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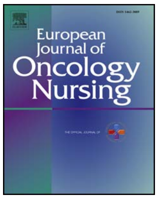

Children's understanding of maternal breast cancer: A qualitative study

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ABSTRACT

Purpose: To explore how children understand their mother's diagnosis of and treatment for breast cancer.
Method: Interpretive description was adopted as the methodology in this study. Eight children aged 8–18 years old, whose mother has been diagnosed with non-terminal breast cancer, were interviewed individually and six of them drew a picture to express their understanding of maternal breast cancer.
Results: Four themes were identified in this study: "the cancer word is scary" – children's understanding of cancer; "scars and tubes" – children's understanding of surgery; "hair loss" – children's understanding of chemotherapy, and "I can't explain it" – children's understanding of other treatments. Children's understanding of maternal breast cancer and its treatment was relatively realistic, although sometimes inaccurate.
Conclusions: Individual evaluation and appropriate explanation is significant to further children's understanding of their mother's illness. Future studies with larger sample size are needed to explore the understanding for children of different ages, in order to provide specific help for these children.

1. Introduction

Breast cancer is the most common type of cancer diagnosed in females in the world (WHO, 2014). The estimated number of new cases was about 1.67 million in 2012, accounting for around 25.1% of female cancers (WHO, 2014). In 2012, 348,457 new cases were diagnosed in women aged 15–44 years old, constituting 20.9% of all new cases globally (WHO, 2014). The age between 15 and 44 years is defined as the reproductive age for women (WHO, 2009), indicating that a large proportion of women with breast cancer may have dependent children.

Some studies have been conducted to explore children's experiences when their mother has been diagnosed with breast cancer. These studies indicated that when confronted with the mother's diagnosis of, and treatment for, breast cancer, children tended to experience a variety of emotional concerns (Huang et al., 2014). When the mother was receiving aggressive treatments, such as chemotherapy and surgery, children experienced extremely apparent concerns (Davey et al., 2005; Hilton and Gustavson, 2002). They were particularly worried about the survival of their mother, which made them feel sad and anxious (Forrest et al., 2006; Kissil et al., 2010; Stiffler et al., 2008). When their mother was ill, children's daily lives were affected, but children tried their best to keep everything normal to distract themselves from the worries about their mother (Davey et al., 2005, 2011).

Although most children had been provided with some information about breast cancer and its treatment after their mother's diagnosis, they still had a strong desire for further knowledge (Davey et al., 2005; Hilton and Gustavson, 2002). They searched information by communicating with parents or others, reading books or exploring the Internet. However, the needs of most children were poorly met (Finch and Gibson, 2009; Hilton and Gustavson, 2002; Kristjanson et al., 2004).

Most previous studies have emphasised the impacts of maternal breast cancer on children's emotions and daily lives; few studies have focused on children's understanding of maternal breast cancer. As children were reported to expect more information about their mother's illness and believe that being given sufficient information can relieve their stress (Fitch and Abramson, 2007; Kristjanson et al., 2004), it is important to determine how much information the children have received. The understanding of children's perceptions of maternal breast cancer could help to further comprehend their reactions within the context of their mother's illness. Therefore, the purpose of this study is to explore how children understand their mother's diagnosis of, and treatment for, breast cancer, in order to provide more information for parents and health care professionals about how to assist these children.

2. Method

Interpretive description methodology was used, which is a well-founded qualitative approach originating from the nursing field and

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includes a clear logical and coherent structure (Thorne, 2008). It intends towards the generation of findings that can contribute to evidence-based practice, rather than generating only theories (Hunt, 2009; Thorne, 2008). This paper reports part of the results of a study of 40 mothers with breast cancer and eight children in China, specifically the children's understanding of maternal breast cancer, with other data concerning the mothers reported elsewhere (Huang et al., 2017).

2.1. Setting and sample

Purposive sampling was used to recruit children whose mother had been diagnosed with primary breast cancer in a large tertiary hospital in China in the past 18 months. Only children who were aged 7–18 years old when interviewed and aware of his/her mother's diagnosis were recruited. Children who had a physical or developmental disability, or psychological distress that precluded communication were excluded. Children were contacted via their mother; they were interviewed only with consent from their parents and assent from themselves. As the hospital claimed that they did not have the right to approve studies involving participants other than patients in the hospital (that is the children of the patients), only the study involving the mothers with breast cancer was approved by the hospital. However, the whole study involving both the mothers and their children was approved by a university ethical review board.

2.2. Data collection

Children were divided into three sub-groups according to their ages. The age range in each sub-group was consistent with Piaget's theory of cognitive development (Piaget, 1964; Wadsworth, 1971) and the age classification system of Chinese schools. Children were interviewed by the first author, accompanied by a paediatric psychologist to ensure that appropriate support was available for the children if necessary. The words used to describe breast cancer or related issues in the interview were discussed with mothers prior to the interviews with children. Sensitive words, such as cancer and death, were not mentioned unless referred to by the children. Specific activities were designed for each sub-group to facilitate the interview process. The whole interview process, including all the activities, lasted for about 60 min.

2.2.1. Sub-group 1: aged 7–11 years

‘The Bears’ cards were used to initiate conversation and help children to express their feelings in this group. ‘The Bears’ cards are conversation-building aids first published in 1995. They consist of a booklet and a set of 48 cards with images of bears of different sizes, gestures, facial expressions and background colours (Deal and Wood, 2011). Then the children were asked to draw a picture about ‘my mother is ill’, and explain the picture they drew. If the children did not like drawing, they were not forced to do so. Five children in this age group were interviewed, and all of them voluntarily drew pictures.

2.2.2. Sub-group 2: aged 12–15 years

Only one girl in this age group was interviewed, with the assistance of ‘The Bears’ cards. Although she was not asked to do drawings, she volunteered to draw a picture about ‘my mother is ill’ to explain her feelings.

2.2.3. Sub-group 3: aged 16–18 years

As children of this age group are cognitively mature (Wadsworth, 1971) and they have similar communication ability to adults, no additional activities were employed as conversation aids. Similar to interviews with adults, the researcher spent a few minutes on casual conversation to build rapport, reduce nervousness and generally prepare them. Two children in this age group were interviewed.

2.3. Data analysis

All interviews were transcribed and imported into QSR NVivo 10 software (QSR International, 2012). The interviews were analysed by constant comparative analysis and coded using three steps of coding: free coding, descriptive coding, and interpretive coding, which has been reported in another paper (Huang et al., 2017).

The drawings were analysed using the framework of interpretive engagement, which was proposed by Drew and Guillemin (2014) for the analysis of visual data generated by participants. There were three stages: meaning-making through participant engagement; meaning-making through research-driven engagement; and meaning-making through re-contextualising (Drew and Guillemin, 2014).

The first stage focused on the participants, the pictures they drew, and their interpretation of the pictures (Drew and Guillemin, 2014). During the data collection process, the children were asked to discuss what they drew and why. The drawings were explored on the basis of the interviews to get a preliminary understanding of the intentions and reasons underpinning the production of the drawings (Drew and Guillemin, 2014).

The second stage was the researcher-driven process (Drew and Guillemin, 2014). The drawings were scanned and imported to QSR NVivo 10 software (QSR International, 2012). The researchers coded the pictures, established themes, and looked for connections between themes using NVivo (Bazeley and Jackson, 2013; QSR International, 2012). The main elements or ideas apparent in each picture were identified and coded (e.g., ‘hair loss’, ‘frowning’). During the process, the drawings were assessed in three different ways: individually; in conjunction with the relevant interview transcripts; and finally together with all the other drawings produced.

During the third stage of meaning-making through re-contextualising (Drew and Guillemin, 2014), Children's cognitive development, and their communication and relationship with their mother was taken into account in this stage, to interpret the drawings in a broader context. During the whole analytical process, the researchers interacted between the analysis of children's drawings and interviews, relating codes to generate final themes.

2.4. Rigour

In this study, diverse techniques were employed to ensure the rigour of the research process and trustworthiness of the research findings. The use of drawings and ‘The Bears’ cards enriched the data collected from the children. These techniques also relieved children's nervousness and made the interview process run more smoothly; thus, data collected from interviews were more reliable. Field notes taken after each interview helped researchers to reflect on the interviews, and refine questions asked in the subsequent interviews. The research team constantly discussed the data analysis process of the interviews and drawings, and reached an agreement on the codes and final themes.

3. Results

Four boys and four girls, aged 8–18 years when interviewed, participated in this study, of which six drew pictures. They were coded according to their mother's clarification number (e.g. C34) and their age and gender (e.g. 10M). The basic information about the children and their mothers is listed in Table 1.

After their mothers were diagnosed with breast cancer, some children obtained knowledge when visiting her in hospital, reading posters on notice boards, or observing other patients, in addition to communicating with their mother and/or others. Children did not passively accept the information obtained through social activities, interpersonal communications, secret searching, and personal observation, without personal critique; instead, they used their own judgement. They tended to integrate the information from different sources, and generate their