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(Accepted 23 February 2006)

doi 10.1136/bmj.38784.384109.2F

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

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BMJ 2006;332:998-1001

### 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

Relatively little has been published about communication with children when their parent is newly diagnosed as having cancer. A recent review of the literature found that communication was important for the children's psychological adjustment.<sup>1</sup> The few 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,<sup>2</sup> but we know little about whether children of different ages notice this information and how they make sense of it. 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 the diagnosis and treatment, and what information they would have liked to have been given and seemed to need.

### 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. Seventy three women were approached. 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.

**Children's interviews**—Thirty one children agreed to be interviewed. Nine children were aged 6-10 years (four girls and five boys), 13 were aged 11-15 (eight girls and five boys), and nine were aged 16-18 (four girls and five boys). A child psychiatrist saw children at home, without their parents present, for an hour long, semistructured interview about their experience of their mother's illness. Twenty five children were seen individually, and six chose to be interviewed with a sibling. A general discussion established a warm relationship, followed by 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.



This is the abridged version of an article that was posted on bmj.com on 13 April 2006: <http://bmj.com/cgi/doi/10.1136/bmj.38793.567801.AE>

**Analysis**—One of two researchers, supervised by a medical sociologist, read and annotated either the children's or mothers' transcripts for initial coding. We used computer software to generate reports on specific codes, 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>3</sup> We made specific comparisons between mother-child pairs.

## Results

### 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 an illness before their mother's diagnosis. Some reported learning about cancer from the media, awareness of celebrities with cancer, direct experience of someone with cancer, and science lessons at school.

The salience of these sources varied considerably. 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, 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 action of chemotherapeutic agents.

### 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. Others 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 wasn't supposed to find out because Mum was trying not to really tell us . . . 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. 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.

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 were thought by their mothers not to care about the fact that she was so ill. Sometimes children reacted with angry behaviour, and the parents found it hard to cope with an apparently selfish reaction.

#### 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

"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 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)

### Reactions to mother's treatment

#### *Surgery*

Children were often upset because their mothers had to be in hospital. Some mentioned that they knew that people could die under anaesthetic and saw surgery as potentially fatal. Few children expressed much concern about the loss of a breast through mastectomy.

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. Several children were reluctant to leave. Those who visited the ward preoperatively and saw their mother a few days after the operation found the experience less alarming.

#### *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. 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, or reluctant for their child to access more information in case it was depressing.

Only the younger children (under 10) said that they had been given enough information. 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. Girls across the age range wondered whether they might be more likely to develop breast cancer.

#### Box 2: Hair loss

"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)

"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)

Several older children said that they needed more information about breast cancer and the available treatments and to find out how others coped. Most of the teenagers would have liked some recommended websites to explore, to supplement leaflets they had seen. Some of the older children said that they wanted direct contact with a health professional, and a few were very keen to talk to their mothers' doctors or nurses 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

We found that even very young children were often aware of cancer as a disease before their mother's diagnosis, but that this awareness was often skewed. 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. Many parents would benefit from preparation to tell their children and consider the ways children at different developmental stages might react.

The interviews were conducted in the family home soon after diagnosis, while the woman was having treatment, and a spread of ages and household compositions were included in the study. 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.

Parents newly diagnosed as having cancer find communicating the news to their children stressful.<sup>4</sup> Even if children are not told, they draw meaning from their observations of the changes within the family.<sup>5</sup> This finding is supported by evidence that children are affected by changes in their parents' facial expressions from early years of life and particularly by parental depression.<sup>6</sup>

Evidence from paediatric cancer shows that giving children appropriate information about the disease reduces anxiety.<sup>7</sup> Children's understanding of cancer and death has a developmental component that needs to be taken into account when talking to children or preparing literature for them.<sup>8</sup> 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.

Judging children's reactions can be difficult, as their reactions 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. Although children cannot be protected from adverse events, the quality of the relationships and communication between family

### 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

mended websites (see [bmj.com](http://bmj.com)). Parents may need help in dealing with communication and providing support for their children, taking into account their child's personal experience, age, and understanding. Staff in hospitals and primary care are well placed to help.

We thank all the children and their parents who so generously took part in the study at such a difficult time in their lives, as well as the staff of the Jane Ashley Unit at the Oxford Radcliffe NHS Trust, breast surgeons Jane Clarke and Mike Greenall for their contribution, and Lucy Curtin for transcription of the tapes. We also thank Lesley Fallowfield and George Smerdon for commenting on the draft.

Contributors: See [bmj.com](http://bmj.com).

Funding: The Ashley Trust (no involvement).

Competing interests: SZ is research director of the DIPEx research group which produces [www.dipex.org](http://www.dipex.org) with the DIPEx charity No 1087019. Cancer Research UK supports SZ with a personal award.

Ethical approval: Oxford Psychiatric Research Ethics Committee

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(Accepted 9 March 2006)

doi 10.1136/bmj.38793.567801.AE

members are important for preventing adverse longer term consequences.<sup>9</sup> 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. 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 recom-

### A memorable patient

#### A funny kind of flu

One Monday morning in the winter of 1958 I woke up to discover that the flu epidemic that had been wreaking havoc in Asia was spreading across Europe and had reached our shores; so it was with a great deal of trepidation that I made my way to the surgery to have my worst fears confirmed. My partners and I shared the colossal visiting lists, my own allocation consisted of more than 30 calls. The morning surgeries were rushed through as quickly as possible to enable us to cope with the urgent pleas of our elderly and infirm patients. I shudder to think what terrible diagnostic errors were made in the process.

It was a matter of dashing upstairs two at a time, making a quick assessment, hastily prescribing whatever seemed appropriate, and dashing downstairs to the next call. Speed was of the essence.

An elderly immigrant from Lithuania was the 15th on the list. She was old enough to be my mother, whom she vaguely resembled, and we had a healthy respect for each other; she had a beautiful face with a warm friendly personality, and she appreciated whatever one did for her; besides, I found her fractured English fascinating to listen to. We had an excellent rapport.

Concluding what passed (at least in my eyes) for a straightforward, albeit hurried, consultation, I made the usual diagnosis, wrote out a prescription, and made my way to the door. With my hand on the handle, I heard a disgruntled voice mutter: "Za funner kind flu." I stopped in my tracks, returned to the bedside, and asked her what she meant. She meant what she had said: "Za funner kind flu."

"Let us start from the beginning," I said. I can't recall any other occasion of concluding a consultation, being challenged by the patient, and then scrubbing the conclusion and starting again from scratch. This time, I elicited a history which left no doubt about the diagnosis. My patient had had a classic myocardial infarction, and I lost no time in getting her admitted to hospital—thanking my lucky stars for having the second chance to get it right.

The story has a happy ending; she made a complete recovery and lived for several years to tell the tale of how she nearly died from an overworked doctor's mistaken diagnosis.

Perhaps, in the forthcoming epidemic so confidently forecast by the experts, there are lessons here to be learnt.

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