Parenting experiences of cancer patients with minor children and their conversations about the possibility of death: a cross-sectional web-based survey for an online cancer community

Yuko Usui1,2 · Kazuhiro Kosugi1,3 · Yohei Nishiguchi4 · Tomofumi Miura1 ○ · Daisuke Fujisawa5 · Yuko Uehara1,6 · Takashi Kawaguchi7 · Kayo Izumi8 · Jun Takehana8 · Yoshihisa Matsumoto1

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Abstract
Purpose Many cancer patients with minor children experience difficulty talking about their illness with their children. This study aimed to investigate the parenting experiences of cancer patients with minor children and their conversations about the possibility of death.

Methods A cross-sectional web-based survey was conducted between April and May 2019. Cancer patients with at least one child aged < 18 years were recruited from an online peer support group called “Cancer Parents.” The participants were asked to complete a questionnaire about their experiences of talking about their illnesses with their children. The participants were classified into those who disclosed their cancer to their children (“disclosing group”), and those who did not disclose (“non-disclosing group”). The association between whether they talked with their children about their cancer, and whether it included conversations about the possibility of death, was examined.

Results A total of 370 parents participated (with 80.8% female parents, with a median age of 43.0 years). The disclosing group (n = 274, 74.1%) wanted to know what their child felt, more than the non-disclosing group did (p < 0.001). Members of the non-disclosing group had a greater tendency than those in the disclosing group to report that they did not want their children to see their suffering (p = 0.002) and did not know how to explain their disease status (p < 0.002). Some members of both the disclosing (42.1%) and non-disclosing (6.5%) groups told their children about the possibility of death.

Conclusion This study showed that 74.1% of the patients with minor children disclosed their cancer to their children. The parents’ feelings when thinking about interacting with their children differed significantly between the disclosing and non-disclosing groups. It is important for healthcare professionals treating patients with cancer to provide appropriate multidisciplinary support for discussing their diagnosis and prognosis with their children.

Keywords Cancer patients · Cancer parents · Minor children · Communication about death

Dedicated to Yohei Nishiguchi passed away during the preparation of this study.

Tomofumi Miura
tomiura@east.ncc.go.jp

1 Department of Palliative Medicine, National Cancer Center Hospital East, Kashiwa, Japan
2 Department of Palliative Therapy, Cancer Institute Hospital of Japanese Foundation for Cancer Research, Tokyo, Japan
3 Department of Psychiatry and Behavioral Sciences, Graduate School of Medical and Dental Sciences, Tokyo Medical and Dental University, Tokyo, Japan
4 General Incorporated Association Cancer Parents, Tokyo, Japan
5 Department of Neuropsychiatry, Keio University School of Medicine, Tokyo, Japan
6 Department of Palliative Medicine, Juntendo University Graduate School of Medicine, Tokyo, Japan
7 Department of Practical Pharmacy, Tokyo University of Pharmacy and Life Sciences, Hachioji, Japan
8 Insight & Analytics Department, Medilead Inc, Tokyo, Japan
Introduction

Cancer is a leading cause of death worldwide. Among deaths in people aged 25–44 in the USA, 13% were due to cancer [1]. The National Cancer Institute estimates that approximately 24% of adult cancer patients have minor children (children under 18 years of age) [2].

Research has shown that for parents with minor children, telling their children about their cancer is a predominant, difficult issue [3, 4]. Parents with cancer struggled to tell their children about their own cancer and deal with their own feelings at the same time [5]. Cancer patients and their partners, as parents, had several concerns and anxieties about communicating with their children regarding the illness [6]. On the other hand, children desired honest information about their parents' health and treatment and usually wanted to have frank conversations with them about their illness [4]. One study showed that the level of anxiety in children who were informed about their parent’s cancer was significantly lower than that in those who were not informed [7]. Moreover, inability to discuss their parent’s cancer has been significantly associated with higher anxiety in adolescents [8]. Most prior studies have focused on the experiences of parents who have already told their children about their own cancer. Knowing how parents with cancer felt about conversations with their children about their illness and death may be helpful for healthcare professionals in providing personalized care.

The aim of this study was to clarify (1) the proportion of parents who disclosed their cancer to their children, (2) the parents' feelings when thinking about interacting with their children, and (3) conversations about the possibility of death between parents and their children.

Methods

Study design

This study was a sub-analysis of a cross-sectional web-based survey using self-administered questionnaires. The detailed methodology has been described previously [9].

Participants

The eligibility criteria for participation in this study were as follows: (1) parents clinically diagnosed with cancer regardless of the primary cancer site and stage, (2) member of the online peer support community “Cancer Parents,” (3) age 20 or older, and (4) with children under 18 years. Participants who were unable to read Japanese were excluded.

“Cancer Parents” (https://cancer-parents.com/) is one of the largest online peer support groups for cancer patients with children in Japan. “Cancer Parents” had more than 3000 cancer patients as active users of this group (as of February 5, 2020). Members can create/read posts, connect to them, and connect to and exchange messages with peers.

Procedures

This study was conducted between April 27 and May 13, 2019. The details of the survey and the questionnaire URL were sent via e-mail to the members of “Cancer Parents” using a web survey system hosted by Medilead Inc. The participants anonymously accessed and answered the questionnaire.

Measurements

An online questionnaire was developed based on the literature [10–12]. The questionnaire was completely anonymous and included age, gender, primary cancer site, cancer stage, number of children, age of first child, disclosure of their own cancer to their children, parents’ feelings when thinking about interacting with their children, and conversations with their children about the possibility of death. Six options were provided for the question regarding parents’ feelings when thinking about interacting with their children: “I am overwhelmed by other issues,” “I have no idea how to interact with my children,” “It is distressing to interact with my children,” “I want to know how my children feel,” “I do not want my minor children to see my suffering,” and “I have no idea how to explain my disease status.” These options were evaluated using a 4-point Likert scale (1, strongly disagree; 2, disagree; 3, agree; 4, strongly agree). Five options were also provided for the question regarding conversations about the possibility of their own death: “I told my children myself,” “I was asked by my children and told them,” “I was asked by my children but refused to answer them,” “It has never been discussed,” and “I have never thought of such a possibility.”

Statistical analysis

Continuous variables were expressed as medians with interquartile ranges (IQR). In the analysis using a 4-point Likert scale, the responses of 1 (strongly disagree) and 2 (disagree) were classified as disagree, and those of 3 (agree) and 4 (strongly agree) were classified as agree. The respondents who disclosed their cancer to their children were defined as the “disclosing group” and those not disclosing as the “non-disclosing group.”

A chi-square test was used to analyze the association between disclosing their cancer to their children and their experiences, conversations about the possibility of death,
Results

Respondents’ characteristics

A total of 3012 patients were eligible, and 370 parents participated (response rate: 12.5%; Fig. 1). The baseline characteristics of the respondents are presented in Table 1. The median age of the participants was 43 years (IQR, 39–47 years), and 299 (80.8%) were female. The most common primary cancer site was the breast (34.3%), followed by the colorectal region (11.9%) and gynecological organs (11.4%), and 103 participants (27.8%) were diagnosed with stage 4 cancer. The median number of children was two (IQR, 1–2), and the median age of the first child was 11 years (IQR, 7–16 years). Among the participants, 274 (74.1%) disclosed their cancer status to their children.

Parents’ feelings when thinking about interacting with their children

The parents’ feelings when thinking about interacting with their children are represented in Table 2. The proportion of respondents who agreed with the statement “I want to know how my child feels” was higher in the disclosing group (85.4%) than in the non-disclosing group (57.3%; p < 0.001; Table 2). Conversely, the proportion of respondents that agreed with the statement “I have no idea how to explain my disease status” was higher in the non-disclosing group (66.7%) than in the disclosing group (28.1%; p < 0.001). The proportion of respondents who agreed with the statement “I do not want my minor children to see my suffering” tended to be higher in the non-disclosing (82.3%) than the disclosing group (72.6%; p = 0.059).

A post-hoc analysis showed that the proportion of respondents under 43 years of age was higher in the non-disclosing group (66.7%) than in the disclosing group (40.2%; p < 0.001; Supplemental Table 1). The proportion of respondents with children under 6 years was higher in the non-disclosing group (55.4%) than in the disclosing group (13.0%), and those with children over 13 years old was lower in the non-disclosing group (12.0%) than in the disclosing group (43.1%; p < 0.001). However, there were no differences between these two groups in the proportion of respondents in terms of gender and cancer stage (p = 0.899 and p = 0.744, respectively).

Conversations about the possibility of death

The respondents in the disclosing group tended more to agree with the statements “I told my children myself,” “I was asked by my children and told them,” and “I was asked by my children but refused to answer them” (Table 3).

Discussion

The present study showed that a majority of parents with minor children disclosed their cancer status to their children. The disclosing group was more likely to want to know how their children felt, and this group more frequently had
conversations about the possibility of death compared to the non-disclosing group.

The present study found that parents with cancer differed in their feelings when thinking about interacting with their children. The parents with cancer in the disclosing group were more likely to want to know how their children felt than those in the non-disclosing group. Conversely, most of those in the non-disclosing group did not know how to explain their disease status to their children. A previous study reported that parents with cancer felt that they did not have sufficient knowledge to tell their children about their disease and wanted information from healthcare professionals [13]. Furthermore, patients with cancer felt unsupported by healthcare professionals and felt that they were not provided with sufficient advice on how to talk with their children about cancer [14]. Healthcare professionals supporting parents with cancer need to communicate with their patients about the disease and the difficulties parents face in communicating with children. It is important for healthcare professionals to provide information tailored to each patient’s needs.

The disclosing group was more likely to have a conversation about the possibility of death with their children, whereas more than half of the non-disclosing group never discussed the possibility of death with their children. The reason for this difference in the results is unclear. A previous study reported that patients’ or their family members’ difficulty in accepting a poor prognosis was an important barrier in discussing advanced care planning [15]. The present study found that there were more parents who had never thought of the possibility of death in the non-disclosing than the disclosing group. This finding suggests that some participants in the non-disclosing group may not have fully accepted their cancer status, including their prognosis. In addition, the present study showed that the non-disclosing

### Table 1: Participants’ characteristics (n = 370)

|               | Disclosing | Non-disclosing | p*  |
|---------------|------------|----------------|-----|
| Gender Male   | 71 (19.2%) | 299 (80.8%)    |     |
| Gender Female | 299 (80.8%)| 71 (19.2%)     |     |
| Age           | Median (IQR*) | 43 (39–47)    |     |
| Primary cancer site Breast | 127 (34.3%) |                |     |
| Primary cancer site Colorectal | 44 (11.9%) |                |     |
| Primary cancer site Gynecological | 42 (11.4%) |                |     |
| Primary cancer site Others | 157 (42.4%) |                |     |
| Cancer stage 1 | 92 (24.9%) |                |     |
| Cancer stage 2 | 85 (23.0%) |                |     |
| Cancer stage 3 | 59 (15.9%) |                |     |
| Cancer stage 4 | 103 (27.8%)|                |     |
| Number of children | Median (IQR*) | 2 (1–2) |     |
| Age of first child | Median (IQR*) | 11 (7–16) |     |
| Disclosing their cancer status to their children Disclosing | 274 (74.1%) |                |     |
| Disclosing their cancer status to their children Non-disclosing | 96 (25.9%) |                |     |

*IQR interquartile range

### Table 2: Parents’ feelings when thinking about interacting with their children (n = 370)

|                                             | Disclosing (n = 274) | Non-disclosing (n = 96) | p*  |
|---------------------------------------------|----------------------|-------------------------|-----|
| I am overwhelmed by other issues            | 32 (11.7%)           | 13 (13.5%)              | 0.630 |
| I have no idea how to interact with my children | 29 (10.6%)       | 15 (15.6%)              | 0.189 |
| It is distressing to interact with my children | 27 (9.9%)       | 14 (14.6%)              | 0.204 |
| I want to know how my children feel        | 234 (85.4%)          | 55 (57.3%)              | <0.001 |
| I do not want my minor children to see my suffering | 199 (72.6%)   | 79 (82.3%)              | 0.059 |
| I have no idea how to explain my disease status | 77 (28.1%)      | 64 (66.7%)              | <0.001 |

### Table 3: Conversations about the possibility of death with children (n = 366)

| Have you ever told your children about the possibility of your own death? | Disclosing (n = 277) | Non-disclosing (n = 93) |
|------------------------------------------------------------------------|----------------------|-------------------------|
| I told my children myself                                              | 115 (42.1%)          | 6 (6.5%)                |
| I was asked by my children and told them                               | 32 (11.7%)           | 4 (4.3%)                |
| I was asked by my children but refused to answer them                  | 32 (11.7%)           | 7 (7.5%)                |
| It has never been discussed                                           | 64 (23.4%)           | 53 (57.0%)              |
| I have never thought of such a possibility                             | 30 (11.0%)           | 23 (24.7%)              |
group had more parents who did not know how to explain their disease or condition. Parents with cancer might not know how honest they should be with their children, and might be unsure of what is appropriate to share with them. Parents with advanced cancer found it difficult to answer their children’s questions, including about their impending death [16]. Fathers with advanced cancer felt that they did not have the communication skills to talk about their situation with their children [17]. In addition, bereaved families who did not disclose their terminal status to their children were more likely to feel distressed [10]. These previous studies suggest that parents with cancer and their family caregivers may find it difficult to tell their children about the possibility of death, and it is even more difficult for parents who do not disclose their cancer status to their children. However, young adult children of terminal patients desired open and honest communication regarding cancer diagnosis, treatment, prognosis, and end-of-life care [18]. They also desired to create memories and spend quality time with their parents before they died [19]. Adolescents with parents with cancer had difficulty taking the initiative to have conversations about their parents’ situation [20]. If children were not given honest information about the disease and its prognosis, they felt anxious, lonely, and sad [21]. A multidisciplinary approach, such as one employing child life specialists (CLS) and psychologists, may be helpful in facilitating communication between parents with cancer and their children. CLS support parents with cancer and their children by teaching the child coping strategies to deal with impending death and communicating the child’s developmental and individual needs and perspectives [22]. In addition, Children’s Lives Include Moments of Bravery (CLIMB) is a multidisciplinary approach that may be helpful in facilitating communication between parents with cancer and their children. CLIMB provides the opportunity to connect with other children who have parents with cancer, share their feelings, and enhance their understanding of cancer [23]. While such an approach was useful, it presupposes that patients disclosed their cancer to their children and did not include patients who did not [24]. Cancer patients might benefit from online peer support networks; a group such as “Cancer Parents,” could be an easily accessible resource that provides emotional support [9].

This study has several limitations. First, the participants preferred using online peer support, which may limit the scope of these findings to be generalized to diverse populations. Second, as this study was a self-administered web survey, the clinical information provided by the participants may not always be accurate. Third, there was a predominance of women in our sample (80.8%), compared with previous studies [25–28]. Fourth, the percentage of respondents was small, and included approximately 10% of all members of the website; thus, it was difficult to identify the number of members who matched all the inclusion criteria. Therefore, the findings may contain response bias, and a self-selection bias.

Future research should investigate the following: (1) gender differences in parents’ feelings when thinking about interacting with their children, and thoughts about telling them and (2) the types of information and support that would help the parents with cancer in non-disclosing group to share their illness with their children.

Conclusion

This study showed that a majority of the patients with minor children disclosed their cancer status to their children, whereas approximately a quarter of patients did not. Parents’ feelings when thinking about interacting with their children were different in the disclosing and non-disclosing groups. It is important for healthcare professionals treating patients with cancer to provide appropriate multidisciplinary support for discussing their diagnosis and prognosis with their children.

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Author contribution Yuko Usui: study design; development of questionnaire; analysis; writing manuscript; review; approval of manuscript. Kazuhiro Kosugi: study design; development of questionnaire; analysis; review; approval of manuscript. Yohei Nishiguchi: study design; development of questionnaire; analysis; review; approval of manuscript. Tomofumi Miura: study design; development of questionnaire; analysis; writing manuscript; review; approval of manuscript. Daisuke Fujisawa: review; approval of manuscript. Yuko Uehara: review; approval of manuscript. Takashi Kawaguchi: study design; analysis; review; approval of manuscript. Kayo Izumi: analysis. Jun Takehana: analysis; review; approval of manuscript. Yoshihisa Matsumoto: review; approval of manuscript.

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Data availability Not applicable.

Code availability Not applicable.

Declarations

Ethics approval This study was conducted according to the Declaration of Helsinki and was approved by the Institutional Review Board of the National Cancer Center, Japan (approval number 2018–360).

Consent to participate The questionnaire included a check box to declare disagreement with participation. Therefore, participants who answered and returned the questionnaire without filling the check box were considered to agree to their participation.

Consent for publication A letter of request explained the publication of this study. Therefore, participants who answered and returned the questionnaire were considered to be in agreement with the publication.
Conflict of interest The authors declare no conflict of interest.

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