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Cancer disclosure to children by parenting patients: A retrospective observational study in Akita Prefecture, Japan

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Abstract

Objective This study investigated how parents with cancer disclose their diagnosis to their children using initial telephone consultation data.

Materials and Methods This retrospective observational study was conducted using data from consultations received between January 2017 and February 2024 through the Akita CLIMB® Program, which supports patients with cancer who have children. The consultation data included information on participants' demographics (e.g., age, sex, and cancer type) and whether the parent disclosed the cancer to the child, the child's reactions, and related concerns. Basic attributes were analyzed descriptively, and consultation content was qualitatively categorized.

Results Data from 388 parents were analyzed. Breast cancer was the most common type of cancer (270 patients, 69.6%). Of the parents, 35.8% had one child and 64.2% had two, and the children's mean age was 8.5 ± 2.6 years. Only 137 (35.3 %) parents disclosed their diagnosis. Parents who informed their children about their cancer regarded them as integral members of the family and prioritized maintaining a peaceful daily life while discussing the illness. Children exhibited proactive responses, such as encouraging their parents and suggesting ways to support the family. On the other hand, many parents who did not inform their children about their cancer cited fear of their children's reactions and their own inability to cope as the reason. Children who were not informed about the cancer exhibited anxiety and confusion, often questioning their parents' behavior.

Conclusion Communicating about cancer fosters trust and stability within the family, but parents often face psychological burdens that can become a barrier. Children's responses indicated a desire to help, whereas non-disclosure could exacerbate anxiety and confusion. It is essential to provide communication strategies and information tailored to the child's developmental stage to help parents appropriately convey their cancer diagnosis.

Keywords: Cancer; Parent Who Have Children; Cancer Communication; Oncology Nursing

1. Introduction

In Japan, it is estimated that approximately 56,000 cancer patients with children under the age of 18 are diagnosed annually nationwide, and their children number around 87,000. [1] In other words, about one in four cancer patients is in the parenting generation.[1] The average age of parents with cancer is 46.6 years for men and 43.7 years for women,

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while that of their children is 11.2 years, with more than half being between 0–12 years old. [1] These figures imply that these parents are in their prime working years, they must balance their societal roles while adjusting their responsibilities within the family. Meanwhile, their children are in a critical stage of growth and development during their school-age years. As a result, a parent's cancer diagnosis has a significant impact on the family.

Parents with cancer face various challenges, including feelings of guilt for being unable to fulfill their parental role and a sense of emotional distance from their children due to treatment and recovery.[2] Furthermore, it has been reported that parents often struggle with how to communicate their illness to their children. [3] On the other hand, children tend to be highly sensitive to changes in their parents at home and may experience anxiety about the future. [4] Additionally, it has been reported that children of cancer patients experience more physical complaints and emotional issues compared to children whose parents are not affected by cancer, and that their quality of life (QOL) is lower. [5, 6] Therefore, in the parent-child relationship, expressing and sharing feelings, as well as exchanging information about the illness and treatment, are essential. However, it has been reported that many parents hesitate to inform their children about their cancer, which can lead to communication difficulties between them.[7]

Previous studies on parents informing their children about cancer have shown that patients are concerned about burdening their children when disclosing their diagnosis [8] and worry about how to discuss their illness with them [7-9] On the other hand, some parents choose not to inform their children about the illness. Reasons for this include concerns about their children's ability to understand based on their age, the fear that explaining the situation without a clear prognosis may burden them, and a resulting desire to handle the situation on their own [10] Overall, previous studies have largely focused on parents' hesitation in informing their children about cancer, as well as the psychological burden and distress they experience. While it is anticipated that parental concern about not wanting to burden their children gives rise to many worries, the way parents perceive their children's reactions has not yet been clarified.

The author has been implementing the CLIMB® Program [11], a support group for cancer patients raising children and their children, in Akita Prefecture since 2017. This program also serves as a contact point for consultations. This study aims to provide an overview of the initial telephone consultations from cancer patients raising children and to clarify the realities of how these patients communicate their cancer diagnosis to their children. With the increasing incidence of cancer at younger ages in recent years, the number of cancer patients raising children is expected to rise. Understanding the realities of how these patients communicate their cancer diagnosis to their children will enable the development of support tailored to their needs and contribute to maintaining and enhancing parent-child communication.

2. Materials and Methods

2.1. Study Design

This was a retrospective observational study.

2.2. Data

This study analyzed the records of initial telephone consultations received at the support service for cancer patients raising children and their children (CLIMB® Program) [13]at Akita University from January 2017 to February 2024. Notably, the consultation support was suspended for one year from March 2021 to March 2022; therefore, data from this period were not included in the study.

2.3. Consultation Records

The interview year, interview duration, and basic attributes (age, gender, cancer type, treatment, and child's age) were recorded. The consultation topics included whether the patient had informed their child about their cancer, reasons for not disclosing the illness if they had not, and concerns regarding the child's reaction in both cases.

2.4. Analysis

The annual number of consultations and the average interview duration were calculated. Next, a simple tabulation was performed for basic attributes and the experience of informing or not informing the child about the cancer. Consultation topics were categorized based on qualitative descriptive similarities. A chi-square test and Fisher’s exact test were conducted, with the experience of disclosing the cancer as the dependent variable and basic attributes as independent variables. Statistical analysis was performed using JMP®, with a significance level set at less than 5%.

2.5. Ethical Considerations

This study was approved by the Ethics Committee of the author's University (Approval No.3148).

3. Results

3.1. Consultation and Participants' Characteristics

From January 2017 to February 2024, there were 388 initial telephone consultations, with a monthly average of 5.6 consultations. The average consultation duration was 49.7 minutes. The average age of the consultees was 38.8 ± 6.0 years. Of the total consultations, 337 (86.9%) were women and 51 (13.1%) were men. All were newly diagnosed cases, with breast cancer being the most common type, accounting for 270 cases (69.6%). Stage II was the most common disease stage, observed in 148 cases (38.1%), followed by Stage III in 128 cases (33.0%). Surgery was the most frequent treatment, performed in 247 cases (63.7%). The average duration from diagnosis to consultation was 1 year and 2 months ± 1 years. The number of children per patient was as follows: 139 patients (35.8%) had one child, while 249 patients (64.2%) had two children. The average age of the children was 8.5 ± 2.6 years. (Table 1).

Table 1 Characteristics of initial consultation participants (*N*=388)

Category	Description	Number (%)	Mean Age ± SD
[Patient]			
Gender	Female Male	337 (86.9) 51 (13.1)	
Age			38.8 ± 6.0 years
Diagnosis	Breast cancer Colorectal cancer Cervical cancer Pancreatic cancer Gastric cancer Endometrial cancer Lung cancer	270(69.6) 36(9.3) 33(8.5) 17(4.4) 15(3.8) 9(2.3) 8(2.1)	
Cancer Stage	Ⅱ Ⅲ Ⅰ Terminal stage Unknown	148(38.1) 128(33.0) 71(18.3) 19(4.9) 22(5.7)	
Treatment	Surgery Surgery + Chemotherapy Palliative care for terminal stage Chemotherapy only	247(63.7) 121(31.2) 19(4.9) 1(0.2)	
Time from Diagnosis to Consultation			1 year 2 months ± 1 year
[Children]			
Number of Children	One child Two or more children	139(35.8) 249(64.2)	
Age			8.5 ± 2.6 years

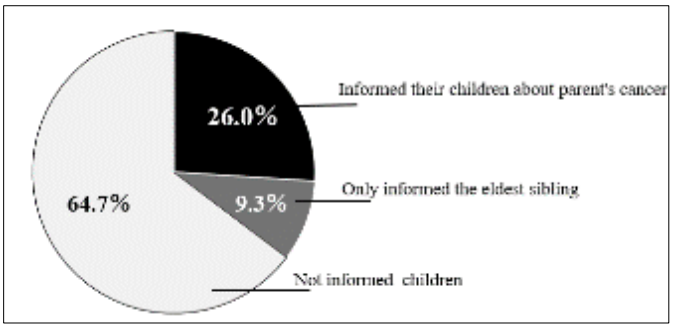

Figure 1 The Reality of Parents Communicating Their Cancer Diagnosis to Their Children (*N*=388)

Table 2 Major reactions of children after parents disclosed the cancer diagnosis to them (*N*=137)

Summary (%)	Contents
The child thought about what they could do and offered encouragement. (21.9%)	The child showed concern for the parent's health and provided encouragement.
	The child encouraged the parent by saying, "Let's face this together."
	The child seriously considered what they could do to help.
The child appeared unresponsive. (19.0%)	The child showed no reaction and remained expressionless.
	The child acted as if they were not listening.
	The child gave an unexpectedly indifferent response.
	The child showed no reaction, making it unclear how they felt after hearing the news.
The child exhibited negative changes (15.3%)	The child started spending more time alone in their room.
	The child began bedwetting.
	The child started having night terrors.
	The child's appetite decreased for several days after the conversation.
	The child stopped going to school, saying they wanted to stay with their parent.
The child expressed their thoughts about informing their younger sibling about the cancer. (10.2%)	The child said that their younger sibling should also be informed.
	The child asked why their younger sibling was not being told.
The child worried that their parent might die and cried. (10.2%)	The child was concerned about whether their parent would die and started crying.
	The child cried loudly, saying, "I don't want you to die."
The child already knew about the parent's cancer. (8.0%)	The child had noticed changes in their parent and said they were glad to finally know the truth.
	The child said, "I already knew."
The child's sad expression. (4.4%)	The child listened with a sad look on their face.
	The child's sadness was particularly memorable.
The child asked questions about the illness and daily life. (2.2%)	The child asked if the disease was contagious.
	The child inquired about specific treatments and their duration.
	The child asked if they could still go to school.
There was nothing particularly memorable. (8.8%)	There was nothing particularly memorable.

Table 3 Primary Reason for Not Informing Children About the Parent's Cancer (*N*=222; with missing values)

Summary (%)	Contents
I'm afraid of my child's reaction and feel unable to cope with it. (50.0%)	I feel scared because I cannot predict how my child might react.
	I'm afraid of my child's reaction and don't feel capable of handling it.
	I don't have the emotional capacity to handle my child's reaction.
I don't think my child will understand. (24.8%)	My child is still too young to comprehend, even if I explain.
	I believe my child cannot understand.
	My child is too young to understand, and I am also afraid of their reaction.
Because I don't know the right timing or how to communicate it properly. (21.6%)	I'm unsure how to convey the news to my child due to its shocking nature.
	I don't know how much information or detail I should share.
	I'm uncertain about the appropriate timing to inform my child.
My family is opposed to telling the child. (1.8%)	My spouse and in-laws have advised that it's better not to tell the child yet.
Because it would place a significant psychological burden on my child. (1.3%)	I think my child would be deeply shocked.
	My child is already struggling with school refusal, so I don't want to add any more stress.
We can manage our daily life without disclosing it. (0.5%)	We can manage our daily life without disclosing it.

3.2. The Reality of Parents Communicating Their Cancer Diagnosis to Their Children

Among the parents, 101 (26.0%) had informed their children about their cancer, while 36 (9.3%) had only informed the eldest sibling. Combining these groups, a total of 137 parents (35.3%) had experience disclosing their cancer. Their average age was 42.6 ± 4.8 years, and the average duration from diagnosis to consultation was 1 year and 3 months ± 5 months.

On the other hand, 251 parents (64.7%) had not informed their children about their cancer. Their average age was 36.6 ± 5.6 years, and the average duration from diagnosis to consultation was 6 months ± 5 months. Among those who had not informed their children about their cancer, 33 parents (13.1%) explained their hospitalization or medical visits as being due to a cold, an injury, or a work-related business trip. The only factor significantly associated with disclosing the cancer diagnosis to children was being male ($p < 0.001$). No other associated factors were identified.

Parents who informed their children about their cancer explained the treatment and its side effects and discussed their children's daily lives during the recovery period. The most notable reactions from children after being informed are shown in Table 2. The most common response was "The child thought about what they could do and offered encouragement." This was followed by "The child appeared unresponsive" and "The child exhibited negative changes."

Next, Table 3 presents the reasons for not informing children about the parent's cancer. The most common reason was "Fear of the child's reaction and being unable to cope with it." This was followed by concerns about the child's ability to understand, the timing of disclosure, and opposition from family members.

Next, parents who had not informed their children about their cancer were asked about their greatest concerns regarding their child's behavior (Table 4). The most common concern was "The child has started questioning the parent's behavior." This was followed by "Being too overwhelmed to notice changes in the child's behavior."

Table 4 Primary Concerns About the Child's Behavior When Not Informed About the Parent's Cancer (*N*=251)

Summary (%)	Content
The child started questioning the parent's behavior. (41.8%)	The child repeatedly asks, "Why do you go out alone?"
	The child looks anxious when asking why the parent is going to the hospital.
	The child frequently asks why the parent is going out more often.
	When the parent is resting due to feeling unwell, the child asks, "Are you sick?"
	The child repeatedly asks, "Why isn't your cold getting better?"
I am too overwhelmed to notice my child's behavior. (37.8%)	I don't have the capacity to remember how my child is doing.
	I don't have time to think carefully about my child.
	I am struggling just to get through each day, and my child's needs have become secondary.
My child has been saying "I feel lonely" more often. (9.6%)	My child has started expressing feelings of loneliness, saying, "I miss you, Mom."
The child has started to distrust the parent, leading to communication difficulties. (6.0%)	The child now says, "You never tell me anything!" and sometimes refuses to speak.
	The child has started saying, "I can't trust you!" and the relationship has become strained.
	I feel like my child is doubting me, making it harder to talk.
	I'm afraid because it feels like my child is starting to sense the truth.
	I feel like my child no longer shares their true feelings with me.
I don't notice any changes. (4.8%)	I don't notice any changes.

4. Discussion

This study aimed to clarify the realities of how cancer patients raising children communicate their diagnosis to their children, based on initial telephone consultations from these patients. Only 35.3% of parents had informed their children about their cancer. Consistent with previous studies, the findings revealed that many parents hesitated to disclose their diagnosis due to fear of their child's reaction or concerns about their child's ability to understand. [7] Compared to those who had disclosed their cancer, parents who had not informed their children were, on average, about six years younger, and the average time from diagnosis to consultation was approximately six months. A cancer diagnosis is often a shocking experience and, in some cases, forces individuals to confront their own mortality. The internal conflict parents face can be seen as a complex emotional response, not only to their own process of accepting their illness but also to their deep sense of responsibility and concern for their children. As a result, explaining the illness to their children at a stage when they themselves are still struggling to cope can be extremely challenging. This is supported by the finding that nearly half of the parents who had not informed their children cited "fear of the child's reaction and being unable to cope with it" as their reason for not disclosing the diagnosis.

According to Nicky, factors influencing the experience of informing children about cancer include the child's age, personality, and need for information. Similarly, in this study, concerns about the child's understanding and psychological burden, as well as uncertainty about the appropriate way to communicate the diagnosis, were identified. [12]

Among parents who informed their children about their cancer, many children responded proactively and positively, such as encouraging their parents and thinking about what they could do to help. However, a certain number of children showed no reaction or exhibited negative changes. When disclosing cancer to children, it is important to recognize them as integral members of the family and share information about the parent's illness. [13] Ensuring the stability of the child's own life contributes to their sense of security. However, these reactions may depend on factors such as the child's age, personality, and family communication style, highlighting the need for further detailed research.

Parents who did not disclose their cancer found it difficult to respond to their children's questions and behavioral changes. At the same time, the study highlighted that they were often too occupied with daily life to fully grasp their children's emotional state. Notably, the most frequently reported concern was that children began questioning their parents' behavior. This reaction reflects children's sensitivity in detecting changes within the household. [14] Furthermore, the lack of information sharing was suggested to increase the risk of heightened anxiety and distrust in children. These findings raise concerns about the potential deterioration of parent-child trust.

4.1. Clinical Implications

4.1.1. Understanding Parents' Resolve and Struggles

This study focused on the realities of parents informing their children about their cancer. However, what is truly important is understanding the resolve, struggles, and emotional conflicts that accompany this experience. The decision-making process regarding whether to disclose a parent's cancer is influenced by various factors. [7] First and foremost, parents need time to come to terms with their own diagnosis. Therefore, it is essential to acknowledge and support this process. Even when parents choose not to inform their children, providing support that enhances their sense of security is crucial. This includes empathizing with their fear of their child's reaction while helping them feel more confident in navigating their situation.

On the other hand, it has been reported that when children are not informed about a parent's illness, they may imagine the situation to be worse than it actually is, leading to significant anxiety. [4] In this study as well, the most frequently observed reaction among children who had not been told about their parent's cancer was "questioning their parent's behavior. "Therefore, while being mindful of the parent's feelings, it is important to provide support that also encourages them to consider their child's emotions and perspective.

4.1.2. Maintaining Parent–Child Communication

It has been reported that a cancer diagnosis affects parent-child communication.[7] Therefore, it is essential not only to consider whether to disclose the illness but also to ensure that communication between parents and children continues as usual. The more natural the parent-child relationship remains, the easier it is for children to feel a sense of security. Supporting parents in maintaining regular, everyday communication with their children is crucial.

There is a plethora of evidence on the impact of a cancer diagnosis on parent–child communication. Based on our findings, it is suggested that the focus should not be placed solely on whether to disclose the diagnosis, but also on ensuring that the parent–child communication remains as natural as possible. The more natural the parent–child relationship, the greater the child's sense of security, rendering it essential to support parents in maintaining their daily communication with their children.

4.1.3. Promptly Providing Information That Patients Seek

When discussing a parent's cancer with a child, organizing information and having a clear idea of how to communicate it can help reduce the psychological burden on parents. Additionally, it is necessary to provide booklets or tools designed to convey the diagnosis in an age-appropriate and developmentally suitable manner. [15] To ensure that this information is readily available when patients seek it, it should be placed in visible locations from the early stages of diagnosis and actively promoted. Furthermore, healthcare providers should convey the message that support is always available, and interdisciplinary teams should deepen their understanding of these communication strategies.

4.2. Limitations

This study has three main limitations. First, sample bias. Since the study focuses on a specific group—first-time telephone consultations from cancer patients raising children—the perspectives of patients who did not seek consultation or those with different backgrounds are not included. Additionally, as the study is based on a particular region and cultural background, nationwide research is necessary for broader generalizability. Second, the lack of a time-based perspective on children's reactions. This study only captures a single-point observation of children's responses after being informed about their parent's cancer. However, children's reactions may change over time or as the parent's illness progresses. A longitudinal study is needed to address this gap. Third, the lack of detailed factors influencing decision-making. The decision to disclose a cancer diagnosis to children is likely influenced by factors such as cancer type, disease stage, parent-child relationships, and available support systems. Future research should incorporate a more comprehensive analysis that considers the diversity of patient backgrounds and parent-child dynamics.

5. Conclusion

A total of 137 parents (35.3%) had experience informing their children about their cancer. Parents who disclosed their diagnosis viewed their children as integral members of the family and prioritized maintaining a peaceful daily life while discussing the illness. On the other hand, parents who chose not to disclose their cancer expressed fear of their child's reaction and feeling unable to cope with it. These findings highlight that the decision-making process regarding whether to inform children about a parent's cancer is a complex issue influenced by multiple factors. Therefore, support providers must not only empathize with parents' struggles but also offer guidance that fosters natural communication between parents and children.

Compliance with ethical standards

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Disclosure of conflict of interest

The authors declare that there are no competing or potential conflicts of interest.

Statement of informed consent

Participants were given the opportunity to opt out, informed consent was obtained from all individual participants included in the study.

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