

# Research

## Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study

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### Abstract

**Objectives** To explore how children of mothers newly diagnosed with breast cancer perceive their mother's illness and its initial treatment; to contrast their accounts with the mothers' perceptions of their children's knowledge.

**Design** Qualitative interview study with thematic analysis.

**Setting** Home based interviews with mothers and children in Oxfordshire, England.

**Participants** 37 mothers with early breast cancer and 31 of their children aged between 6 and 18 years.

**Results** Awareness of cancer as a life threatening illness existed even among most of the youngest children interviewed. Children described specific aspects of their mother's treatment as especially stressful (seeing her immediately postoperatively, chemotherapy, and hair loss). Children suspected that something was wrong even before they were told the diagnosis. Parents sometimes misunderstood their children's reactions and underestimated the emotional impact or did not recognise the children's need for more preparation and age appropriate information about the illness and its treatment.

**Conclusions** As part of their care, parents newly diagnosed with a life threatening illness need to be supported to think about how they will talk to their children. General practitioners and hospital specialists, as well as nurses, are well placed to be able to help with these concerns and if necessary to be involved in discussions with the children. The provision of appropriate information, including recommended websites, should be part of this care. More information specifically designed for young children is needed.

### Introduction

Cancer is relatively common among women of childbearing age. Approximately 1 in 9 women in the Western world develop breast cancer,<sup>1</sup> and more than a quarter of them do so while they have children living at home.<sup>2</sup>

Although the importance of communication with patients and their families has been recognised,<sup>3–5</sup> relatively little has been published about communication with children when their parent is newly diagnosed as having cancer. Parents with cancer often underestimate their children's emotional and behavioural difficulties.<sup>6</sup> A recent review of the extant, albeit limited, literature found that communication was important for the children's psychological adjustment.<sup>7</sup> The few well conducted studies that have involved direct interviews with children have been very small, have explored aspects at different stages of the mother's illness, or have not provided accounts from both child and parents. Children are exposed to an enormous amount of information

about cancer, including health campaigns, advertisements, soap operas,<sup>8–10</sup> and the internet. However, we know little about whether children of different ages notice this information, how they make sense of it, and, in particular, how they integrate information from the media with information about their parent's illness.

In this study, we explored the accounts of mothers with breast cancer and their children to identify children's awareness and understanding of their parent's cancer, their reactions to being told about the diagnosis and the different types of treatment, and what information they would have liked to have been given and seemed to need. We also contrast the children's and mothers' accounts to highlight areas where their perspectives differ.

### Methods

#### Mothers' interviews

We recruited mothers with stage I–IIIa breast cancer and children under 18 from one dedicated cancer centre. Their treatment for a new diagnosis of breast cancer involved surgery (lumpectomy or mastectomy), supplemented by chemotherapy and radiotherapy as necessary (table 1).

Nurses in the breast cancer surgical ward gave women written information about the study towards the end of their stay. Seventy three women were approached. Those who were interested in participating provided contact details for the research assistant (CP). With written consent, we conducted detailed semistructured interviews with 37 mothers about their experience of talking about their illness with their family and their perspectives of their children's reactions to the diagnosis and treatment. At the end of the interview we gave the mothers information for any of their children aged 6–18 whom they thought might participate. We prepared separate information sheets for children aged over 9 and for children aged 6–9 years.

#### Children's interviews

Thirty one children agreed to be interviewed. Children over age 9 gave their assent, in addition to written informed consent from the parents of all the children.

An experienced child psychiatrist (GF) saw children at home, without their parents present, for an hour long, semistructured interview about their experience of their mother's illness. It was made clear to all the children that they could stop the interview at any time. Twenty five children were seen individually, and six chose to be interviewed with a sibling. Children's interviews were always conducted after the mother's interview, so that the words that had been used by parents to describe the illness were known, and the term "cancer" was used only if the children used it. A general discussion established a warm relationship, followed by

**Table 1** Sociodemographic and treatment information for 37 women with breast cancer. Values are numbers of women unless stated otherwise

| Variable  | Women with breast cancer (n=37) |
|---|---------------------------------|
| Mean (SD) age (years)                                     | 46.2 (5.9)                      |
| Marital status:   |                                 |
| Single  | 4                               |
| Married   | 24                              |
| Remarried   | 2                               |
| Partner   | 7                               |
| Socioeconomic class:                                      |                                 |
| 1   | 1                               |
| 2   | 16                              |
| 3 nm  | 16                              |
| 3 m   | 3                               |
| 4   | 1                               |
| 5   | 0                               |
| Treatment planned:  |                                 |
| Lumpectomy only   | 22                              |
| Mastectomy  | 15                              |
| Chemotherapy  | 23                              |
| Radiotherapy  | 30                              |
| No of children under 18 years:                            |                                 |
| Mean (SD)   | 1.6 (0.6)                       |
| 1 in family   | 17                              |
| 2 in family   | 17                              |
| ≥3 in family  | 3                               |
| Mean (SD) age of children under 18 (years)                | 12.3 (4.6)                      |
| Mean (SD) interval between diagnosis and interview (days) | 64.7 (37.7)                     |

questions about the child’s awareness of cancer before the mother’s illness; experience of the illness, diagnosis, and further treatment; and sources of support and information about breast cancer.

### Analysis

All interviews were audiotape recorded and transcribed verbatim. Supervised by SZ (a medical sociologist), GF read and annotated the children’s transcripts for initial coding. CP led the coding for the mother’s interviews. We used the NVivo version 2.0 computer package (QSR International, Melbourne, Australia) to assist with coding, sorting, and retrieval.

For the qualitative thematic analysis reported here, we generated NVivo reports on specific codes, containing excerpts from all relevant transcripts, and analytic themes were developed in discussion with all authors. We used constant comparison to explore anticipated and emergent themes and to search for deviant cases.<sup>11</sup> We made specific comparisons between mother-child pairs.

## Results

Themes included children’s awareness of cancer before their mother’s illness, how children learnt of their mother’s diagnosis, their reactions to this news, their reactions to their mother’s treatment, and their expressed need for information. We will discuss these in turn and relate them to developmental stages.

### Awareness of cancer

Box 1 lists some children’s ideas about cancer. All children except for two of the youngest said that they had heard of cancer as a disease or illness before their mother’s cancer was diagnosed. Some reported learning about cancer from the media (television advertisements for cancer research or health promotion, soap operas, and films), awareness of celebrities with cancer, direct experience of someone with cancer (family, neigh-

bour, or parent of a school friend), and science lessons at school (from year 6). One mother had already been treated for breast cancer several years earlier.

The salience of these sources varied considerably. In particular, several children seemed to be markedly affected by the television adverts showing people with cancer who had since died. Many children linked smoking to cancers of all kinds, including breast cancer, and were troubled when their family or friends continued smoking.

Children with school friends whose mothers had recovered from cancer drew encouragement from their survival. In contrast, school science lessons concentrated on the biology of cancer cells and cellular action of chemotherapeutic agents. Only one child—a 15 year old girl who said that she had always been a worrier about illness—distinguished different outcomes for different types of cancer.

### Box 1: Children’s ideas about cancer

#### A common disease

“I do wonder if I’m going to get it as well because I think it’s becoming more and more common.” (15 year old girl)

#### A very rare disease

“Yeah because after Mummy did have it I noticed how common it was but before I thought like one in every million people get it or something.” (10 year old boy)

#### A disease that kills

“It was a scary word I mean like um ... I didn’t know how often it happened, I thought it was quite rare but obviously that’s wrong. I generally thought that people nearly always died from it.” (17 year old boy)

“I thought that before that there was no cure from it; that you just died basically.” (10 year old girl)

#### A disease that is treatable sometimes

“... that it was quite treatable, there was quite a lot of chance that they can treat it if it’s found early and that.” (16 year old boy)

#### A disease where you lose your hair

“I used to think that a lot of people went bald when they had it.” (12 year old girl)

#### A disease caused by smoking

“I knew that smoking could cause it and I knew that it could kill people but I didn’t really know how it got there or what it does.” (8 year old girl)

#### A disease you can catch if you have a gene

“If it’s in the same family you may catch it if you have the gene.” (8 year old girl)

#### A disease made worse by stress

“I was a bit, because I just got worried when she got worried because stress makes it worse doesn’t it? So I thought if she gets stressed out too much it might make it worse.” (14 year old boy)

#### The more treatment you have, the worse it is

“It’s been gradual but it was when I found out my mum didn’t need chemotherapy, that she only needed radiotherapy, that obviously made me feel much happier, the doctors coming out with it’s not quite as serious.” (17 year old boy)

#### The more treatment you have, the less likely it is to come back

“Well, the more treatment she has, the less likely the cancer’s going to come back so it’s kind of good in a way. It’s going to make her better than if she just had chemo.” (12 year old girl)

Interviewer: "Do you think, before your mum got ill, your feeling about [cancer] was negative or ...?"

Respondent: "It depends what kind of cancer it was because my uncle died of throat cancer just before mum got ill, no actually while mum got ill."

### Mothers' awareness of their children's knowledge of cancer as life threatening

Several mothers, with children as young as 7, were sure that their child was aware that cancer could be life threatening. They did not always know how much their children knew, however. Mothers sometimes thought their children did not know that cancer could be life threatening and were shocked when their children's comments or questions revealed concerns that she might die:

"I remember weeks, a few weeks later, when I was putting him to bed one night, him saying to me 'Mummy some people die when they have cancer.' I don't know where he'd heard that from, TV or school or you know other people talking about me ... I was actually really thrown at that." (Mother of 7 year old boy)

### Learning about the mother's diagnosis

Children often said that they had suspected that something was seriously wrong before they were told. They had sometimes picked this up from changes in their mother's mood and behaviour, overheard conversations, or seen hospital correspondence. Several suspected that their mothers were hiding the seriousness of the situation and felt upset at being excluded from discussions:

"I just realised she wasn't herself and she wasn't really feeling right, I could tell that and she got a bit stroppy at times. I actually found out myself because mum didn't tell me. I wasn't supposed to find out because Mum was trying not to really tell us because I wasn't having such a good time at school and she didn't want to worry us. So I actually found out for myself because she left a book around or something, so then I found out." (12 year old girl)

Most children were told by both parents together as soon as the diagnosis had been confirmed. A few children were told by their mother or father alone, sometimes without careful preparation—for example, while driving in the car. One child was told several weeks after her mother's operation, by which time she strongly suspected the truth. Children over 10 were usually told straight out that their mother had breast cancer and what the immediate treatment plans were:

"She just sat on my dad's hand on the sofa and said, 'There's no easy way to tell you, I've got cancer.' I just lost it. I just burst into tears and then my mum did, and then my dad did. It was just the most terrible thing in the world." (17 year old girl)

The 6-10 year olds had all been told that their mother was ill, that she had a lump, and needed to go to hospital. Two guessed immediately that the lump meant their mother had cancer, and one 7 year old discovered by reading a poster about cancer in the ward.

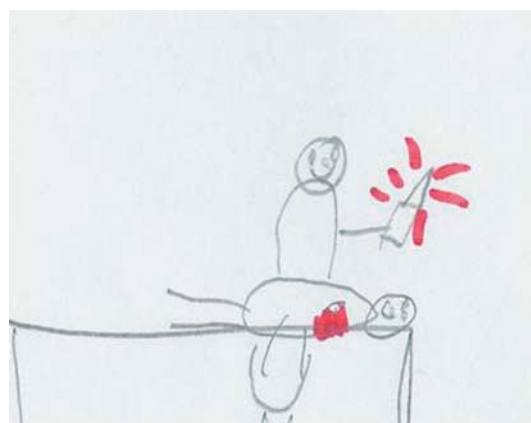
The reactions of younger and older children were remarkably similar. They described much emotional upset, shock, tears, fear, and anxiety. Some expressed anger at God, the mother herself, or their teachers or peers at school.

R: "When mummy told me it got into a big argument because I said to Mummy 'You shouldn't have told me that' because I was crying."

I: "So you were cross with mummy were you? And what did she tell you? Do you remember what she said?"

R: "She got cross."

I: "She got cross. Right. But what did she tell you about what was wrong?"



Mother's operation, drawn by young son

R: "That she had to go to hospital." (6 year old boy)

We found a disparity between some mothers' interpretations and the child's account of their reaction to the diagnosis. Some of the children who described feeling "shocked" and overwhelmed by the news were thought by their mothers not to care about the fact that she was so ill. A few mothers thought that their children's "good coping" suggested that they were not really upset, yet the children themselves described being very upset and concerned. Sometimes children reacted with angry behaviour, and the parents found it hard to cope with an apparently selfish and inconsiderate reaction.

### Reactions to mother's treatment

We discuss the children's reactions to their mother's hospital admission and surgery and to chemotherapy.

#### Surgery

Children were often upset because their mothers had to be in hospital, although they usually did not mind the ward environment. Some mentioned that they knew that people could die under anaesthetic and thus saw surgery as potentially fatal. One of the younger children associated surgery with much blood and drew a picture of a surgeon standing over his mother with a knife dripping blood (figure). Few children expressed much concern about the loss of a breast through mastectomy, although a very young child was having recurrent nightmares about his mother's operation.

Children whose initial visit was on the first or second postoperative day described being shocked by their mother's drowsiness and by seeing blood on the sheets or in the drainage tubes. A 15 year old girl thought her mother was dead when she approached her bedside a few hours after the operation. Several children were reluctant to leave and said that their concentration was poor at school throughout their mother's stay in hospital. Those who visited the ward preoperatively and saw their mother a few days after the operation found the experience less alarming.

#### Chemotherapy

Interviews with 19 of the mothers and their children took place during the period when the mothers were having chemotherapy. Children often said that chemotherapy, with its debilitating side effects and hair loss, was the worst aspect of their mother's treatment. Hair loss was a key issue for children across the age range; box 2 gives some of their comments.

If it was decided that the mother did not need chemotherapy after all, this could be marked by relief and celebration in the family. During one such celebration, an 8 year old girl said, "Oh



## Research

good, this means you're not going to die after all Mummy." In contrast, other children said they were glad that their mother was having chemotherapy because it meant that everything was being done to help her.

### What did children of different ages wish to know?

Mothers often said that they had given "about the right amount" of information, taking into account the ages of their children and the balance they wanted to strike between containing their children's anxiety and being honest. However, some were confused themselves, unable to provide much information about their treatment, or reluctant for their child to access more information in case it was depressing.

Children in different age groups expressed different needs for information, but only the younger children (under 10) said that they had been given enough information (table 2). One 8 year old informed us: "I'm too young to know more." However, younger children were confused about several aspects of cancer, particularly the causes. One reported being worried about her friend catching cancer, and another thought it could be "caught" from a gene:

"Um well I'm worried that I might catch it [breast cancer] in the future because I can't catch it now, because I'm too young obviously. And unlike Mummy, I might not survive it in the future." (9 year old girl)

Younger children were also particularly distressed and frightened by the early hospital experience and their mother's hair loss, suggesting that more information and preparation might

**Table 2** Awareness and information by age group of 31 children interviewed

| Characteristic                               | Age (years)         |                      |                     |
|--|---------------------|----------------------|---------------------|
|  | 6-10                | 11-15                | 16-18               |
| No in group                                  | 9 (4 girls, 5 boys) | 13 (8 girls, 5 boys) | 9 (4 girls, 5 boys) |
| Aware that cancer is life threatening        | 7                   | 12                   | 9                   |
| Reported having had insufficient information | 0                   | 8                    | 4                   |

have been helpful. Girls across the age range wondered whether they might be more likely to develop breast cancer, probably assuming they were at greater risk than they were.

Several older children said that they needed more information about breast cancer and the available treatments (especially chemotherapy) and to find out how others coped with a similar situation. Most of the teenagers would have liked some recommended websites to explore, to supplement the leaflets they had seen.

I: "And what's been the worst aspect of it all for you?"

R: "Um er, the chemo was quite difficult. I think had I known what to expect, because it was very much a shock. I didn't know, but maybe that was my fault for not asking. I just presumed it would be quite easy and quick and I didn't know it was going to be a long process. So I think if I had known in advance that it would, that it was going to be, yeah, it might have helped." (16 year old girl)

As well as wanting general information about breast cancer, some of the older children said that they wanted direct contact with a health professional so that they could learn more about their own mother's treatment regimen and prognosis. Although most children in the study did not express a wish to meet their mothers' doctors or nurses, a few were very keen to talk to them and had felt excluded:

"Usually when they (the doctors) wanted to say something, they made me and my sister go somewhere else while they talked to my dad and mum. But I think it would have been better if they kind of spoke to all of us so, like, we knew exactly what was going on instead of just hearing it from mum and dad." (12 year old girl)

## Discussion

This study builds on previous work by interviewing children aged 6-18 years old as well as mothers recently diagnosed with breast cancer. We found that even very young children were often aware of cancer as a disease before their mother's disease was diagnosed, but that this awareness was often skewed. Stories and reports in the media, including antismoking advertisements, were important sources of information for children but were sometimes misleading. Many children associated the word cancer with death. Children who knew (of) someone else with cancer could mistakenly assume that their mother's experience would be the same. Parents are often unaware how much their children know and, often reeling from the diagnosis themselves, may not be in the best position to decide what and how to tell them. Our results suggest that many parents would benefit from preparation to tell their children and consider the ways children at different developmental stages might react.

The qualitative method of semistructured interviews is particularly appropriate for exploratory work to identify meanings and perspectives.<sup>11</sup> Another strength of the study is that the interviews were conducted in the family home soon after diagnosis, while the woman was having treatment, and that a spread of ages and household compositions were included in the

### Box 2: Hair loss

"She had a blonde wig... well it wasn't actually intentionally blonde, it was sort of just light brown whereas my mum has, you know, dark brown hair. So that was a shock, that was really hard, just kind of you can just tell something was wrong. My friends were like 'oh it looks so good' and I was like 'it's not my mum.' And then that evening she took her wig off and showed me and I was, that was difficult, so I kind of said 'I'm off now,' went out to see my boyfriend, 'I'm going, I can't stand it.' It is quite difficult. I, you know, I feel for my dad—I feel for my mum most—I mean there were times when she was standing doing her make up and she'd just burst into tears. I found it really difficult." (17 year old girl)

I: "I think it was when she lost her hair it was quite scary. I'm used to it now but when it first happened I was a bit scared and I didn't really tell my friends. So for about a month we didn't have anyone round and then when I told my friends I was ok about it." (13 year old girl)

"Losing hair and, well yeah, that was an issue yeah. I wasn't overly worried about that, all I was concerned about was my mum getting better again." (17 year old boy)

"Yeah we all try to joke about it really. I think my mum was more worried about it because she hadn't tried to hide it really because everyone knew. But I think seeing herself with no hair was sort of, is sort of an obvious sign of cancer." (17 year old girl)

"My friend's... just gone through it so she said, you know, what's going to happen next and how her mum's hair got much curlier and stuff and it's really nice to hear from someone like that." (12 year old girl)

I: "And what did she look like when she lost all her hair?"

R1: "Weird, definitely weird because I never saw her like that."

R2: "But I think she kind of looked like a zombie coming back from the dead." (7 and 9 year olds)

R: "Yeah and did you know my mummy's got a wig but she has some teeny weeny medicine and it might make her hair fall out?"

I: "And how do you feel about that?"

R: Um... really sad." (6 year old boy)

study. Wherever possible the mother, father (or partner), and children were all interviewed separately (data from the fathers' interviews will be reported in a separate paper). However, only just over half of the invited women chose to take part and not all of their children decided to. Families that participated may have been more confident about their communication than those who did not.

These findings are important because evidence exists that parents newly diagnosed as having cancer find communicating the news to their children very stressful.<sup>12</sup> To provide comprehensive care, their doctors and nurses need to be able to help. The data show that even if children are not told, they draw meaning from their observations of the changes within the family (behaviour and emotional states), from their understanding of the parent's visits to surgeries and hospitals, and from their parent's mood and facial expression.<sup>13</sup> This finding is supported by strong evidence that children are affected by changes in their parents' facial expressions from early years of life and particularly by parental depression.<sup>14</sup> A recent study has shown that approximately 50% of women develop a depressive disorder after the diagnosis of breast cancer.<sup>15</sup>

Evidence from paediatric cancer shows that giving children appropriate information about the disease reduces anxiety.<sup>16</sup> Children's understanding of cancer and death has an incremental, developmental component that needs to be taken into account when talking to children or preparing literature for them.<sup>17</sup>

Judging children's reactions can be difficult. Children may be very distressed yet may deal with the situation by becoming detached, leading parents to believe that they are unaffected by the news.<sup>18</sup> Although children cannot be protected from adverse events, the quality of the relationships and communication between family members are important for preventing adverse longer term consequences.<sup>19</sup> Thus, in developing appropriate interventions to support children and parents, the children's perspective must be understood and taken into account.

Further work is needed to develop and evaluate information for children of parents with cancer about cancer and its treatments. Although some useful literature is available,<sup>20 21</sup> not all parents (or children) find written information helpful, and literature for younger children is lacking. Some parents and older children would find it useful to be given a list of recommended websites—for example, [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk), [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk), [www.cancerlink.org](http://www.cancerlink.org), [www.dipex.org](http://www.dipex.org) (see breast cancer module, Talking to children), and [www.riprap.org.uk](http://www.riprap.org.uk) (for teenagers).

Parents facing the challenge of coping with cancer and its treatment also face the challenge of meeting their children's needs. This is a very difficult time for families, and they may need considerable help in dealing with communication within the family and determining how support could be provided for their children as well as themselves. Parents may need help to take into account their child's personal experience, exposure to the media, age, and understanding. Staff in hospitals and primary care are well placed to help (box 3). Expertise in child psychiatry or psychology and development is rarely necessary if clinicians are aware of the information needs and the range of reactions highlighted in this study.

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Ethical approval: Oxford Psychiatric Research Ethics Committee

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### Box 3: Implications for clinical practice

General practitioners and hospital specialists and nurses can enhance the care of parents newly diagnosed with cancer by helping them to think about how they will talk to their children. The key points are:

- Individual differences, as well as age, developmental stage, and previous experience, need to take into account
- Many children will have already picked up that something is seriously wrong from changes in their parents' mood or behaviour
- From as young as 7, children may associate the diagnosis of cancer with the threat of dying. Not talking about this connection does not protect children from anxiety
- Children's reactions to bad news may belie their feelings. Thus withdrawal, lack of upset, or angry challenging behaviour does not necessarily indicate indifference, a lack of distress, or lack of sympathy or empathy
- Parents may underestimate their children's needs for information to try and protect them, and children may not ask about emotionally charged subjects. However, the more children are prepared and informed, as appropriate for their age and development, the more it seems to help them cope
- Some families may need their doctors and nurses to take part in the discussions with the children

As well as leaflets, several helpful websites for parents and teenagers now exist. Families should routinely be offered resources or lists of recommended websites.

### What is already known

The diagnosis of breast cancer is associated with high levels of psychological distress in patients and their children

Mothers find talking to their children about their breast cancer challenging, and many would like help with this

Most parents aim to protect their children from undue anxiety as far as possible, but open communication may reduce anxiety in children

### What this study adds

Before their mother's diagnosis, children from age 7 were more aware of the life threatening nature of cancer than their parents and other adults realised

Many children needed more preparation for seeing their mother postoperatively and wanted more information about chemotherapy, radiotherapy, and the causes of breast cancer

Some children wanted to talk to their mother's clinicians

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