-stage breast cancer	—	Descriptive qualitative	Semi-structured interviews	Content analysis	To describe children's worries when their mothers are newly diagnosed with early-stage breast cancer	1.Worrying mother was going to die 2.Feeling confused 3.Worrying something bad would happen 4.Worrying about the family and others 5.Worrying when mother did not look good 6.Worrying mother would be changed 7.Wondering if the family would have to cut back financially 8.Worrying about talking to others 9.Wondering if the child would get cancer
Chalmers *et al.*, 2000; Canada [46]	31 adolescents, $A = 12–20$; $M = 9$, $F = 22$	Mother: breast cancer	Systems theory and the theory of symbolic interactionism	Exploratory, qualitative	(1) Semi-structured interviews (2) Focus groups	Content analysis	To describe the perceptions of adolescents about the role of the school in assisting them in dealing with the cancer experience	1.Information needs 2.Timing and amount 3.Support needs
Nelson *et al.*, 1994; UK [49]	24 adolescent children, $M = 16$, $F = 8$	Parent: cancer between 2 and 6 years previously	—	Mixed-method	(1) Semi-structured interviews	(1) Content analysis (2) Quantitative data analysis	To determine whether the children of cancer patients experience problems and anxieties related to the parent's diagnosis and treatment	1.Home and family life 2.Knowledge and perceptions of parents' cancers 3.Schoolwork and attendance 4.School's knowledge of parent's cancer 5.Social and leisure activities 6.Sons: factors associated with high anxiety

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Table I. *(Continued)*

Authors/year/country	Participants	Diagnosis of parent	Theoretical framework	Methodology	Method	Data analysis	Purpose	Themes/results
	Daughters: I: A = 11–18; D: A = 6–12; sons: I: A = 11–21; D: A = 7–16				(2) Self-report questionnaires			7.Long-term anxiety
Issel *et al.*, 1990; USA [48]	81 children, A = 6–20	Mother: breast cancer within the past 2.5 years	Family systems and cognitive development theories	Qualitative	Semi-structured interviews	Content analysis	To describe the ways in which school-aged children cope with the mother's breast cancer and the ways in which their families help them cope	1.What the family did that helped the children cope 2.What children did by themselves that helped them cope 3.Who helped the children cope 4.Domains of dealing with the mother's illness

A, age; MA, mean age; M, male; F, female; D, when the parents were diagnosed; I, when the children were interviewed.

the diagnosis of parental cancer, many children expressed that they were shocked by the event [41,44,45,50]. They did not believe the occurrence of such a distressing event in their families, and they intended to deny such bad news [51]. Many felt annoyed and irritated [42,45,51] and did not understand why the cancer could happen to their parents, which they felt to be unfair [42,45]. Some children were sad and cried frequently [42]. Others felt lonely, solated and even upset, as they perceived that their feelings were ignored by others [40,44,50,52]. In addition, younger children may perceive a sense of guilt and wondered if they had caused the cancer [52].

It has been demonstrated that their parent's prognosis was a major concern for children. Despite their age, children tended to connect their parent's diagnosis of cancer to potential death [40,42,43,45,49–54]. They wondered about their future life without their ill parent, which resulted in a sense of uncertainty and insecurity [40,47,50,51,54]. Some of these notions may have arisen from previous experience with someone they knew dying from cancer [49,53].

The debility of parents due to cancer and its treatments caused children great strain. Children's concerns were extremely apparent in the period of chemotherapy with their parents' symptoms of hair loss, vomiting and fatigue [43,44,47,53]. Hair loss was most disturbing for school-aged and adolescent children, and they felt fearful when their parents became bald [43,44,53]. Surgery also disturbed children as they did not expect the appearance and weakness of their parents after surgery; thus, they worried about their parents when they looked sick and pale or if blood was discovered in parents' clothes [44,54]. The separation from their ill parent because of hospitalisation also added emotional stress to children because they could not stay with their parents, and they did not know what would happen to their parents when they were resident in the hospital [43,54]. The financial burden caused by illness and treatments was another annoyance for some children, and they were worried about moving house, changing holiday plans or being poor [52,54].

Some children worried that other family members and friends would get cancer after their parents were diagnosed and treated [44,54]. More prominently, they feared inheriting cancer gene themselves and developing cancer in the future [40,44,46,49,52–54]. Especially when a mother was diagnosed with breast cancer, teenage daughters expressed significant fear of suffering from cancer [52]. Some young girls also reported their sense of cancer risk and even wondered about their own survival in the future [44]. Some boys also had similar concerns and were afraid of getting cancer and going through what their parents experienced during the treatments [54].

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Table 2. Themes of meta-synthesis

Analytical themes	Descriptive themes	Davey *et al.*, 2011 [40]	Kissil *et al.*, 2010 [41]	Clemmens, 2009 [55]	Finch & Gibson, 2009 [50]	Stiffler *et al.*, 2008 [51]	Thastum *et al.*, 2008 [43]	Fitch & Abramson, 2007 [45]	Forrest *et al.*, 2006 [44]	Davey *et al.*, 2005 [47]	Kristjanson *et al.*, 2004 [52]	Helseth & Ulfsæt, 2003 [42]	Hilton & Gustavson, 2002 [53]	Zahlis, 2001 [54]	Chalmers *et al.*, 2000 [46]	Nelson *et al.*, 1994 [49]	Issel *et al.*, 1990 [48]
Being informed of parental cancer	Learning about the diagnosis	×		×	×		×	×	×				×				
	Knowing without being informed	×			×				×							×	
Emotional concerns	Various feelings	×	×		×	×		×	×		×	×					
	Fear of parental death	×				×	×	×		×	×	×	×	×		×	
	Fear of getting cancer	×							×		×		×	×	×	×	
	Worrying about chemotherapy, surgery and so on						×		×	×	×		×	×			
Changes in daily life	Impact on children's daily activities	×		×		×	×			×			×		×	×	×
	Impact on parents and family relationships	×	×	×		×	×			×			×			×	
	Comforting parents	×	×	×		×	×	×		×							×
	Being normal	×		×	×	×	×	×		×	×	×	×				×
Seeking factual information	Children's understanding of cancer		×	×	×				×				×				
	Importance of enough information	×			×		×	×		×							
	Not enough information								×	×	×		×				
	Contents of information required	×						×			×				×		
	Ways of obtaining information	×		×	×			×	×		×		×		×	×	
Seeking emotional support	Talking about parental cancer	×		×	×	×	×	×		×	×	×	×				×
	Reasons of not sharing feelings			×	×		×			×	×	×	×		×	×	

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Changes in daily life

Parental cancer could intrude on the children's daily lives and their roles played in the family. A large proportion of children actively or passively took extra responsibilities for household chores, such as cooking, cleaning, shopping and taking care of younger siblings, during the treatment of their parents. This meant that they had to reduce the time with their friends, and their social lives could be interrupted [40,43,47–49,51,53,55]. Some children had to relinquish their hobbies and sports because their parents could not drive them to the activities [49]. Some found it stressful without parental company in their daily lives and extra-curriculum activities, or if someone, other than the mother, helped with household responsibilities [51,53,55]. A few children isolated themselves from others [48,55]; in addition, some reported distraction from schoolwork and lowered school attendance because of parents' illness [46,49].

Many children described reduced energy, emotional vulnerability and negative behaviours of the ill parents [40,43,47,51,53,55]. So as to help their parents, some children shouldered the role of providing emotional support by concealing their own emotional stress, being considerate and empathic, avoiding quarrelling with them, comforting them verbally, visiting them in hospital, accompanying them to see doctors, managing medication or spending more time with them at home or outside [40,41,43,45,47,48,51,55]. Some children witnessed additional emotional and practical stress in their healthy parents, sometimes perceiving it on their own rather than being told [43,49,53]. The changes of emotional climate in the family were recognised by some children, and increased conflicts in the family were reported [40,53]. Children's interactions with their parents were influenced as well. Although the relationship with parents deteriorated for some children, others narrated becoming emotionally closer to their parents after the occurrence of cancer [41,49].

A majority of children noticed that their lives were profoundly affected by parental cancer; nonetheless, some children sensed little alteration [42,53]. In fact, for most children, it was hard to adapt to the life changes in the first place, but many were likely to get used to it with time [40,42,50]. Cancer was gradually integrated into their normal life and became an indivisible part [40,42,50]. It was important for the children to maintain their daily routine, because it gave them a sense of reassurance [42,47,50–53,55]. Children, therefore, tried their best to keep everything on a normal track by distracting themselves from thinking of parents' illness with personal activities, such as watching TV, listening to music, doing sports, drawing pictures, reading books, being with friends, playing alone and focusing on academic activities [40,42,43,45,47,48,51,53,55].

Seeking factual information

Children's understanding of cancer and its treatments varied depending on ages, personal experience, existing knowledge and information provided. Generally, most children, regardless of age, were aware that cancer is a serious and fatal disease that would affect their lives even though they may have been unable to distinguish different cancer types or fully understand the treatments and the side effects [41,44,50,53]. Children might suspect worse than the reality when they were not clear on the diagnosis, treatments and prognosis [55], hence, the importance of precise information and knowledge of parental cancer asserted in the reviewed studies [43,50]. Sufficient and factual information about the changes that would happen because of a cancer diagnosis and treatment would make children less stressful [40,43,45,47].

Even though most children had been provided with some information about their parents' disease, they still had a strong desire for further understanding of cancer and its related knowledge. However, most, especially adolescents, claimed that their needs were poorly met [44,47,53]. Despite the high demand for information by most children, the information needs of some younger children were relatively low, and some thought they had been given enough information [44]. In addition, some children might shield themselves from information as they thought that more information might make the situation more complicated or make them confused [53].

The information and knowledge that children wanted to acquire might be different between different age groups [44], and adolescents emphasised the importance of meeting the unique needs of each individual [52]. Nonetheless, the required information generally referred to all aspects of parental cancer, including the definition of cancer, causes, incidence rates, treatment choices, potential side effects, prognosis of their parents and risks of children getting cancer [45,52]. Apart from the knowledge of physical aspects of cancer, children also appreciated information about psychological reactions of both children and parents induced by the diagnosis [52].

Children searched for information from a variety of resources. Parents who were open in communication were one of the main sources of information, and they also helped explain information gained from others [44,49,52,53,55]. Older siblings, relatives, friends and school staff members were also asked for help [46,50,52,53]. Children, especially teenagers, found it beneficial to talk to a health care professional who could provide information in plain language, respect them and be available to answer questions when required [44,52,53]. School was another salient channel for seeking information [46,52]; however, the amount, content and timing of the knowledge provided in classes were usually not compatible with the specific needs of children living with parental cancer [46]. Moreover, written

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books were also regarded as important information sources, and dictionaries, encyclopaedias, library collections and brochures were checked for information [40,45,50,52,53]. For adolescents, the internet played a significant role in searching for information relevant to parental cancer [40,45,50,52], whereas young children found media including pictures and videos helpful [53].

Seeking emotional support

It has been noted that children needed emotional support, and they sought assistance from a wide array of sources [52]. Talking about the experiences and feelings of living with parents' cancer was the main approach to obtaining emotional support [45]. Many children desired to talk about their parents' cancer openly even though some of them may have found it difficult at first [48]. When confronted with parental cancer, the majority of children found family a safe refuge from the experience, and open, sincere and honest communication in the family, especially talking with parents was valued by them [40,42,47,48,50,53]. However, it was pointed out that some children did not obtain or perceive any assistance from their families in terms of coping with the experience of parental cancer [48].

Apart from family members, friends of similar ages were also identified as one of the primary support providers [43,48,50], and more adolescents than young children sought support from peers [48]. For school-aged children, the communication with close friends was more likely to be limited to informing them of the parents' diagnosis [42]. In comparison, for adolescents at an age of treasuring friendship, a large proportion of them shared their concerns with their friends who were considerate and were good listeners [43,50]. In addition to old friends, it was demonstrated in many studies that children found peer support groups with those who were facing a similar situation extremely supportive, and they wished to talk to these peers to share their own experiences with each other [40,47,50,51,53]. Moreover, some children found school staff members, such as teachers, counsellors and coaches supportive, especially those who had experience relating to family members' cancer [52,55]. Apart from communicating with others, some children found talking to their god helpful, so they sought spiritual support by going to church and reading the bible together with their parents [40,47,53,55].

Although talking to others was an identified coping strategy, children reported mixed feelings about sharing their concerns with others. Although some children would have liked to communicate with others about their personal experience, others may have kept their feelings to themselves and were reluctant to express concerns pertaining to parents' cancer [53]. Various reasons may contribute to the unwillingness of disclosing their experience. First of all, many children had a perception that those who had never undergone a similar situation may not understand how the cancer affected their lives and how they felt [47,53]. Furthermore, the experience may be too stressful for some children to recall, so they rarely initiated communication, which was thought to be protective of themselves [43,50,53]. Sometimes, children may hide their emotions so as to protect their parents and other family members as they did not want to burden them emotionally [47,55]. In addition, a few children may feel uncomfortable or embarrassed to talk to friends, or worry about upsetting and troubling them, so they kept quiet [42,53]. Last but not least, many children were unwilling to mention their parents' illness at school, as the school was a harbour of refuge from the suffering of parental cancer where they could relinquish their role as children of cancer parents. They had high demands for being treated as normal by their peers and teachers [46,47,49,52].

Discussion

According to the findings of this review, children's experiences when a parent is diagnosed with non-terminal cancer are individualised and vary from person to person. However, common characteristics of their perceptions within the context of parental cancer can be deduced from the included studies. The importance of talking openly and honestly with children across the age ranges is emphasised in these results. As indicated, children are likely to experience mixed feelings when facing a parent's cancer. On the one hand, they attempt to find out factual information; on the other, they may want to avoid negative results of their parents' disease. They have a strong desire to share their feelings with someone, yet it is difficult for them to find a suitable person in whom to confide. Furthermore, they would like to reduce their parents' burden by offering emotional and practical help within their capacity; however, they may at the same time, feel reluctant to do so as they want to focus on themselves. Being normal is often important to children, and they are sometimes unwilling to have their lives affected by their parents' disease.

As revealed in the findings, when confronted with the unexpected event of parental cancer, children, regardless of age, suffer from a variety of emotional distress. In contrast, according to one systematic review of quantitative data [13], the overall psychological problems of children and adolescents whose parents had cancer were not significantly higher than reference groups although they experienced marginally higher risk of internalising problems, such as depression and anxiety. Two previous literature reviews on this topic [15,16] also indicated that more psychological and social difficulties of children of cancer patients were found in qualitative studies than in quantitative studies. The difference may be because of the relatively small sample sizes of the existing quantitative

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studies which made the statistical analysis less valid, as well as the low sensitivity of the standard scales when being used in assessing the specific concerns of children of cancer patients [11,13,15], as quantitative research relies on relatively large sample sizes to produce statistical difference [19]. Besides, the low sensitivity of the standard scales when being used to assess the specific concerns of children of cancer patients may also affect results [11,13,15,16]. For this reason, this systematic review of qualitative data complements previous reviews to some extent, providing a broader view of the issues pertaining to the children living with parental cancer. The findings of this review covered all aspects of the situation when children were confronted with parental cancer, including the disclosure of parental cancer, the impact of the diagnosis and treatment, children's reactions and coping strategies, as well as their information and support needs. In addition, this review analysed and synthesised findings of several studies from children's perspectives, which enables health care professional to understand children's feelings and coping strategies that may be concealed in order to protect the parents [47,55]. Furthermore, the results can be used as a reference to help health care professional develop interventions for those children and their parents.

Implications for future qualitative studies

Some directions for future qualitative studies on this topic have been identified from this review. Most of the studies included in this review focused on children of mothers with breast cancer, which was consistent to findings from previous reviews [11,14–16]. None of the studies probed into children's experience when the father had cancer or compared children of ill fathers with those of ill mothers. The high incidence and high survival rate of female breast cancer [2] may make the issues relevant to children of breast cancer patients more prevalent than those of other cancers and provide the primary studies with enough participants. Nonetheless, further studies should investigate children's emotional and behavioural changes when a father is diagnosed with non-terminal cancer to discover if there are any differences in contrast to the situation of a mother's cancer diagnosis.

Furthermore, despite an attempt to explore the experience of children of different ages, most studies ($n = 10$) interviewed adolescents exclusively, whereas others ($n = 4$) recruited both adolescents and school-aged children without separating findings on the basis of age groups. Only one study [42] emphasised school-aged children who were 7–12 years old when they were interviewed. This may be because of the ethical issues about recruiting young children to studies of such a sensitive topic or because of worries about the limited capacities of young children in terms of sharing their experiences [56]. In addition, the intention of parents to protect their children may interfere with the researchers' access to the children [57]. Despite this apprehension, recent studies concerning children have demonstrated that they have both the right and capacity to express their feelings, and their rights could be protected if appropriate measures were adopted [56,58]. Future studies focusing on school-aged children or pre-schoolers should be conducted to explore these younger children's specific concerns.

In addition, for many included studies, the interval between diagnosis of parents and interview of children in the same study was heterogeneous, which may make the results and conclusions less typical and convincing. As indicated in the findings, children tend to have severe emotional reactions and difficulties in coping within the first few months during the period of initial diagnosis and treatments, especially chemotherapy. After this time, they may gradually adjust to the situation of living with parental cancer. Therefore, the results from children suffering from short-term and long-term impact of parental cancer should be separated and compared in future research in order to help health care providers offer appropriate advice and support to children affected by the diagnosis of parental cancer.

Limitations of this study

Although it contributes to knowledge about children confronted with parental cancer, there are several limitations to this review. First, this review searched only English literature. Studies conducted in non-English speaking regions, such as Africa, Asia and Southern Europe, may have been overlooked. Future literature review of studies published in languages other than English should be undertaken to compare the cultural differences between different areas. Second, this study searched literature published after the year of 1990. Although the authors intended to do a systematic review which aimed at finding latest evidence on this topic, some related studies published earlier than 1990 that may have potential to further understanding of this topic may have been neglected. Third, during the data analysis and synthesis process, the authors did not conduct the coding independently or compare their codings, so the 'inter-rater reliability' could not be provided. Although there is no consensus regarding the independent analysis in a meta-synthesis process [21], coding independently and contrasting codings may have potential to increase the reliability of the findings in meta-synthesis. Lastly, the findings of this study should be used in caution. The findings of the reviewed qualitative studies were interpreted from subjective experience of specific participants within specific context, which may not represent the wider population in other contexts.

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Conclusions

This systematic review of qualitative studies provides insight into children's subjective worlds when a parent is diagnosed with non-terminal cancer, in which the children's concerns, coping strategies and needs are often unclear. Individualised information and support should be provided to enable children to experience this detrimental event with minimal disruption. The experience of children of cancer patients is still a relatively new research topic; further studies should be conducted to delve into children's experience when a father has cancer, as well as young children's specific understanding and concerns when facing this scenario. The short-term and long-term impact of parental cancer on children from different cultures should also be compared to help health care professionals deeply understand this situation and then develop suitable interventions. Understanding the needs of all family members involved in the disease and treatment process provides the best outcomes for all affected.

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References

1. World Health Organization. *Global Status Report on Noncommunicable Diseases 2010*. WHO Press: Switzerland, 2011;11.
2. Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 2010;**127**(12):2893–2917. DOI: 10.1002/ijc.25516.
3. World Health Organization. GLOBOCAN 2008: Estimated cancer Incidence, Mortality, Prevalence and Disability-adjusted life years (DALYs) Worldwide in 2008. http://globocan.iarc.fr/. [cited 24 July 2013].
4. World Health Organization. *Women and Health: Today's Evidence Tomorrow's Agenda*. WHO Press: Switzerland, 2009;39.
5. Kristjanson LJ. The family's cancer journey: a literature review. *Canc nurs* 1994;**17**(1):1–17.
6. Faulkner RA, Davey M. Children and adolescents of cancer patients: the impact of cancer on the family. *Am J Fam Ther* 2002;**30**(1):63–72. DOI: 10.1080/019261802753455651.
7. Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer Nurs* 2010;**33**(2):110–118. DOI: 10.1097/NCC.0b013e3181c024bb.
8. Ernst J, Götze H, Krauel K, *et al*. Psychological distress in cancer patients with underage children: gender-specific differences. *Psycho-Oncology* 2013;**22**(4):823–828. DOI: 10.1002/pon.3070.
9. Ernst J, Gotze H, Brahler E, Korner A, Hinz A. Quality of life of parents diagnosed with cancer: change over time and influencing factors. *Eur J Canc Care (Engl)* 2012;**21**(4):535–541. DOI: 10.1111/j.1365-2354.2012.01330.x.
10. Zahlis EH, Lewis FM. Mothers' stories of the school-age child's experience with the mother's breast cancer. *J Psychosoc Oncol* 1998;**16**(2):25–43. DOI: 10.1300/J077V16N02_02.
11. Grabiak BR, Bender CM, Puskar KR. The impact of parental cancer on the adolescent: an analysis of the literature. *Psycho-Oncology* 2007;**16**(2):127–137. DOI: 10.1002/pon.1083.
12. Christ GH, Christ AE. Current approaches to helping children cope with a parent's terminal illness. *CA: Canc J Clin* 2006;**56**(4):197–212. DOI: 10.3322/canjclin.56.4.197.
13. Osborn T.. The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psycho-Oncology* 2007;**16**(2):101–126. DOI: 10.1002/pon.1113.
14. Krattenmacher T, Kuhne F, Ernst J, Bergelt C, Romer G, Moller B. Parental cancer: factors associated with children's psychosocial adjustment—a systematic review. *J Psychosom Res* 2012;**72**(5):344–356. DOI: 10.1016/j.jpsychores.2012.01.011.
15. Visser A, Huizinga GA, van der Graaf WTA, Hoekstra HJ, Hoekstra-Weebers JEHM. The impact of parental cancer on children and the family: a review of the literature. *Cancer Treat Rev* 2004;**30**(8):683–694. DOI: 10.1016/j.ctrv.2004.06.001.
16. Huizinga GA, Visser A, Zelders-Steyn YE, Teule JA, Reijneveld SA, Roodbol PF. Psychological impact of having a parent with cancer. *Eur J Cancer* 2011;**47**(3 Suppl):S239–S246.
17. Niemelä M, Hakko H, Räsänen S. A systematic narrative review of the studies on structured child-centred interventions for families with a parent with cancer. *Psycho-Oncology* 2010;**19**(5):451–461. DOI: 10.1002/pon.1620.
18. FIRESTONE WA. Meaning in method: the rhetoric of quantitative and qualitative research. *Educ Res* 1987;**16**(7):16–21. DOI: 10.3102/0013189x016007016.
19. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 9th ed. Wolters Kluwer Health/Lippincott Williams & Wilkins: Philadelphia, 2012.
20. Wilson SF, Giddens JF. Health assessment for nursing practice. 4th ed. Mosby/Elsevier: St. Louis, Mo, 2009.
21. Walsh D, Downe S. Meta-synthesis method for qualitative research: a literature review. *J Adv Nurs* 2005;**50**(2):204–211. DOI: 10.1111/j.1365-2648.2005.03380.x.
22. Bondas T. Challenges in approaching metasynthesis research. *Qual health Res* 2007;**17**(1):113. DOI: 10.1177/1049732306295879.
23. Finfgeld DL. Metasynthesis: the state of the art—so far. *Qual Health Res* 2003;**13**(7):893–904. DOI: 10.1177/1049732303253462.
24. Finfgeld-Connett D. Generalizability and transferability of meta-synthesis research findings. *J Adv Nurs* 2010;**66**(2):246–254. DOI: 10.1111/j.1365-2648.2009.05250.x.
25. Hannes K, Lockwood C. Pragmatism as the philosophical foundation for the Joanna Briggs meta-aggregative approach to qualitative evidence synthesis. *J Adv Nurs* 2011;**67**(7):1632–1642. DOI: 10.1111/j.1365-2648.2011.05636.x.
26. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;**8**(1):45–54. DOI: 10.1186/1471-2288-8-45.
27. Jones ML. Application of systematic review methods to qualitative research: practical issues. *J Adv Nurs* 2004;**48**(3):271–278. DOI: 10.1111/j.1365-2648.2004.03196.x.
28. Finlayson K, Dixon A. Qualitative meta-synthesis: a guide for the novice. *Nurs Res* 2008;**15**(2):59–71.
29. Zimmer L. Qualitative meta-synthesis: a question of dialoguing with texts. *J Adv Nurs* 2006;**53**(3):311–318. DOI: 10.1111/j.1365-2648.2006.03721.x.
30. Public Health Resource Unit. Critical Appraisal Skills Programme. http://www.casp-uk.net/find-appraise-act/appraising-the-evidence/. [cited 2 March 2013].
31. Sears HA, Sheppard HM. "I just wanted to be the kid": adolescent girls' experiences of having a parent with cancer. *Can Oncol Nurs J* 2004;**14**(1):18–25.
32. Spira M, Kenemore E. Adolescent daughters of mothers with breast cancer: Impact and implications. *Clin Soc Work J* 2000;**28**(2):183–195. DOI: 10.1023/A:1005106301713.
33. Davey M. Parent and adolescent responses to non-terminal parental cancer: a retrospective multiple-case pilot study. *Fam Sys health* 2003;**21**(3):245–258. DOI: 10.1037/1091-7527.21.3.245.
34. Hilton BA, Elfert H. Children's experiences with mothers' early breast cancer. *Cancer Pract* 1996;**4**(2):96–104.

35. Huizinga GA, van der Graaf WT, Visser A, Dijkstra JS, Hoekstra-Weebers JE. Psychosocial consequences for children of a parent with cancer: a pilot study. *Cancer Nurs* 2003; **26**(3):195–202.
36. Patterson P, Pearce A, Slawitschka E. The initial development of an instrument to assess the psychosocial needs and unmet needs of young people who have a parent with cancer: piloting the offspring cancer needs instrument (OCNI). *Support Care Cancer* 2011;**19**(8):1165–1174. DOI: 10.1007/s00520-010-0933-7.
37. Wong ML, Cavanaugh CE, Macleamy JB, Sojourner-Nelson A, Koopman C. Posttraumatic growth and adverse long-term effects of parental cancer in children. *Fam Syst Health* 2009; **27**(1):53–63. DOI: 10.1037/a0014771.
38. Wong M, Ratner J, Gladstone KA, Davtyan A, Koopman C. Children's perceived social support after a parent is diagnosed with cancer. *J Clin Psychol Med Settings* 2010;**17**(2):77–86. DOI: 10.1007/s10880-010-9187-2.
39. QSR International. The NVivo workbook. QSR International Melbourne, 2012.
40. Davey MP, Tubbs CY, Kissil K, Niño A. 'We are survivors too': African–American youths' experiences of coping with parental breast cancer. *Psycho-Oncology* 2011;**20**(1):77–87. DOI: 10.1002/pon.1712.
41. Kissil K, Nino A, Jacobs S, Davey M, Tubbs CY. "It has been a good growing experience for me": growth experiences among African American youth coping with parental cancer. *Fam Syst Health* 2010;**28**(3):274–289. DOI: 10.1037/a0020001.
42. Helseth S, Ulfsæt N. Having a parent with cancer: coping and quality of life of children during serious illness in the family. *Cancer Nurs* 2003;**26**(5):355–362.
43. Thastum M, Johansen MB, Gubba L, Olesen LB, Romer G. Coping, social relations, and communication: a qualitative exploratory study of children of parents with cancer. *Clin Child Psychol Psychiatr* 2008;**13**(1):123–138. DOI: 10.1177/1359104507086345.
44. Forrest G, Plumb C, Ziebland S, Stein A. Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. *Bmj* 2006;**332**(7548):998–1003. DOI: 10.1136/bmj.38793.567801.AE.
45. Fitch MI, Abramson T. Information needs of adolescents when a mother is diagnosed with breast cancer. *Can Oncol Nurs J* 2007; **17**(1):16–25.
46. Chalmers KI, Kristjanson LJ, Woodgate R, *et al*. Perceptions of the role of the school in providing information and support to adolescent children of women with breast cancer. *J Adv Nurs* 2000;**31**(6):1430–1438. DOI: 10.1046/j.1365-2648.2000.01449.x.
47. Davey M, Gulish L, Askew J, Godette K, Childs N. Adolescents coping with mom's breast cancer: developing family intervention programs. *J Marital Fam Ther* 2005;**31**(2):247–258. DOI: 10.1111/j.1752-0606.2005.tb01558.x.
48. Issel LM, Ersek M, Lewis FM. How children cope with mother's breast cancer. *Oncol Nurs Forum* 1990;**17**(3 Suppl):5–12.
49. Nelson E, Sloper P, Charlton A, While D. Children who have a parent with cancer: a pilot study. *J Cancer Educ* 1994;**9**(1):30–36. DOI: 10.1080/08858199409528262.
50. Finch A, Gibson F. How do young people find out about their parent's cancer diagnosis: a phenomenological study. *Eur J Oncol Nurs* 2009;**13**(3):213–222. DOI: 10.1016/j.ejon.2009.03.010.
51. Stiffler D, Barada B, Hosei B, Haase J. When mom has breast cancer: adolescent daughters' experiences of being parented. *Oncol Nurs Forum* 2008;**35**(6):933–940. DOI: 10.1188/08.ONF.933-940.
52. Kristjanson LJ, Chalmers KI, Woodgate R. Information and support needs of adolescent children of women with breast cancer. *Oncol Nurs Forum* 2004;**31**(1):111–119. DOI: 10.1188/04.ONF.111-119.
53. Hilton BA, Gustavson K. Shielding and being shielded: children's perspectives on coping with their mother's cancer and chemotherapy. *Can Oncol Nurs J* 2002;**12**(4):198–217.
54. Zahlis EH. The child's worries about the mother's breast cancer: sources of distress in school-age children. *Oncol Nurs Forum* 2001;**28**(6):1019–1025.
55. Clemmens DA. The significance of motherhood for adolescents whose mothers have breast cancer. *Oncol Nurs Forum* 2009;**36**(5):571–577. DOI: 10.1188/09.ONF.571-577.
56. Jokinen P, Lappalainen M, Meriläinen P, Pelkonen M. Ethical issues in ethnographic nursing research with children and elderly people. *Scand J Caring Sci* 2002;**16**(2):165–170. DOI: 10.1046/j.1471-6712.2002.00076.x.
57. Bushin N. Interviewing with children in their homes: putting ethical principles into practice and developing flexible techniques. *Child Geogr* 2007;**5**(3):235–251. DOI: 10.1080/14733280701445796.
58. Grover S. Why won't they listen to us? On giving power and voice to children participating in social research. *Childhood* 2004;**11**(1):81–93. DOI: 10.1177/0907568204040186.