Original Article

The Self-Disclosure Process for a Survivor of Childhood Cancer in Connection with Society: A Qualitative Descriptive Study

Junko Ito, RN, MHSc
Research student, Niigata University Graduate School of Health Sciences, Niigata, Japan

Tomoko Sumiyoshi, RN, PhD
School of Health Sciences, Niigata University, Niigata, Japan

Correspondence: Tomoko Sumiyoshi, Professor, School of Health Sciences, Niigata University. 2-746 Asahimachi-dori, Chuo-ku, Niigata-shi, 951-8518, Niigata, Japan. Email: sumiyosi@clg.niigata-u.ac.jp

Place where study was conducted: Bunkyo Gakuin University, 1-19-1 Mukougaoka, Bunkyo-ku, 113-8668, Tokyo, Japan

Abstract

Background: Survivors of childhood cancer need special support because they face many life events after completing treatment. Effective self-disclosure is necessary to receive support from people close to them.

Aims: To describe the self-disclosure process for survivors of childhood cancer and obtain suggestions for social-adaptation support.

Methodology: Semi-structured interviews were conducted with eight survivors of childhood cancer aged 20–35 years. The data obtained were analyzed using a modified grounded theory approach.

Results: Analyzing the self-disclosure process for survivors of childhood cancer to people close to them comprises 【4 categories】 , [7 subcategories], and <21 concepts>. The core category was 【still want to connect】. Survivors of childhood cancer were hesitant and wavering regarding self-disclosure through 【seeking disclosure stance】 to examine their own disclosure attitude and 【assessment of interpersonal relations】 to estimate their disclosure choices to form better relationships with others. However, they were certain regarding disclosing, saying they 【still want to connect】 , such as <confidence of being sufficiently close to confide>, [getting creative], and [leaving some ambiguity]. Following disclosure, they experienced 【blending into the group】 that led to new social relationships.

Conclusions: Self-disclosure by survivors of childhood cancer led to the building of good relationships with others close to them. The decision to self-disclose was driven by a desire to connect with society. Maintaining relationships with society and improving self-disclosure skills can lead to social independence for survivors of childhood cancer.

Key Word: childhood cancer, childhood cancer survivor, self-disclosure, posttraumatic growth

Introduction

Although the rate for cancer cure has improved significantly in recent years, yet, providing post-treatment support remains a challenge. In particular, the support required by survivors of childhood cancer is different from that for adults because the period after treatment completion is long and the cancer occurs during a period of rapid growth and development. Experiencing childhood cancer treatment not only has physical and psychological effects but also entails many complex social aspects. It has been reported that compared to their peers who have not experienced cancer, many survivors of childhood cancer are more likely to exhibit social maladjustment, isolation from their peers, and delayed social independence (Brinkman et al., 2018; Erdmann et al. 2021). A higher proportion of school-age survivors of childhood cancer have no trusted or close friends and experience problems building social relationships (Barrera et al., 2005). We conjecture that their ineptness in building social relationships delays social independence during adulthood.

In a review of social isolation among survivors of childhood cancer, it was found that while older age during diagnosis and late complications were deemed as risk factors, receiving social support and satisfaction therewith and having a sense of belonging to a peer group were deemed risk-reducing factors (Pahl et al., 2021). For school-aged survivors of childhood cancer, maintaining connections with peers and teachers while in treatment impacts positive adjustment on their return to school (Martinez-Santos et al., 2021). It is speculated that survivors of childhood cancer build good social relationships by self-disclosing their cancer experiences to those close to them, receiving the support they need, and maintaining a sense of belonging to a social group.

Self-disclosure refers to verbally communicating information about oneself to others, and the self-disclosure of traumatic experiences is believed to lead to understanding these experiences and reducing mental problems (Moriwaki 2005). The choice to self-disclose among survivors of childhood cancer is reported to be associated with the social relationship they have with the recipient of the disclosure and that person's reaction. However, the psychological changes leading up to the self-disclosure and their mutual impact on the people surrounding them have not been examined. As survivors of childhood cancer confront various post-treatment life events, the process of conflict and choice must be extracted from their own experiences of how they self-disclose to the people around them.

Based on the above, this study aims to describe and analyze the process of disclosure among survivors of childhood cancer who have self-disclosed to others; it asks them to describe and analyze the process leading to the disclosure, along with the changes to their relationships with the people around them. Identifying the self-disclosure process allows us to obtain suggestions on how to ideally support the social independence of survivors of childhood cancer.

Aims: To describe the self-disclosure process of survivors of childhood cancer and obtain insights on how to support their social adaptation.

Methodology

Definitions of terms: Survivors of childhood cancer are defined as individuals who have previously been diagnosed with and treated for childhood cancer. In this study, this was determined through self-reporting by the subjects.

Self-disclosure is defined as the act of a survivor of childhood cancer verbally conveying information about their experiences of cancer during childhood to others aside from their family or medical professionals.

Study design: This study is a qualitative descriptive study using semi-structured interviews.

Subject selection: The subjects were survivors of childhood cancer aged 20 years or older who had been previously treated for childhood cancer, had been notified of the name of their disease, were in remission, and had not been treated for underlying diseases during the interviews. Participants were recruited either via the researcher's personal website, through postings with permission in self-help groups, or through the researcher's personal snowball sampling. The participants' willingness to co-operate in the study was accepted only through direct contact with the researcher, and eight offered to participate. Individuals who had self-reported to regularly visiting a psychiatrist, received prescriptions for psychiatric medications, or were hospitalized for treatment at the time were excluded in the study. As a result, no participants met the exclusion criteria and the final sample comprised eight participants. The investigation period was from March to June 2022.

Ethical considerations: This study was approved by the Ethics Committee of the Faculty of Health Science Technology, Bunkyo Gakuin University (Approval no. 2021-0024). All study participants were informed that their participation was voluntary, and that they had a right to withdraw. Additionally, they were informed that their privacy and anonymity would be protected. Written consent was obtained.

Data-collection methods: Interview-guideline content: 1. basic attributes (current age, sex, and employment/educational status); 2. information about childhood cancer (name of disease, age at onset, any recurrences, treatment details, any late complications, and frequency of hospital visits at present); 3. information regarding disease notification (time of notification and person notified); 4. self-disclosure experience (recipient, opportunity for disclosure, willingness to disclose, and considerations accompanying disclosure); 5. perception of the recipient's reaction

(recipient's listening attitude, changes in the relationship after disclosure, and reflection about the disclosure); 6. support from the surroundings following disclosure (if support was given, details of the support and expectations regarding the support); and 7. intention to disclose.

Data-analysis methods: Data collection was conducted in a private room at the researcher's university, separate from the research laboratory to ensure privacy, and following the interview guide, 30–60 minutes of semi-structured interviews were conducted. However, considering the spread of infection, an online conferencing system was used to conduct non-face-to-face interviews for subjects who preferred them. Interviews were recorded with consent from the subjects, transcribed verbatim, and subjected to continuous comparative analysis using the modified grounded theory approach (M-GTA) (Kinoshita 2021). The M-GTA is an analytical method of generating practical theories, including the prediction and explanation of human behavior related to social interactions. The analysis focused on "survivors of childhood cancer aged 20 years or older who were not receiving treatment at the time and did not suffer from mental illness," and the analysis theme was set as "the process of disclosing to someone close to you that you are a survivor of childhood cancer." The average of the subjects was 24.3 years (range 20-35). First, the verbatim transcripts were carefully read, the data were interpreted, highlighting the analytic themes and analytic focus, and "concepts" were generated. In generating concepts, we used an analysis worksheet and described the names of the concepts, definitions, variations (specific examples), and theoretical notes. Next, the following concepts were generated from a comparative perspective for similar and opposite examples, highlighting the generated concept definitions. Continuous comparative analysis was conducted until the end of the analysis so that arbitrary interpretations could

be avoided by viewing the data from a comparative perspective and corrections were made where necessary. Last, the relationships between the generated concepts were examined, [subcategories] and [categories] were generated based on the unified meaning of each concept, the overall relationship was diagrammed as a result diagram, and story lines were created to turn the result diagram into text. Theoretical saturation was determined in two stages: when no new concepts were generated based on the analysis worksheet, and when the interrelationships among categories stabilized and the structure of the analysis themes was integrated based on the result diagram and story-lines. At each stage of the analysis process, advice was obtained from researchers familiar with the M-GTA to ensure reliability and validity.

Results

Summary of subjects (Table 1.) A summary of the study participants is shown in Table 1. This study had 8 participants whose mean age was 24.3 years (20–35 years old), and their mean age at first onset of cancer was 9.5 years. Six of them were aware of the symptoms of late complications. The average interview duration was 43.8 minutes (28–59 minutes).

Story line (Figure 1. Table 2.): The self-disclosure process for survivors of childhood cancer to people close to them is shown in Figure 1. The story line, with the concepts denoted in < >, subcategories in [ ], and categories in 【】 , is as follows. The concepts included in each category are in Table 2.

After being diagnosed with childhood cancer and when undergoing treatment, survivors of childhood cancer go through the process of 【seeking disclosure stance】 . In this process subjects consider whether or not to disclose their childhood cancer experience to those close to them.

Table 1. Overview of subjects

	Age at interview	Sex	Social attributes	Cancer diagnoses	Age at diagnoses	Recurrence	Transplantation	Late effects	Outpatient frequency
A	24	woman	non-employed	leukemia	11	no	yes	yes	6 m
B	21	man	student	leukemia	8	yes	yes	yes	3-6 m
C	23	woman	full-time	brain tumor	11	yes	yes	no	2 m

D	20	woman	student	leukemia	7	no	no	no	1 y
E	20	woman	student	other	7	no	no	yes	non
F	35	man	full-time	leukemia	7	yes	yes	yes	1 m
G	30	man	full-time	leukemia	16	no	yes	yes	3 m
H	21	woman	student	neuroblastoma	9	yes	yes	yes	3-4 m

Table 2. Table of categories, subcategories, and concepts

| Categories	Subcategories	Concepts
seeking disclosure stance	want to confide but cannot	dilemma of wanting to confide but cannot
		insufficient information to disclosure
	do not want others to know about it	want to be the same as everyone else
		worry about what others think
		want to say
		want to remember
	want others to know about it	want to be myself
		want to accept everyone
		want to use my cancer experience
assessment of interpersonal relations	sensing the need	not the same as everyone else
		need to speak as an explanation
	better to tell	not noticeable at a glance
		better to say in advance
still want to connect		confidence of being sufficiently close to confide
	become creative	obtain advice
		set the scene
		talk humorously
	leave some ambiguity	dare not to check
		maybe others did not want to hear
blending into the group		grateful for people's understanding
		recommend disclosure
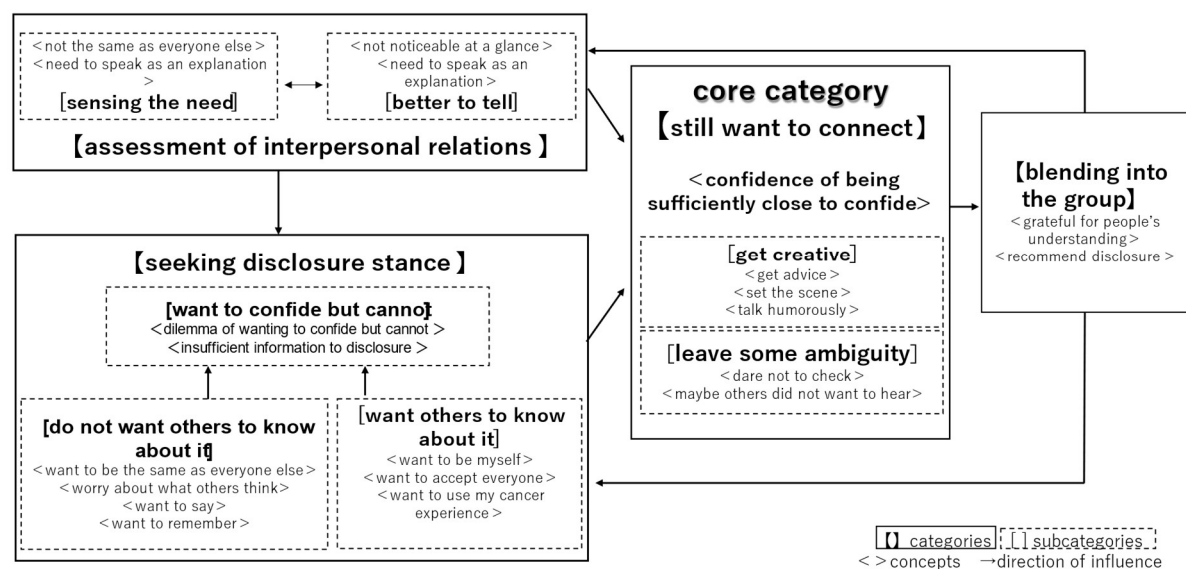
Figure 1. The process of self-disclosure as a survivor of childhood cancer for people close to them

They experience [wanting to confide but cannot] due to their conflicting stance on self-disclosure: on the one hand, they [do not want others to know about it]; on the other hand, they want people close to them to know, or they are unopposed to them knowing, and thus they [want others to know about it]. In addition, survivors of childhood cancer experience [sensing the need] to disclose themselves to others, and although it is not always necessary, they should disclose their status: it is [better to tell] others in order to build good relationships with them, and thus, they conduct an 【assessment of interpersonal relations】 to gauge relationships with others.

This 【assessment of interpersonal relations】 affects the 【seeking disclosure stance】 that survivors of childhood cancer have, and although they are confused and waver in their relationship with themselves and society, they orient themselves toward the realization of disclosure and 【still want to connect】 (core category) with others and the group to which they belong.

In this category, 【still want to connect】 mindset, they self-disclose by building a relationship of trust at the <confidence of being sufficiently close to confide> level, [getting creative] with what they disclose, and [leaving some ambiguity] without seeking for confirmation in accordance with others' receptiveness. Through self-disclosure, others show understanding, and survivors of childhood cancer experience 【blending into the group】, leading to the formation of relationships without resistance. In addition, 【blending into the group】 affects the new 【seeking disclosure stance】 and 【assessment of interpersonal relations】, which will be the cornerstone of the new self-disclosure.

Seeking disclosure stance: In this category, the subjects wavered between conflicting stances of [do not want others to know about it] and [want others to know about it] on whether they should disclose being survivors childhood cancer and sought their own disclosure stance as [wanting to confide but cannot]. In [do not want others to know about it], subjects had negative feelings about being survivors of childhood cancer, and as much as possible, they did not want the people close to them to know that they were survivors childhood cancer. However, in [want others to know about it], they viewed being survivors of childhood cancer as something positive and wanted those close to them to know about it, or they thought it was acceptable for them to know. These two subcategories affect opposing attitudes toward disclosure, with [wanting to confide but cannot] indicating a situation in which the subjects want to tell people close to them that they are survivors of childhood cancer but cannot do so.

Assessment of interpersonal relations: In this category, the subjects chose to disclose while assessing their relationships with others through situations in which they were [sensing the need] for disclosure from others, or experiences in which they themselves thought it might not be necessary to disclose but it was [better to tell] to build good relationships with others. This category also affected the 【seeking disclosure stance】.

Still want to connect: This category is affected by the subjects' process of hesitation to disclose, that is, 【seeking disclosure stance】 and 【assessment of interpersonal relations】, and it is the core category in which they orient themselves toward self-disclosure by having the <confidence of being sufficiently close to confide> or by [getting creative] and [leaving some ambiguity].

<Confidence of being sufficiently close to confide> indicated building a deep relationship of trust with a particular person to the extent that the subject deemed it acceptable to self-disclose. This was a concept that had the same level of explanatory power as the other subcategories in orienting toward self-disclosure. [Getting creative] meant finding ways to encourage others to accept the information that one was disclosing and wanted others to know, while [leaving some ambiguity] meant believing it was best not to check how receptive others were to the disclosure.

Blending into the group: In this category, the subjects sought to build good relationships with others and expand their ideas to peers who had the same experiences through the self-disclosure that occurred in 【still want to connect】. This category was acquired through the process of survivors of childhood cancer self-disclosing to people close to them, while simultaneously, it became a factor that influenced newly 【seeking disclosure stance】 and 【assessment of interpersonal relations】,

denoting that the disclosure process led to the next disclosure.

Discussion

This study revealed that, despite the wavering feelings and hesitation of survivors of childhood cancer about self-disclosing to people close to them, they made their choice based on their desire to connect, and therefore, they could establish comfortable relationships. This is similar to the finding that survivors of childhood cancer who actively self-disclose to their partners are more satisfied with their relationships than those who do not (Bos-van den Hoek et al. 2023). For survivors of childhood cancer, self-disclosure can be considered among the essential social skills that facilitate building relationships with others.

When choosing to self-disclose, the subjects of this study considered 【seeking disclosure stance】, which was their own self-contained thoughts, and 【assessment of interpersonal relations】, which was their social thoughts. The survivors' own attitudes on disclosure and predictions about relationship changes influence their disclosure behavior, which is consistent with previous research (Barnett et al. 2014, Bos-van den Hoek et al. 2023).

【seeking disclosure stance】 includes [want others to know about it], which denotes a positive attitude toward self-disclosure, and [do not want others to know about it], which denotes a negative attitude, and survivors of childhood cancer hesitated and wavered between these conflicting disclosure stances and experienced [wanting to confide but cannot]. While the experience of childhood cancer is traumatic, there is also growth that can be acquired through it, and it is believed that this duality is expressed in the self-disclosure process. [Want others to know about it] includes <want to be myself>, <want to use my cancer experience>, and <want to accept everyone>, and in these, survivors of childhood cancer, who had experienced cancer, perceived themselves positively. It was believed to be necessary to make sense of the cancer experience as a basis for affirming oneself in order to show a positive attitude toward self-disclosure.

Moreover, in 【assessment of interpersonal relations】, survivors of childhood cancer wavered between [sensing the need] and [better to tell]. This is a process that examines the significance of disclosure from the perspective of the recipient of the disclosure. Believing that disclosing their own cancer experiences would change how the recipient thought of and responded to them, they assumed the other person's position and needs. This means that self-disclosure is a phenomenon that arises from mutual relationships with others, and this is consistent with the results of previous studies wherein the fact that disclosure of childhood cancer experience is believed to be important even to the recipient was given as the primary reason for self-disclosure at work or at school (Rabin 2020). Generally, people with high self-immersion tendencies who are prone to focusing their attention on themselves are more likely to engage in maladaptive self-disclosure (Moriwaki 2005); however, in this regard, it was assumed that the self-disclosure by the subjects of this study was a choice they made after considering it from a social perspective: that is, in terms of its impact on others and on the changes in relationships, and it resulted in good social adjustment.

Meanwhile, after going through the stage of hesitation and wavering, what prompted them to self-disclose was the fact that they 【still want to connect】, the desire for a continued relationship with society. The degree to which the subjects wanted to be understood by those around them as the reason for taking the initiative to disclose was consistent with prior research (Hatanaka 2013).

The method of self-disclosure chosen by the subjects had the characteristic of <confidence of being sufficiently close to confide>, which involves openly disclosing based on a deep relationship of trust. The influence of closeness to friends on self-disclosure about illness was also reported in a study of other chronically ill children (Aoki 2012). For school-aged survivors of childhood cancer, friends who have known them before the onset of cancer and understand the process they went through of returning to school after hospitalization and treatment become their support in building social relationships after they return to school (Nagayoshi 2021). People who have experienced chronic diseases recognize that their experience of those rare diseases makes them different from others; thus, it is assumed that they 【still want to connect】 with recipients who will accept this difference and take that step toward self-disclosure. It has been reported that those who have disclosed their diseases receive higher amounts of social

support than those who have not (Aoki 2012). Supporting self-disclosure to close friends, which the survivors of childhood cancer themselves desire, leads to receiving social support and becomes the foundation to creating relationships with new friends and society.

Meanwhile, it was also revealed that, in self-disclosure, there were ways to [getting creative] and [leaving some ambiguity], such as changing methods or limiting content depending on the situation and the recipient. Generally, considering the choice of time and place as well as context are considered to be significant for effective self-disclosure (Moriwaki 2005), and the participants of this study believe that being able to choose from these methods helped them achieve 【blending into the group】 after self-disclosure. Numerous previous studies have reported similar methods in survivors of childhood cancer (Barnett 2014, Rabin 2020), and it has been suggested that support was required to improve the self-disclosure skills of survivors of childhood cancer, both in self-disclosure situations and in the stage of choosing the recipient.

Conclusions: In summary, survivors of childhood cancer engage in self-disclosure due to their desire to maintain and develop connections in their ongoing relationships with society. It has been suggested that survivors of childhood cancer need support in devising ways to self-disclose according to the situation and recipient.

Limitations: In future, the self-disclosure process revealed in this study should be utilized to support the independence of survivors of childhood cancer and to verify its effectiveness. However, the bias in the subject-selection criteria in this study may have resulted in the inclusion of survivors of childhood cancer who could already effectively self-disclose, and negative factors related to self-disclosure could not be extracted. It is necessary to clarify the relevant factors in maladaptive self-disclosure that hinder self-disclosure support.

References

Aoki M. (2012) Disclosure dilemmas experienced by school-aged children with congenital heart disease. The Journal of Child Health71(5):715-722.

Barnett M. E., Shunk E. M., Conway F. P. & Ford J. S. (2014) Cancer-related disclosure among adolescent and young adult cancer survivors: A qualitative study. Journal of Adolescent and Young Adult Oncology 3(3):123-129.

Barrera M., Shaw A. K., Speechley K. N., Maunsell E. & Pogany L. (2005) Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. Cancer 104(8):1751-1760.

Bos-van den Hoek D. W., Tuinman M. A., Hillen M. A., Huigens F. L., Kurpershoek E., Calaminus G., Kaatsch P., Hagedoorn M. & Lehmann V. (2023) Disclosing a history of childhood cancer to romantic partners. Psycho-Oncology: 904-912.

Brinkman T. M., Recklitis C. J., Michel G., Grootenhuis M. A. & Klosky J. L. (2018) Psychological symptoms, social outcomes, socioeconomic attainment, and health behviors among survivors of childhood cancer: Current state of the literature. Journal of Clinical Oncology 36(21):2190-2198.

Erdmann F., Frederiksen L. E., Bonaventure A., Mader L., Hasle H., Robison L. L. & Winther J. F. (2021) Childhood cancer: Survival, treatment modalities, late effects and improvements over time. Cancer Epidemiology 71:1-20.

Hatanaka M. (2013) Information disclosure after the returning to school of adolescent children with cancer. The Journal of Child Health72(1):41-47.

Kinoshita Y. (2021) Modified grounded theory approach qualitative research methodology for theorizing practice. Igakushoin, Tokyo, Japan.

Martinez-Santos A., Fernandez-De-La-lglesia J., Sheaf G. & Coyne, I. (2021) A systematic review of the educational experiences and needs of children with cancer returning to school. Journal of Advanced Nursing 77(7):2971-2994.

Moriwaki A. (2005) Clinical psychology of depression and self-disclosure. Kazama-shobo, Japan, 4-75.

Nagayoshi M., Adachi K., Sito T., Takahashi Y. & Tanigawa H. (2021) Local friendships among childhood cancer survivors from pre-hospitalization to post-return to school: Factors that maintain friendships.Education and Healthcare for Children with Health Impairments.68:1-9.

Pahl D. A., Wieder M. S. & Steinberg D.M. (2021) Social isolation and connection in adolescents with cancer and survivors of childhood cancer: A systematic review. Journal of Adolescence 87:15-27.

Rabin C. (2020) Cancer-related self-disclosure in the workspace/school by adolescent and young adult cancer survivors. Journal of Adolescent and Young Adult Oncology 9(4):528