

# Talking with Children about Cancer: A Content Analysis of Text in Children's Picture Books

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## Abstract

**Introduction:** To tell children that they are diagnosed with cancer is challenging for any healthcare professional and family. Pictures books are one of the communication tools for talking with children about severe diseases. However, little research is available about the contents of picture books about cancer for children. Therefore, this study aimed to examine the contents of children's picture books about cancer and explore the advantages and disadvantages of using picture books to communicate with children about cancer. **Methods:** We searched the picture books about cancer written for children aged under ten years old on the Amazon.com Web site on 5 July 2019 and hand-searched on the cancer-related institutes' Web site. We extracted the texts of relevant picture books and conducted a content analysis of them. **Results:** We identified 2555 picture books and included 30 of them. We identified three main contents, 1) cancer-related knowledge, 2) impacts of cancer, and 3) dealing with cancer. These contents were written with simple words and illustrations. Some of them included the essential contents, which might be misunderstood by children. **Conclusions:** Picture books might be helpful for children to understand about cancer. However, as these books do not include all contents, it is necessary to select and use multiple books depending on the content which is wanted to tell the child. Further research should evaluate the impacts of these books as a communication tool when talking with children diagnosed with cancer.

## Keywords

Cancer, Oncology, Pediatrics, Communication, Picture Books, Contents Analysis

## 1. Introduction

Among the most common illnesses is cancer in the world, and approximately

300,000 children and teens under the age of 19 are diagnosed with cancer every year [1]. One of the hardest challenges for any healthcare professional (HCP) and family is to tell children that they have a life-threatening disease. Previous studies have been shown that talking with children about their illnesses reduces their anxiety and depression [2]. Conversely, if children received no information or lack of information about illnesses, they experienced negative emotions because of the illness uncertainty [3]. Some children experience childhood cancer to be stressful and traumatic [4] [5]. While the benefits of talking about illnesses have been known, there are little specific evidence-based guidelines about how to talk about life-threatening illnesses directly with children [6]. Although children want medical information to be provided by HCPs or parents [7] [8], they tend to avoid sensitive communication with the children. HCPs and families need specific strategies for talking to children about cancer.

One of the specific tools to communicate with children are books. Books have been recognized to help children deal with severe problems [9], and shared reading has significant influences on educational and health outcomes [10] [11]. The books can be chosen based on children's developmental stages and understanding. Huang, Lee, Hu, Gao, & O'Connor (2015) analyzed text in picture books about mother's breast cancer [12]. However, there were no studies that examined picture books written for children who are diagnosed with cancer. It is not yet clear what the contents of these books include, nor whether they match the information that the children want to know. Therefore, this study aimed to examine the contents of these children's books and summarize the perspectives related to telling children about cancer. Also, we explored the possibilities of using picture books to communicate with children about cancer when they are diagnosed with cancer.

## **2. Methods**

### **2.1. Study Design and Procedure**

We conducted a qualitative study. Data were obtained from a systematic search and we used qualitative content analysis of the text from children's picture books about cancer. Content analysis is a research method whereby researchers can quantify and analyze the words and concepts from a variety of communicative languages such as books, book chapters, essays, interviews, discussions, and articles [13]. We used content analysis because it is most appropriate in examining the contents of a particular body of materials through identifying patterns, contents, or bias from narrative data particularly when there is little research on the topic [14].

### **2.2. Picture Books Selection and Analysis**

Picture books were selected based on the following criteria: 1) written for children under ten years old, 2) focusing on the contents of cancer such as disease, mechanism, treatment, social experiences, and daily life, 3) written in English or

Japanese. Even though the picture books were not written about cancer directly, we included them if the cancer-related institutions recommended it. Picture books which focused on death and family members' diagnosis were excluded.

The first author selected the picture books that the institutions related to childhood cancer, such as American Childhood Cancer Organization, Yale Cancer Center, Live Better With Cancer, Ehime prefectural library recommended for children with cancer under the age of 10. To find relevant picture books, the first author also searched the websites of Amazon Japan (<https://www.amazon.co.jp/>). Amazon is one of the most popular online bookshops globally, and it is accessible to everyone in the world; therefore, it was used to identify the eligible picture books. The first author searched the picture books using the keyword "cancer" after focusing on children's books in foreign books. The screening was conducted in two stages to select relevant books; screening of the title, product description, and product details, including language and reading level, and full-text screening. The first author extracted all texts of relevant picture books and written on word file. Two researchers independently coded the patterns and contents of all the material. In these processes, we solved the disagreements by discussion. Following the selection of articles, two researchers lumped into sub-contents, then categorized the contents. Agreement between the coding of two researchers was calculated using Cohen's kappa coefficient. We assessed agreement values 0 - 0.20 as none to slight, 0.21 - 0.40 as fair, 0.41 - 0.60 as moderate, 0.61 - 0.80 as substantial, and 0.81 - 1.00 as almost perfect agreement [15] (Table 2).

### 3. Results

The picture books were searched on 5 July 2019 and identified were 2555 potentially relevant picture books using Amazon's internal search engine and manual searching; 2509 books were excluded based on titles and abstract reviews. Of the remaining 46 full-text books, 16 were eliminated because of different inclusion criteria. Finally, 30 picture books that met the inclusion criteria were selected (Figure 1) [16]-[45]. The picture books included in this study were published from 1988 to 2018 in the United States of America, the United Kingdom, Japan, and Canada. Most of these picture books were written based on the experiences of children diagnosed with cancer, or on information about cancer. HCPs were involved in the development of some picture books. However, there were none based on the survey results for children and families. Most of the picture books directly described the experience with the protagonist's cancer, and two tried to explain cancer through another story such as an analogy [26] [30]. For example, one book showed cancer as a distinctive flower among the flowers that bloom in the garden. Another book showed cancer as a journey to cure the disease. Some books, which were recommended by cancer-related institutes focused on feelings, not cancer. Word counts ranged from 177 to 2030 words, and there were more than 5457 characters in two Japanese picture books [16] [45]. This value corresponded to approximately 2729 to 3410 words in English. While the range

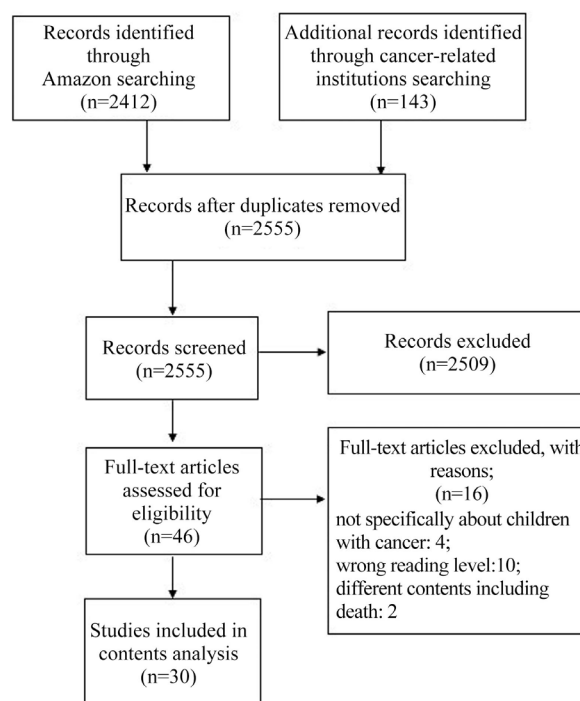
of reading level was one year and up, some books had no maximum age limit. Some of them did not correlate reading level with the number of pages and words. We summarized the characteristics of the included picture books in **Table 1**. The main contents of these picture books were identified as 1) cancer-related knowledge, 2) impacts of cancer, and 3) dealing with cancer (**Table 2**).

### 3.1. Cancer-Related Knowledge

Cancer-related knowledge refers to the information about what is going on and what children have to do, including “basic information about cancer” (number of books (percentage of books): 21 (70%), agreement: substantial), “examinations/procedures” (number of books (percentage of books): 10 (30%) agreement: substantial), and “treatments” (number of books (percentage of books): 19 (63.3%), agreement: moderate).

#### 3.1.1. Basic Information

While some books focused on specific cancer types such as leukemia and brain tumors, most books focused on the generic term of cancer. They explained that there were many different kinds of cancer. In many books, cancer was generally interpreted as an illness that turned healthy cells into abnormal cells, and the body could not function because they were proliferating. Some books described that cancer was not contagious, and no one knew what causes cancer. It emphasized and explained that it is not caused by their behavior, thinking, or what they said.



**Figure 1.** Process for the selection of picture books.

**Table 1.** Characteristics of included picture books.

Authors, Year	Grade level (years)	Country	Topic	Main character	Paperback (Pages)	Word count of main text	Kindle version available
Bergman, 1989 [16]	6 - 12	Japan	Basic information on cancer	Children with cancer	47	7491*	N/A
Billups, 2017 [17]	0 and up	USA	Experience of cancer	Child with cancer	36	1148	×
Brent & Knutsson, 2008 [18]	6 - 8	USA	Basic information on leukemia	Child with cancer	48	1260	N/A
Carney, 1998 [19]	4 - 8	USA	Coping	Animal	32	1236	N/A
Dawson, 2013 [20]	2 and up	USA	Basic information on cancer	Child with cancer	26	441	×
Demaio, 2014 [21]	4 - 8	USA	Basic information on cancer	Child with cancer	32	624	N/A
Filigenzi & Tadgell, 2016 [22]	7 - 9	USA	Experience of cancer	Child with cancer	16	292	N/A
Fisher & Huie, 2010 [23]	4 and up	USA	Experience of cancer	Child with cancer	32	1045	N/A
Fox & Lew, 2017 [24]	0 and up	USA	Basic information on cancer & fighting against cancer	Child with cancer	19	808	×
Gaynor, 2008 [25]	6 - 8	UK	Experience of cancer	Child with cancer	30	695	×
Gullia, 2017 [26]	0 and up	Canada	Basic information on cancer	Animal	28	739	×
Hoard, 2019 [27]	4 - 10	UK	Experience of cancer	Child with cancer	12	254	×
Hoffman & M-D., 2015 [28]	1 - 5	USA	Experience of cancer	Child with cancer	31	337	N/A
Karst & Stevenson, 2000 [29]	4 - 8	USA	Coping	Children and mother	36	511	×
Leonard & Fox, 2013 [30]	4 - 8	USA	Basic information on cancer	Animal	32	870	N/A
Moss, 2016 [31]	2 and up	USA	Experience of cancer	Child with cancer	34	523	×
Parr, 2005 [32]	0 - 3	Canada	Coping	No setting	24	177	N/A
Reynolds, Wright, Smith, & Jacson, 2017 [33]	1 and up	USA	Experience of cancer	Child with cancer	35	2030	×
Robert & Ely, 2018 [34]	0 and up	USA	Experience of cancer	Child with cancer	34	1141	×
Robinson, 2012 [35]	3 and up	N/A	Basic information on chemotherapy	Fancy characters	44	197	×
Romain, 2008 [36]	3 - 10	USA	Coping	Animals	22	212	N/A
Schmidt, 1988 [37]	4 and up	N/A	Basic information on cancer	Child with cancer	25	798	×
Snow & Snow, 2007 [38]	1 - 3	USA	Coping	No setting	22	180	N/A
Snow, Snow, Espeland, Hartman, 2007 [39]	3 and up	USA	Coping	No setting	30	967	N/A
Snyder & Engelsgerd, 2014 [40]	6 - 8	USA	Basic information on cancer	No setting	22	365	×
Spicer, 2018 [41]	Children to adults	USA	Experience of cancer	Child with cancer	17	544	×
Strenge, 2015 [42]	4 - 8	USA	Basic information on cancer	Child with cancer	30	347	N/A
Tillman, 2010 [43]	4 - 8	USA	Coping	Child	32	265	×
Van, 2017 [44]	3 and up		Experience of cancer	Child with cancer	24	370	×
Watanabe, 2002 [45]	4 - 12	Japan	Basic information on leukemia	No setting	28	5457*	N/A

\* Japanese. USA: United States of America, UK: United Kingdom.

**Table 2.** Main contents of picture books about cancer.

Authors, Year	Cancer-Related Knowledge			Impacts of Cancer			Dealing with Cancer		
	Basic Information	Examinations/ Procedures	Treatments	Daily Life	Children's Emotions	Parent's Emotions	Children's Coping Strategies	Message for Readers	Social Support
Bergman, 1989 [16]	×	×	×	×	×	×			×
Billups, 2017 [17]	×	×	×	×	×	×	×		×
Brent & Knutsson, 2008 [18]	×	×	×	×			×	×	×
Carney, 1998 [19]	×			×	×		×		×
Dawson, 2013 [20]	×	×	×	×			×		×
Demaio, 2014 [21]	×		×	×			×	×	×
Filigenzi & Tadgell, 2016 [22]	×			×	×		×		×
Fisher & Huie, 2010 [23]	×	×	×	×	×	×	×		×
Fox & Lew, 2017 [24]	×	×	×		×		×	×	×
Gaynor, 2008 [25]	×		×	×			×	×	×
Gullia, 2017 [26]	×		×	×	×		×		×
Hoard, 2019 [27]				×	×	×	×		×
Hoffman & M-D., 2015 [28]	×	×	×	×			×	×	×
Karst & Stevenson, 2000 [29]					×				×
Leonard & Fox, 2013 [30]	×		×	×	×	×	×		×
Moss, 2016 [31]	×				×		×	×	×
Parr, 2005 [32]							×	×	
Reynolds, Wright, Smith, & Jacson, 2017 [33]			×	×	×		×		×
Robert & Ely, 2018 [34]	×		×	×	×		×	×	×
Robinson, 2012 [35]					×		×	×	×
Romain, 2008 [36]					×		×	×	×
Schmidt, 1988 [37]	×		×		×				×
Snow & Snow, 2007 [38]							×		
Snow, Snow, Espeland, Hartman 2007 [39]							×		
Snyder & Engelsgerd, 2014 [40]	×		×		×			×	×
Spicer, 2018 [41]	×	×	×	×				×	×
Streng, 2015 [42]	×		×		×		×	×	×
Tillman, 2010 [43]							×	×	×
Van, 2017 [44]	×	×	×		×		×		×
Watanabe, 2002 [45]	×	×	×				×	×	×
Cohen's Kappa	0.66	0.66	0.49	0.48	0.65	1.0	1.0	1.0	0.66

× There was a description of the contents.

*Mom always knows what I'm thinking. "No one is sure why you have cancer, Clara," she says. "But we do know that it isn't because of anything you did, or thought, or said". "Thank goodness!" I smile ([34], p. 11).*

Symptoms caused by cancer, such as feeling sick, sleepy, and tired, were described in many books. In most books, symptoms have emerged within the story about the main character who had been diagnosed with cancer, and later recovered from cancer after treatments. A few books mentioned a recurrence of cancer.

### 3.1.2. Examinations/Procedures

Many picture books covered the examinations and procedures such as blood tests, vital sign measurements, bone marrow aspiration, and X-ray. These were described to allay the reader's fear, for example, that anesthesia could be taken before undergoing invasive procedures and it makes them fall asleep.

### 3.1.3. Treatments

In most books, chemotherapy was described as an effective treatment that could help eliminate cancer cells. Moreover, side effects such as hair loss, fatigue, nausea, and bone marrow suppression were described. Some books dealt with the main topic of hair loss, indicating that patients spent time wearing hats or wig during treatments, and their hair grew back eventually.

## 3.2. Impacts of Cancer

The impact of cancer refers to the impact of having a child with cancer, including their "daily life" (number of books (percentage of books): 16 (53.3%) agreement: moderate), "children's emotions" (number of books (percentage of books): 19 (63.3%) agreement: substantial), and "parent's emotions" (number of books (percentage of books): 5 (16.7%) agreement: almost perfect agreement).

### 3.2.1. Daily Life

In most books, it was brought up that after the diagnosis of cancer the child's daily life had changed from normal. Hospitalization was often explained. Children's negative and positive emotions were both described. For example, hospitalization separated them from family members and friends, and so they felt alone and sad.

### 3.2.2. Children's Emotions

There were descriptions of various types of feelings, such as being sad, scared, angry, embarrassed, and alone. The books described what kind of atmosphere there was for each situation. In the picture story books, emotions were described as the main characters' emotions with a short description of why they felt that way. After they were diagnosed with cancer, they felt sad because they saw their parents cry. They felt scared when they took the treatments, examinations, and procedures. Also, they felt angry and expressed that it was unfair.

*"Ally got mad at the cancer. She said, "That is not fair! I do not want to be*

tired. I want to run and play again. How do we fight the cancer? How do we make it go away?” ([26], p. 15).

They felt embarrassed of the change in body image when their hair fell out.

“Her hair fell out and when it was gone, her head was white as snow. At first, she felt embarrassed, and sometimes had to cry.” ([24], p. 13).

On the other hand, there were a few descriptions of positive emotions such as being happy and amazed when they played with their friends; when they reconfirmed their love; when they went back home, and when they recovered from cancer. Some books emphasized that it was normal to have many feelings and that they could tell someone anything.

“I have so many feelings. I don’t know what to do. But I don’t have to feel guilty or ashamed about my feelings. They are a part of me. And it’s okay to let my feelings out.” ([22], p. 13-15).

### 3.2.3. Parents’ Emotions

Some picture books described parent’s feelings, such as being sad and anxious when their children were diagnosed with cancer. Also, how they were deeply moved when their children recovered from cancer.

## 3.3. Dealing with Cancer

Dealing with cancer refers to the actions to reduce or minimize stressful events that had been described, including “children’s coping strategies” (number of books (percentage of books): 25 (83.3%) agreement: almost perfect agreement), message for readers (number of books (percentage of books): 15 (50%) agreement: almost perfect agreement), and “social support” (number of books (percentage of books): 27 (90%) agreement: substantial).

### 3.3.1. Children’s Coping Strategies

The main characters who were diagnosed with cancer tried to cope with the stressful events that they had to do but did not want to do and about which they had negative feelings. For children, stressors varied, such as cancer, treatments, procedures, hair loss, and hospitalization. Also, there were a variety of children’s coping strategies, including emotion-focused coping, which changed their emotional response to the stressor. Another one was problem-focused coping, where they directly approached to the problem. They had a way of coping with stressful events by changing their minds and taking other actions.

“I may lose all of my hair but I hope to win life. Cancer will be beaten. Captain Chemo is on my side.” ([35], p. 5-6).

### 3.3.2. Message for Readers

At the end of the story, it was emphasized that the main character was a valuable person and should be loved by others, even if they were diagnosed with cancer.

“The truth about cancer is ... It does not define who you are or who you will be. You and only you get to write your story.” ([42], p. 22).



### 3.3.3. Social Support

The main characters were supported by their family members, HCPs, teachers, and friends. They realized that they were not alone and that they were fighting against cancer together. Most of the picture books that mentioned family referred to the parents; few books referred to siblings.

*“Since kicking cancer is hard work for our whole family. Mom and Dad make sure we still do a lot of fun things together. It’s great to know I don’t need to kick cancer all on my own.”* ([17], p. 24).

## 4. Discussion

The study systematically identified picture books about cancer and coded the contents. The results of this study could contribute to a concrete way to communicate with children about cancer.

### 4.1. Advantages of Picture Books

Being open and honest when talking about cancer has been widely expanded [46]. Likewise, early palliative care, including communication with the patients about the illness and its prognosis has been found to improve the quality of life [47]. Some studies suggest that reading and using picture books before procedures promote children’s understanding and reduce stress [48] and anxiety [49]. Picture books about cancer might help children understand not only cancer but also their daily lives more deeply. Because most picture books were written using simple words with illustrations to explain information related-cancer. Jalmsell *et al.* (2016) suggested that children with cancer desire be given accurate information as positively as possible to preserve hope [8]. The content of “dealing with cancer” might support children to express their emotions and cope with cancer through the main character’s emotions or learning directly from the books. Indeed, some picture books include meaningful sentences that can correct children’s common misunderstandings. For example, some picture books explain that cancer is not the child’s fault.

### 4.2. Disadvantages of Picture Books

A similar study that analyzed 45 picture books about maternal breast cancer assessed all the books to be beneficial to children and adults. However, some contents such as school life and financial burdens, and instructions about age-appropriateness were not enough [12]. Likewise, this study indicated that the picture books written about cancer for children were lacking similar information. Although cancer-related institutes and Amazon described the age-appropriateness, some picture books have too many words and are challenging to understand for children of the target age. Sharing information with them should be according to their developmental stages [50]. The minimum target age for children to read and understand should be clarified. Although, siblings need the information to understand the situation that their sibling has cancer [51], there are few books, which include them in the stories.

Katz, & Webb (2016) asserted that children's involvement in the discussion of their medical condition is part of standard patient care. However, this practice is yet to be widespread and there is a lack of evidence-based specific guides on how to tell children about cancer considering children's developmental stages and emotions [6] [52]. Although picture books might be helpful as a communication tool about cancer, picture books have limited information and we should choose the multiple relevant picture books to the child's particular medical condition.

### **4.3. Implications for Practice and Future Research**

Disclosure has been asserted to be a child's right [53] [54], and many studies have shown that open communication is beneficial to keep good relationships with children [55] and reduce children's stress [56]. However, disclosing a cancer diagnosis is sometimes challenging for HCPs and parents because there are some communication barriers, including lack of skills, and the preferences of parents [57]. By selecting and using a picture book that suits the purpose to inform, the picture books might help HCPs to communicate with children about cancer. However, most books are written based on cancer survivor's experiences, and there was no picture book listed based on surveys that were conducted to understand the preferences of children and families. Also, these picture books are not evaluated whether these are beneficial to use as a communication tool. If these picture books are used as an educational tool, HCPs should consider the various factors, including medical conditions, developmental stages, children's emotions, family's preferences, and contents of the picture books.

Further research should evaluate the impacts of these picture books for children with cancer, including using it as a communication tool. Additionally, the development of the materials, including a picture book to communicate with children, should be created based on children's and their family's information needs.

### **4.4. Limitations**

There are some limitations to this study. First, we included only books that were searched on the Amazon Web site and some others recommended by a few cancer-related institutes. Further research should be conducted using several more comprehensive databases and keywords. Second, while pictures and drawings are essential for younger children, picture books that were selected for this study were evaluated using their texts. Younger children who do not have enough literacy to read the words can learn more by using functions other than reading. Although no method for synthesizing illustrations was available, further analysis of each picture book is necessary to include illustrations. Third, although HCPs might use the picture books as the educational tools to communicate with children, only the contents of these picture books were assessed in this study. Future study should assess the effects of picture books, including the process of their actual use.

## 5. Conclusion

Picture books can be useful tools for HCPs and families as a communication tool for talking to children about cancer and can be helpful for children to understand and cope with cancer. However, it is necessary to select and use multiple books depending on the contents. Further research should assess the impacts of these books as a communication tool when talking with children diagnosed with cancer.

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## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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