

## Parents' experiences of a Family Support Program when a parent has incurable cancer

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**Aims and objectives.** The Family Support Program was created to support children and parenting when one of the parents has incurable cancer. We chose a family-based approach to support parent's coping and to help families pull together, identify strengths in the family and learn how to seek help.

**Background.** Cancer is usually a new experience for young families. In most cases, parents do not have the necessary knowledge about their children's need for information and support about their parent's serious illness and impending death.

**Design.** A qualitative evaluation study based on data collected through in-depth interviews focusing on parent's experiences with the Family Support Program.

**Methods.** Participants were patients with incurable cancer and their partners and ex-partners with children aged between 5–18 years. Thirteen parents were in-depth interviewed.

**Results.** Parents described how the Family Support Program helped them gain greater insight into their children's thoughts and reactions and into how the situation affected their daily living. Parents reported that conflicts were reduced, they could talk more openly about the situation in the family and that they were shown how to support their children's coping.

**Conclusion.** The Family Support Program met the parents in the study's needs for more information and support about how to cope with their children during the patient's terminal illness.

**Relevance to clinical practice.** The Family Support Program is described in detail in a manual that makes it easy for other health workers to use the same programme. The Family Support program was in use in outpatient clinics, oncology wards and palliative care units and was provided both from nurses and social workers trained in cancer care. Parent's in the study would like the Family Support Program to be available to all patients who receive the poor prognosis that their cancer cannot be cured.

**Key words:** cancer, children, communication, family nursing intervention, parents, qualitative study

Accepted for publication: 14 July 2008

### Introduction: When a parent has incurable cancer

It is not surprising to find that parents who face a life-threatening illness such as cancer experience anxiety, distress, depression and other emotional difficulties (Maguire 1994, Barnes *et al.* 2002), which has a direct

impact on their parenting and relationships with their children.

The balance of evidence indicates that children of parents with cancer are at increased risk of developing psychological disturbance and problems. Anxiety levels among children relate to whether and how they are told about their parent's

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illness and to the quality and openness of communication and relationships that they have with their parents (Nelson *et al.* 1994, Siegel *et al.* 1996, Welch *et al.* 1996, Sneeuw *et al.* 1999, Benzein *et al.* 2001, Buxbaum & Brant 2001). It may be especially hard for younger parents to face their own death and to confront the prospect of having to 'leave' their children to grow up without them (Kuuppelomäki & Lauri 1998). Studies have shown that children struggle with fear, sorrow, anxiety, anger and withdrawal when a parent has cancer. It is especially difficult for a child to deal with a parent's cancer if the disease is both unstable and incurable (Helseth & Ulfsaet 2003).

Studies show that parents find it difficult to talk with their children about cancer and that they are reluctant to have these discussions with their children because they are afraid of frightening them and of seeming to take away any sense of hope (Barnes *et al.* 2000, Buxbaum & Brant 2001). One study showed that, in most cases, parents did not have the necessary knowledge about children's reactions to information about their parents' serious illness and impending death, or how to respond to their reactions in an appropriate way (Helseth & Ulfsaet 2005). Such knowledge is essential for parents if they are to understand their children's needs at this time.

Parents also tend to underestimate their children's need for information and their reactions to the situation (Kroll *et al.* 1998). Elmberger *et al.* (2005) described parents' experiences of how cancer intruded on their family life and interrupted the continuity of the care they could give their children. These parents wanted to be 'capable parents' coping with the situation, but it was very hard to cope alone. Parents reported needing considerable support in relation to telling their children that they had cancer, dealing with the children's feelings and reactions to the diagnosis and prognosis and supporting their children in the aftermath of this news.

Research suggests that there is a clear role for nurses in helping parents and their children at this difficult time. Nursing's mandate is to care not only for individual patients or clients but also for families. However, the needs of these children and the challenges facing their parents with cancer are rarely addressed in hospitals (Helseth & Ulfsaet 2005). Parents with cancer have articulated how they would value such a supportive family service (Barnes *et al.* 2000). It is in response to this pressing need that our programme was developed for families with children age 5–18, taking into account children's developmental stage and individual maturity. It is not sufficient, however, merely to develop and implement programmes and interventions. If we are to be genuinely critical, reflective and understanding in relation to if and how such programmes work and how they are

experienced by patients or clients, then it is crucial to incorporate evaluation into the process. This article reports such an evaluation of parents' experiences.

## The 'Family Talks in Cancer Care' programme (Family Support Program)

### Purpose and philosophy of the programme

The Family Support Program was developed in response to identified gaps in service provision and was informed by research about the specific needs of parents and children where a mother or father was facing death from an incurable form of cancer. The Family Resilience Theory (Allison *et al.* 2003) involves the use of strategies and processes to meet and overcome challenges. These include pulling together by increasing open communication, predictability, confirmation and association within the family. This enables family members to use family strengths to reframe the crisis and increase intra-family support. This also helps families plan the future with the knowledge of what will be best for both children and parents and with awareness where to seek help (Allison *et al.* 2003). Libo and Griffith (1996) proposed a coping theory for children based on two central components: the experience of belonging and competence as important elements of children's ability to cope in difficult situations. Libo and Griffith's (1996) coping theory for children and the Allison *et al.*'s (2003) Family Resilience Theory were the framework informing the Family Support Program.

Beardslee *et al.* (2003) found that preventive interventions that are manual based and relatively brief can have long-standing positive effects in helping families manage problems around parental illness. Beardslee *et al.* (2003) studied healthy children at risk for psychopathology attributable to their parent's mood disorder and demonstrated a significant reduction in risk factors and increase in protective factors over a long time interval. In the Family Support Program, we combined elements from the Beardslee *et al.* (2003) preventive family intervention together with theories of resilience and coping and incorporated knowledge about common reactions and coping strategies of children, adolescents, parents and families during the progress of untreatable cancer. The Family Support Program was prepared in a manual format that detailed the background of the programme, supporting theories, goals for participants, records of family meetings, strategies for approaching specific problems and 'tips' to increase communication and understanding between children and their parents. Communication with and support provided for children in different age groups were described according the child's developmental stage, for

example preschool children, children under 10 years, children aged 11–13 and 14–18 years of age. Materials such as books and films were selected to help parents understand their children's possible reactions and coping strategies and to help them encourage their children's strengths and skills.

### Aims of the Family Support Program

Overall, the Family Support Program aimed to help parents meet the challenges regarding their children and to support family resilience. More specifically, it aimed to:

- help the family to talk about the illness and related subjects;
- help parents to understand the needs of their children and how best to support them; and
- help the family to plan for the future.

We chose a family-based approach to help the family to pull together by increasing positive interactions between parents and children. We identified the strengths in the family to reframe the crisis and guided the family in seeking help from the Family Support Program and other sources.

### Approach and operation of the Family Support Program

The Family Support Program was conducted in three Norwegian hospitals between October 2005–August 2006 for patients who had been informed about their incurable status and who had at least one child aged between 5–18 years. None of the institutions had any programme for family support before we started the Family Support Program. All family members were invited to participate in the programme and the invitation extended to separated or divorced parents and their new partners. It was ultimately the patient's decision as to who would participate.

A team of six health workers specialising in cancer care (four nurses, a sociologist and an art therapist) conducted the Family Support Program with two workers based in each hospital. All undertook further training to improve their communication skills with children, parents and families and to understand fully the purpose of the programme. Information about the Family Support Program was provided to doctors and nurses in oncology, cancer care and palliative care units within the three hospitals and suggestions offered as to which families could benefit from the programme.

The programme consisted of four (five including one 'after death' meeting) meetings conducted over six weeks. Each family was met and helped in an individualised way based on their particular resources and family dynamics. Variation between social classes are not addressed in this study. The aim of the four meetings was to initiate and support a process

in the family that the parents could build up on and also to clarify if the family needed more or different help and to locate such support.

## Study approach and methods

### Purpose of the study

Programme development may focus on many aspects of both process and outcome (White & Walter 2006). In this article, we focus specifically on parents' experiences and perceptions of the Family Support Program. A subsequent article will present children's experiences and perceptions of the Family Support Program. A central evaluative question was; did the programme support family resilience by increasing the use of strategies and processes to meet and overcome challenges and did it enable them to use the strengths within the family to reframe the crisis and to plan the future?

### Taking a qualitative approach as part of programme development and evaluation

The Family Support Program was based on the premise that to provide a sensitive, responsive and valuable service for parents, it is essential to gain a clear understanding of how such services are experienced and perceived by those who receive them (Darbyshire 2003). Qualitative interviews elicited family members' understandings and perceptions of the programme and allowed participants to articulate their situation from their own perspective and in their own words (Kvale 1996). Analysis of these interviews enabled us to discover how the programme met families' needs within the context of having a terminal illness and to capture multiple perspectives, contextualised meanings and experiences of programme participation.

### Ethical issues and approval

Research into terminal care is distinguished by the short remaining life expectancy of participants and their potential vulnerability to unrealistic expectations or benefits. There may also be risks of emotionally distress or even psychological disturbance as a result of some qualitative research (Masso *et al.* 2004). It was, therefore, crucial that parents' and families' were afforded genuinely free and informed choice as to whether they wished to take part in the study at such a difficult time in their lives and give them the possibility for further support from health professionals after the study if needed.

All parents who participated in the research were given detailed information about the study prior to providing written consent to participate. The Regional Medical Ethics Committee in Norway reviewed the research plan and the written information provided to the participants and gave formal approval for the study. The families were free to withdraw from the research at any time but could still participate in the Family Support Program. The confidentiality of participants was assured and the interview tapes were stored in safe, locked environments and destroyed after transcription, in accordance with the guidelines of the Norwegian Data Register.

### Recruitment and characteristics of the study sample

We planned to conduct in-depth interviews with families who had undertaken the complete Family Support Program and all four meetings. We proposed to stop recruitment to the study at a point when existing interviews had yielded sufficient information and when little or no 'new' information was emerging in relation to parents' experiences with the Family Support Program. This point was reached following interviews with 13 parents who fulfilled the selection criteria. Research about saturation and variability suggest that if the goal is to describe a shared perception and experience among a relatively homogenous group, then a sample of 12 will likely be sufficient (Guest *et al.* 2006). Patients with incurable cancer who had at least one child between 5–18 years were invited to participate. They were provided with verbal and written information (to take home to discuss with the family) about both the Family Support Program and research from health workers in palliative care units, cancer wards and outpatient clinics. In this study 11 patients were invited to take part; one patient declined, 10 patients agreed to participate but of them four patients had to leave the study because of the progress of the illness. Six patients, with all together 12 children age 6–16, who fulfilled the programme criteria were included in the study. Altogether 13 parents, six fathers and seven mothers, were interviewed.

The participating parents' illness period ranged from three months to eight years (four years since onset of metastases) with a mean period of 2.3 years. The severity of the illness was the inclusion criteria, not the illness duration or daily functioning of the patient. The families were different in their make-up, dynamics, concerns and circumstances. The prognoses were unsure for most of the patients and none of them had been offered the possibility of cure. The patients' mean age was 42 years. Three of the patients were divorced and two of them had new partners. Five spouses/partners (two male and three female), three ex-partners (two female and one male) and the new partner of one patient's ex-husband participated (see Table 1).

### Data collection

All parents involved in the Family Support Program were interviewed once. One of the researchers (KB), who was trained and experienced in talking with parents in a difficult life situation, conducted all of the interviews. Interviews were held in the patient's homes or in the hospital, depending on the participant's wishes. Interviews took place up to six weeks after the programme was finished. All interviews were tape recorded and transcribed and each interview lasted between 60–90 minutes.

The interviews incorporated questions relating to why the parents chose to attend the Family Support Program, whether the programme met their needs, how the programme could be improved and what other types of support the family had experienced. The researcher transcribed all interviews verbatim and listened to these repeatedly to become fully familiar with the data. Listening and transcription were vital first steps in the analysis, which followed Kvale's approach (1996).

### Data analysis and interpretation

The interview texts were analysed qualitatively, according to Kvale (1996), in three interrelated contexts, namely self-

**Table 1** Participating parents and children

Gender	Age	Illness	Number of children	Healthcare	Interviewed
Female	38	Breast cancer (with metastases)	3	Palliative care outpatient	Yes
Female	34	Breast cancer (with metastases)	2	Home care	No*
Male	35	Brain tumour	2	Day care Hospice	Yes
Male	45	Bowel cancer (with metastases)	2	Cancer ward	No*
Male	48	Pancreas cancer (with metastases)	2	Outpatient	Yes
Male	54	Bowel cancer (with metastases)	1	Cancer ward	Yes

\*Two of the patients were not interviewed as they died before the interviews were conducted.

understanding, common sense and theory. Each interview transcript was read and analysed in detail and in depth to condense or 'distill' the essence of the parents' experiences. The main themes were elicited and constructed for 'commonsense understanding' and subsequently synthesised with all other participants' themes, structured, explained and illustrated. Lastly, the theories and research informing the Family Support Program were reincorporated and refined in the light of the parents' articulated experiences of the meanings and practices associated with the Family Resilience Theory. Fellow researcher (SH) reanalysed the interviews of two families to establish a qualitative form of 'inter-rater reliability'. She also critiqued and questioned the main findings and their presentation in the article.

## Results of the study

### Parents' experiences of the Family Support Program's impact on family resilience

Resilience theory for families (Allison *et al.* 2003) with strategies to overcome challenges including pulling together, reframing the crisis and seeking help establishes the framework for the presentation of parents' experiences of the Family Support Program.

### Support the family pulling together by increasing open communication, parents' understanding and support strategies for their children

#### *Support as help in talking with and telling the children*

Parents knew that this was a traumatic time for their children and wanted to prepare them and support them as best they could, but lack of knowledge and experience made them unsure about what was best for their children, both in the current situation and for their adjustment in the future. They wanted to minimise any potential future problems for their child by joining the Family Support Program:

We have three children in different age groups, with different needs and understanding. It is difficult to know how and when to inform small children. In a situation like this, we want to do the right things for all of the children. We have little knowledge both about cancer and how to cope with crisis.

The parents were concerned that they could do their children harm by telling them about the incurable illness in a 'wrong way', not at the 'right time' or without taking into account the children's different ages and needs. They were especially concerned about younger children. Most parents had already

informed their children about the incurable disease, but two families had not and they were relieved to have help to do this: 'It is hard to know what is the right moment to inform children. I told my daughter about the illness situation in one of the family talks. We can talk together in a new way now.'

Parents experienced their children's reactions on being told about the parent's illness and found this very difficult to handle. They wanted professional guidance and needed to share responsibility for the child's well-being with a health professional:

I had no-one to help me with this and had to find everything out myself – how to tell the children, how to talk with them, how to deal with their reactions. I wanted someone to give advice and to share the responsibility with.

#### *Support as confirmation that parents had done well*

Parents needed confirmation that they had positively helped and supported their children and had said and done the 'right things':

They confirmed what we had done already. We had already told our children about the illness situation.

Ex-partners had more information about the illness situation. They were also thanked for their contribution:

My ex-husband and his wife told me what they wanted and what they want me to do. Everything has become easier since that.

#### *Support as help in dealing openly with 'the difficult questions and tasks'*

Parents described how everyone in the family tried to make the situation easier for others and that this could make asking hard questions more difficult. Parents were appreciative when the project workers asked the 'difficult questions' and believed that this was important for the togetherness of the family. As this parent observed:

It was good they asked about things we did not take up ourselves. It is difficult. We don't want to hurt the others. We try to protect each other.

The project workers occupied a position between the participating parent and other family members. Parents reported that conflicts were reduced and they could talk more openly about the situation:

I thought it was fine. They (the project workers) were there as 'buffers' between me, my ex-partner and the children. It was a good way to talk about it.

For the ill parent's estranged partner it was hard to ask about the illness situation because they felt that they did

not have the right to 'interfere' in the patient's 'new life', but they needed to know details about their former partner's condition to support their children. As one parent observed:

I feel I'm in the middle of the situation, but at the same time I'm on the sideline. I have the daily care of the children, but I have no information.

Divorced parents wanted the programme to acknowledge and incorporate the idea that parents could actually have quite different views about what was best for the children.

#### *Support as help in dealing with the feelings and reactions*

Parents described how the programme helped them gain greater insight into their children's thoughts and reactions and into how the situation affected their daily living. Parents explained how their children were helped to ask questions and to speak about their situation in the family talks:

They (the children) didn't want to talk about it at home. But the next time, in the family talk, yes. They did describe the situation, how they understood what was going on, their relationship with friends, homework and the school.

The children's reactions were 'normalised' and this was especially valuable in relation to children's reactions involving anger and rejection that parents initially found difficult. One parent commented here that:

I was hurt and irritated (because of the children's reactions) and I was angry. I did not have knowledge. Then I had information from the project workers and had books about children in their situation. Then I could understand. They were completely normal.

#### **Reframing the crisis by identifying and using family strengths in the illness situation**

##### *Help in identifying resources inside and outside the family*

Asking the children to draw their social networks gave parents insight into the important people and supports available in their children's world. For some parents it was reassuring to see that their children had many caring people around them and for others this made it possible to do something about the situation. As these parents explained:

It was a confirmation, they have a lot of people around them. It comforts me that others will take care when I'm gone' and 'It made it clear to us that their (the children's) friends did not know anything about what they were going through. And we had help from them (the project workers) to plan information for friends and classmates.

##### *Help in using family strengths to make memories and strengthen relationships*

The family task of writing 'nice things to each other' was helpful in making memories. Parents spoke of finding it a valuable coping approach to be encouraged to use their strengths to make memories. In one family, the ill parent and one of the children were both musical and decided to make a CD together: 'I told him (the son) that he was good at playing the piano. He was proud. We are going to make a CD together here in the hospice.'

Divorced families that had new partners or children had the opportunity to talk about their relationship after death and this made it easier to decide how to stay in contact with each other. As this parent explained: 'I hope to keep up the contact with his daughter. She is welcome whenever she likes.'

#### **Seeking and using help**

##### *Help in planning the future and the help needed*

Parents reported that their children asked and looked for signs of when death might actually occur, but that they could not tell them because they themselves did not receive such information from their doctors: 'My six-year-old child often asked: 'will you die today mum?'; 'my nine-year-old child looked for signs that my situation had worsened (how much I ate, walked, etc.)'.

Being able to sit down and talk through the various situations made it clearer to parents how to help their children and how to plan for the future. As this patient noted:

To have help to plan the terminal phase was helpful for us. I want to die at home if it is possible. Then they can come to me when they like and need it; if I come to hospital, all the visits must be planned. But if I have a lot of seizures it is not nice for the children and I will go to hospital.

Parents also stressed that it was important that programme staff asked parents for their suggestions and opinions before they offered any solutions. It was also important that those carrying out the Family Support Program had a good understanding of the patient's illness situation and how it could affect the family and children.

#### **Discussion**

##### **The importance of helping and supporting parents with incurable cancer**

Parents joining our Family Support Program certainly wanted help to talk with their children and had felt this need for a long time. This study found that parents were

inexperienced and profoundly uncomfortable in having to 'deal with' a diagnosis of incurable cancer and had a pressing need for confirmation and reassurance that they had done well. It is ordeal enough to move through a terminal illness without having to bear the added burden of feeling that you have somehow 'damaged' or 'traumatised' your child. One study (Thastrum *et al.* 2006) found that the main reasons why parents sought counselling during cancer illness were insecurity in relation to their children, problems with communication, high levels of conflict and role changes within the family. We found similar concerns and responded to them in ways that parents found helpful and valuable. Our study echoes many of the findings of similar studies undertaken internationally. Other studies in cancer care have shown that parents wanted the kinds of help and support that our Family Support Program provided (Siegel *et al.* 1996, Kroll *et al.* 1998, Barnes *et al.* 2000, Benzein *et al.* 2001).

Parents found it hard to talk about the future in view of impending death and did not usually raise the subject themselves. We found that it was important to introduce such 'unpleasant subjects' to prepare the family so they could plan in the best possible way. Many parents in the study reported that their children asked about and looked for signs of when death might actually occur. This was often a very difficult question for parents to deal with. In one study (Hoff *et al.* 2007) patients in the terminal phase of their illness reported that doctors had not talked to them about death and about when death was likely to occur. Parents in our study did not expect a precise, accurately dated prognosis but did expect at least an indication of when death was most likely to occur. Parents appreciated being encouraged to make the situation as 'child-friendly' as possible, allowing children to be with them at their time of dying and death.

### **The importance for parents of open, honest communication in understanding and supporting their children during their parent's illness**

Parents described how their relationship with their children improved as a result of the Family Support Program because they had been honest about the illness situation and thus everyone felt more comfortable. Parents found it especially hard to give information to younger children. Similar difficulties were found by Barnes *et al.* (2002) in their study where children under 10 years of age were given more general and less detailed information than the older ones. It is perhaps unsurprising that telling children about their parent's incurable illness and impending death is one of the hardest

things that parents will ever have to do and that consequently, they need and appreciate professional help and support to do this as well as possible.

Despite all participating families being united by the common denominator of having a parent who was dying from cancer, they were very different in their unique make-up, dynamics, concerns and circumstances. Thus, it was vital that the Family Support Program undertook careful, individualised assessments and dealt individually with each family's concerns.

Parents in our study described gaining a clearer understanding of their children and felt that the programme had strengthened the bonds between them. This accords with other research into family support in cancer care where researchers found that family programmes enabled a better understanding of the emotions and reactions of other family members, promoted a greater sense of intimacy and cohesion within the family (Thastrum *et al.* 2006).

In Visser *et al.* (2005) investigation of the emotional and behavioural functioning of children of a parent diagnosed with cancer, children's willingness to express and experience emotions were related to their parents' expressivity. It is possible that parents joining a support program are less afraid of expressing their emotions than other parents (Valiente *et al.* 2004).

### **The importance of identifying and using family strengths in the illness situation**

The family task in the Family Support Program of reassuring and telling their children that they were 'doing well' was also used as an opportunity to create memories together with the ill parent, which the children and family could value and cherish in the future. This is an important process for children and families. It may help them in their grief after death and help children avoid feeling guilty about the 'things you should have done' and 'what you did wrong' and to avoid being left with only bad or distressing memories about the last times spent with their parent (Worden 1996, Bugge 2006). It is also extremely important for family closeness after death that families plan how to stay in contact where parents are divorced or separated.

### *Limitations of the study*

When researchers report small-scale qualitative studies, it is prudent to be cautious and not to over-generalise findings by suggesting that they would be applicable to all settings and populations. However, we would argue that a degree of modest or 'moderatum' generalisability (Payne & Williams 2005) is not only defensible but obligatory.

**Box 1** Recommendations for practice

- Make the Family Support Program available to all patients who receive the poor prognosis that their cancer cannot be cured and integrate the service into the patient's mainstream medical and palliative care treatment.
- Hospitals should have a contact person who knows what services are available for families with children and can advise families accordingly.
- Hospitals should have guidelines on helping divorced and separated families and their children. Changes in children's situation following the parent's death should be discussed and agreements/contracts about the children's future should be made.
- Doctors should be prepared to give specific information about the prognosis to the patient and the family and to do this earlier in the illness trajectory to give them the opportunity to plan for the future.
- Patients and their partners should have more emotional support from nurses and health professionals during their illness and hospitalisation.
- Follow-up programmes are needed when a parent with children under 18 years dies.

This study reports on a comparatively small sample group of parents participating in a Norwegian Family Support Program. While it has shown promising results, further research is needed, for example involving a larger sample size of participating families of different social classes and more diverse ethnic/cultural background. It may also be valuable to undertake complementary quantitative evaluation measures where appropriate and to introduce a longitudinal element to future evaluations to assess the programme's impact on children and families over time and following the parents' death.

**Recommendations for practice**

We are cautious in posing recommendations for practice based upon a small study, but it is nevertheless a responsibility of researchers to answer the 'So what?' question. Several strong themes emerging from the parents' in this study to improving care provision for patients with a life-threatening or terminal illness (see Box 1).

**Conclusion**

Parents, who are dying, and their partners have many concerns and anxieties. Our study shows that parents need more knowledge and support about how to cope with their children during a parent's terminal illness and that it is essential that children are involved and informed if they are to cope with this situation. Parents valued and appreciated this service and reported many benefits in relation to family functioning, communication and openness. The anticipated death of a parent from a terminal illness is a family crisis from any perspective. Nurses and their colleagues have an important role to play in helping children, parents and families at this testing time.

**Contributions**

Study design: KB and SH; data analysis: KB and SH and manuscript preparation: KB, SH and PD.

**Acknowledgements**

The Foundation for Health and Rehabilitation sponsored the project activities in the hospitals. Oslo University College sponsored the time needed to undertake the evaluation research. Ullevaal University Hospital, Akershus University Hospital and Innlandet Hospital helped to create and implement the intervention programme.

**References**

- Allison S, Stacey K, Dadds V, Roeger L, Wood A & Martin G (2003) What the family brings: gathering evidence for strengths based work. *Journal of Family Therapy* 25, 263–284.
- Barnes J, Kroll L, Bruke O, Lee J, Jones A & Stein A (2000) Qualitative interview study of communication between parents and children about maternal breast cancer. *British Medical Journal* 321, 479–482.
- Barnes J, Kroll L, Lee J, Burke O, Jones A & Stein A (2002) Factors predicting communication about the diagnosis of maternal breast cancer to children. *Journal of Psychosomatic Research* 52, 209–214.
- Beardslee WR, Gladstone TR, Wright EJ & Cooper AB (2003) A family-based approach to the prevention of depressive symptoms in children at risk: evidence of parental and child change. *Pediatrics* 112, 119–131.
- Benzein E, Norberg A & Saveman B (2001) The meaning of lived experience of hope in patients with cancer in palliative home care. *Palliativ Medicine* 15, 117–126.
- Bugge KE (2006) *Støtte til mestring i sorg for barn, ungdom og deres familier*. No. 10: HiO rapport, Oslo.
- Buxbaum L & Brant JM (2001) When a parent dies from cancer. *Clinical Journal of Oncology Nursing* 5, 135–140.
- Darbyshire P (2003) Mothers experiences of their child's recovery in hospital and at home: a qualitative investigation. *Journal of Child Health Care* 7, 291–312.
- Elmberger E, Bolund C & Lutzen K (2005) Experience of dealing with moral responsibility as a mother with cancer. *Nursing Ethics* 12, 253–262.
- Guest G, Bunche A & Johnson L (2006) How many interviews are enough? *Field Methods* 18, 59–82.
- Helseth S & Ulfsaet N (2003) Having a parent with cancer. *Cancer Nursing* 26, 355–362.
- Helseth S & Ulfsaet N (2005) Parenting experiences during cancer. *Journal of Advanced Nursing* 52, 38–46.



- Hoff L, Tidefelt U, Thaning L & Hermeren G (2007) In the shadow of bad news – views of patients with acute leukaemia, myeloma or lung cancer about information, from diagnosis to cure or death. *British Medical Journal Palliative Care* 6, 1.
- Kroll L, Barnes J, Jones AL & Stein A (1998) Cancer in parents: telling children. *British Medical Journal* 316, 880.
- Kuuppelomäki M & Lauri S (1998) Ethical dilemmas in the care of patients with incurable cancer. *Nursing Ethics* 5, 283–293.
- Kvale S (1996) *Interviews. An Introduction to Qualitative Research Interviewing*. Sage Publications Inc, Thousand Oaks.
- Libo LM & Griffith CR (1996) Developing mental health programs in areas lacking professional facilities: the community consultant approach in New Mexico. *Community Mental Health Journal* 2, 163–169.
- Maguire P (1994) ABC of breast diseases – psychological aspects. *British Medicine Journal* 309, 1649–1652.
- Masso M, Dodds S, Fildes D, Yeastman H & Eagar K (2004) *Ethical Research In Palliative Care: A Guide Through the Human Research Ethics Committee Process*. Department of Health & Ageing, Canberra, Australia. Available from: [http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-rsch-ethic.htm/\\$FILE/ethicall.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-rsch-ethic.htm/$FILE/ethicall.pdf).
- Nelson E, Sloper P, Charlton A & While D (1994) Children who have a parent with cancer. *Journal of Cancer Education* 9, 30–36.
- Payne G & Williams M (2005) Generalization in Qualitative Research. *Sociology* 39, 295–314.
- Siegel K, Karus D & Raveis VH (1996) Adjustment of children facing the death of a parent to cancer. *Journal of the American Academy of Child and Adolescent Psychiatry* 35, 442–450.
- Sneeuw K, Aaronson N, Sprangers MAG, Detmar LDV & Schornagel SH (1999) Evaluating the quality of life of cancer patients: assessments by patients, significant others, physicians and nurses. *British Journal of Cancer* 81, 87–94.
- Thastrum JM, Munch-Hansen A, Wiell A & Romer G (2006) Evaluation of a short-term preventive counselling project for families with a parent with cancer. *Clinical Child Psychology and Psychiatry* 11, 529–542.
- Valiente C, Eisenberg N, Faber RA, Shepard S, Cumberland A & Losoya SH (2004) Prediction of children's empathy-related responding from their effortful control and parents expressivity. *Development Psychology* 40, 911–926.
- Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WT, Klip EC, Pras E & Hoekstra-Weebers JE (2005) Emotional and behavioural functioning of children of a parent diagnosed with cancer: a cross informant perspective. *Psychooncology* 14, 746–758.
- Welch AS, Wadsworth ME & Combas BE (1996) Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. *Cancer* 77, 1409–1418.
- White R & Walter M (2006) *Social Research Methods - An Australian Perspective*. Oxford University Press Melbourne, Victoria.
- Worden W (1996) *Children and Grief*. Guildford Press, New York.