

Original Article

Adolescent childhood cancer survivors talking about cancer: A socioecological perspective

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ABSTRACT

Objective: This study aimed (1) to investigate the communication patterns of adolescent childhood cancer survivors (ACCSs), including their motivations, methods, context, and outcomes and (2) to identify factors influencing their cancer-related communication (cancer communication) at each level of the socioecological model. **Methods:** A qualitative descriptive research design was adopted to explore ACCSs' experiences of communicating about cancer and the factors influencing such experiences. Semi-structured interviews were conducted, and the collected data were analyzed using thematic analysis. This study was conducted according to the Standards for Reporting Qualitative Research.

Results: The ACCSs were motivated to engage in cancer-related communication by acquiring social support and an altruistic perspective. Although ACCSs rarely initiated cancer-related communication proactively, they communicated with close friends and family members about their cancer experiences. The motivation to communicate with friends shifted from sharing factual information, such as their daily lives in the hospital, to seeking emotional connections shaped by psychosocial development. Dissatisfaction with the limitations of school life and concerns about cancer were primarily discussed with parents. Furthermore, parents' perceptions of cancer and their explanations of the illness to their children appeared to influence the children's perceptions of their cancer experiences and their communication about cancer. Cancer-related communication among ACCSs was influenced by factors at multiple levels. Furthermore, institutional- and community-level factors affected individual and interpersonal factors.

Conclusions: A multilayered approach involving ACCSs, parents, educators, school peers, and the broader community is essential for enhancing communication about cancer within this population.

Introduction

In social contexts, communication of adolescent childhood cancer survivors (ACCSs) regarding health issues is a sensitive and complex topic, posing significant challenges for ACCSs, their families, school personnel, and peers.^{1,2} Advances in treatment have improved survival rates for pediatric patients with cancer, with pediatric cancer now considered a chronic disease that requires long-term observation and management of complications.³ Treatment involving anticancer drugs and irradiation can impair cognitive function⁴ and may affect social competence because of emotional and behavioral difficulties.⁵ Furthermore, increased school absences due to hospitalization and treatment, as well as activity restrictions, reduce interaction and communication

between ACCSs and their peers.^{6,7} Such circumstances may adversely affect the communication skills of ACCSs.^{8–12}

The literature focusing on adolescents and young adults highlights several motivations for cancer-related communication (cancer communication). These include fostering understanding and acceptance of changes in appearance and behavior following diagnosis^{13–16} and recognizing the significance of their cancer experience in the context of their lives.^{13,16} Cancer communication can facilitate social support acquisition and promote adaptation to cancer.^{12,17} In contrast, peer reactions and ACCSs' underdeveloped communication skills may pose risks, leading to discomfort and a sense of vulnerability among them.^{12,15,18} For instance, although adolescent and young adult cancer survivors may wish for their cancer experiences to be understood, they may limit the

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disclosure of information due to a simultaneous desire to be treated as typical young individuals.^{13,19} Such limitations in information sharing can hinder friends' understanding. This conflicting perception among ACCSs further complicates and challenges the process of cancer communication. However, many studies have targeted a broad young population, with only a limited number particularly focusing on survivors in early- to mid-adolescence (ages 11–15 years). Consequently, cancer communication during adolescence remains poorly understood. To develop interventions that ensure cancer communication yields beneficial outcomes, gaining a deeper understanding of how ACCSs perceive their cancer experiences and cope with cancer communication is essential. Communication during adolescence contributes to building friendships and peer relationships and plays a crucial role in identity formation.^{20,21} Adolescents' knowledge regarding childhood cancer is limited and superficial,²² making it challenging for their peers to understand the changes that ACCSs experience following a cancer diagnosis. School reentry programs aimed at facilitating the adaptation of childhood cancer survivors to school life have been shown to improve classmates' knowledge regarding cancer and their attitudes toward survivors.²³ However, not all ACCSs receive satisfactory support from reentry programs, schools, or medical institutions.^{2,24–26}

Previous studies have sought to understand communication factors associated with personal (e.g., motivation and perception) and interpersonal (e.g., reactions of others) aspects based on the experiences of ACCSs.^{12,18} However, communication about cancer is likely influenced by multiple levels of social factors, such as the context of the place, culture, and climate of the organization or region. However, only a few studies have investigated their overall impact. The socioecological model (SEM) is a framework that describes the multiple contexts and interactions of individual health and behavior with society and the environment. McLeroy's SEM model we have adopted comprises five levels: intrapersonal, interpersonal, institutional, community, and policy.²⁷ Each level interacts with individual factors and other levels, influencing ACCSs' cognition, behavior, and emotions, and is associated with communication about their cancer experiences. By identifying the determinants of cancer communication at each level, we can pinpoint areas for intervention and develop effective programs to improve communication. This study aimed (1) to investigate the communication patterns of ACCSs, including their motivations, methods, context, and outcomes, and (2) to identify the determinants influencing their cancer communication at each level of the SEM. In this study, the term “communication patterns” is broadly defined as encompassing the motivations, methods, context, and outcomes of communication.

Methods

Design

A descriptive qualitative research design was adopted to explore the experiences of ACCSs in communicating about cancer and the factors influencing this communication. This methodology enables the explanation of phenomena that are difficult to quantify.²⁸ This study was conducted according to the Qualitative Research Guidelines.²⁹

Participants

The study participants were recruited from pediatric cancer follow-up outpatients at Nagasaki University Hospital in Japan. The inclusion criteria were as follows: (1) hospitalized and treated for childhood cancer, (2) informed of diagnosis, (3) returned to regular school from elementary school to high school, and (4) aged between 10 (fifth grade elementary school) and 25 years at the time of the interview. The exclusion criteria were as follows: (1) patients who experienced a relapse at the time of the interview and (2) those with intellectual disabilities. Patients and their families who met the participation criteria, as assessed by the outpatient physician (YH), were referred to NH as potential

participants. NH explained the study details to potential participants and obtained verbal and written consent. The appropriate sample size was determined based on data saturation.³⁰ If a participant requested the presence of a parent or guardian during the interview, it was conducted accordingly.

Data collection

A researcher experienced in conducting semi-structured interviews (NH) conducted interviews with each participant between August 2019 and August 2021. The data collection period was extended because of the COVID-19 pandemic, which often limited the author's (NH) contact with potential study participants. To ensure the quality of the interviews, a pediatric nurse with extensive experience (YM) participated in the interviews with two participants to prevent over-collection and under-collection of data. The interviews were conducted using an interview guide based on an SEM, which included questions relevant to each level of the model: (1) individual level (participant demographics and medical history), (2) interpersonal level (postdiagnosis contact and interaction with friends and communication about cancer), (3) organizational level (postdiagnosis contact and interaction with educational institutions), and (4) community level (interaction with local sports clubs and other stakeholders after diagnosis) (Table 1). Interviews at the policy level were not conducted due to the adolescent demographic of the study subjects, which presupposed limited knowledge and interest in policy matters. NH had no prior professional relationship with any of the participants. Each interview lasted between 17- and 50-min. Interviews were scheduled on a date, time, and location requested by the ACCSs and their parents. All participants preferred to conduct the interviews during follow-up outpatient visits. They were then held in a quiet, private room within the hospital. During the interviews, the parents present assisted the ACCSs in answering the questions and provided additional information if the ACCSs had difficulty recalling specific details. With the participants' consent, the interviews were recorded using a recorder. To gain deeper insights into the participants' experiences, the interviews incorporated follow-up prompts, such as “Can you tell me more about that?” as necessary. After each interview, a brief summary of the interview content was provided to the participants to confirm its accuracy. The interview data were analyzed in parallel with data collection, and

Table 1
Interview guide structure using the socioecological approach.

Levels of SEM	Interview questions
Intrapersonal	<ul style="list-style-type: none">• Age, grade and occupation of participants• Age of participants at return to school• Participant's current treatment• Name of participant's disease• Willingness to disclose cancer
Interpersonal	<ul style="list-style-type: none">• Have you informed your school teachers, peers or close friends about your illness? If so, could you please share with us whom you spoke to and what their responses were?• What are some of the positive and happy experiences you've had when talking about your illness with others?• Can you tell us about any difficulties or problems you have experienced when talking about your illness with others?• During your hospitalization, did you stay in touch with friends? If so, who did you contact, how did you contact them, and what did you talk about?• Do you discuss your illness with your family? If so, what motivates these discussions and what do you usually talk about?
Institutional	<ul style="list-style-type: none">• Did you contact a teacher at your school about your illness? If so, who did you contact and what was the nature of your conversation?• Was your illness explained to your peers by a teacher at school? If so, what was the nature of the explanation?
Community	<ul style="list-style-type: none">• Did you contact anyone in the community about your illness? If so, who did you contact and what was the nature of your conversation?

SEM, socioecological model.

data saturation was achieved when no new themes emerged. The data collection process is illustrated in Fig. 1.

Data analysis

The verbatim transcripts of the interviews conducted by YM and NH were obtained from the audio recordings. To mitigate transcription bias, the recorded audio and transcribed data were cross-checked and meticulously reviewed. Thematic analysis (TA) was performed following the approach by Braun and Clarke.³¹ Analysis was performed using the six-phase TA framework: familiarization with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and writing up the report. TA is flexible and does not require adherence to a particular philosophical stance.^{31,32} Familiarization with the data started with multiple readings of the transcripts to ensure a comprehensive understanding of the content and to identify emerging themes. NH then entered the data into qualitative data analysis software (MAXQDA Plus2022). Next, the key ideas and experiences expressed by the participants were coded according to the analytical focus. The codes were then examined and grouped based on shared similarities, leading to the development of themes and subthemes. To ensure rigor, two researchers independently performed the process, from thorough reading to the generation of themes and subthemes. Furthermore, the generated themes and subthemes were analyzed using a social-ecological approach across four levels (i.e., intrapersonal, interpersonal, institutional, and community) in a deductive manner. The hybrid approach, which incorporates theory, is described as reducing interpretive bias by the analyst.³² The interview notes provided contextual information for the data and enhanced interpretation. Furthermore, the themes and subthemes generated were categorized into four levels of the socioecological approach²⁷ intrapersonal, interpersonal, institutional, and community. Discrepancies in coding were resolved through discussions within the research team.

Ethical considerations

This study was approved by the Ethics Committee of Nagasaki University Hospital (IRB No. 19081921-4). Before the interviews, ACCSs and their parents were informed, using age-appropriate explanatory forms, about the purpose and content of the study and interview. They were

assured that the participants' identities would remain confidential and be used solely for scientific purposes and that participation was voluntary. Verbal consent was obtained from participants aged < 16 years, whereas written consent was obtained from those aged ≥ 16 years. For participants aged < 20 years, written consent was obtained from the participants' parents before the interview.

Results

This study enrolled 22 participants (Table 2), among whom nine (aged 11–20 years) had a parent or guardian present. All invited participants agreed to participate. Of the nine participants whose parents or

Table 2
Participant demographics (N = 22).

Characteristics	n (%)	Mean ± standard deviation (range)
Female	11 (50.0)	
Age at the time of interview in years		14.59 ± 2.98 (11–22)
Age groups		
Early adolescence (11–13 years)	8 (36.4)	
Mid-adolescence (14–17 years)	10 (45.5)	
Late adolescence (18–22 years)	4 (18.2)	
Age at the time of school reentry in years		10.45 ± 2.90 (6–16)
Age at the time of diagnosis in years		9.05 ± 3.11 (5–15)
Period of hospitalization (months)		8.15 ± 4.49 (40 d–16 m) ^b
Cancer diagnosis		
Leukemia	10 (45.5)	
Central nervous system tumor	7 (31.8)	
Lymphoma	1 (4.5)	
Ewing sarcoma	1 (4.5)	
Other	3 (13.6)	
Maintenance treatment at time of the interview		
Yes	3 (13.6)	
No	19 (86.4)	
Treatment		
Surgery	7 (31.8)	
Chemotherapy	22 (100.0)	
Radiation therapy	6 (27.3)	
Bone marrow transplant	3 (13.6)	
Parent's present during the interview	9 (40.9)	

^b d, days; m, months.

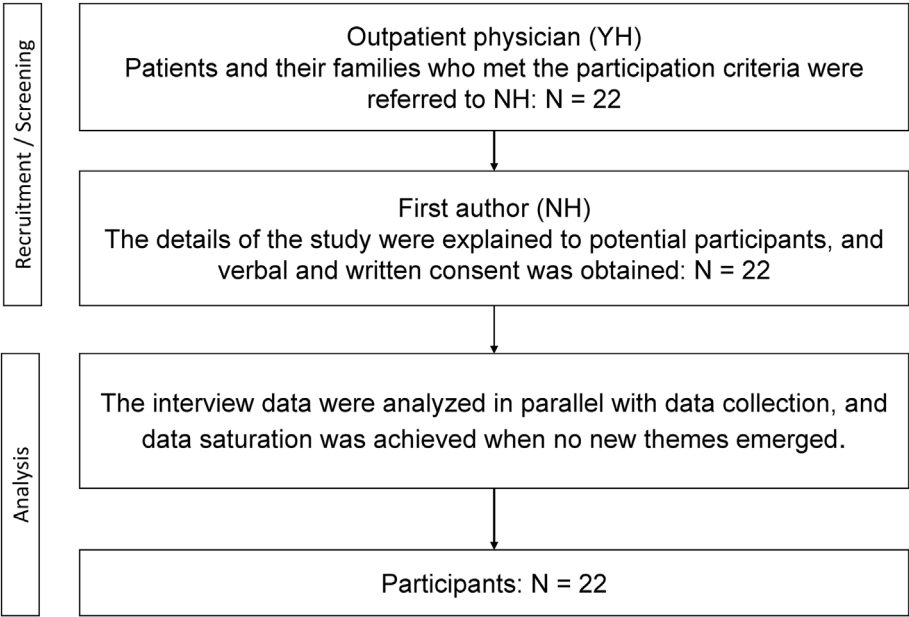


Fig. 1. Participant flowchart.

guardians were present, seven were with their mothers, one was with their father, and one was with both parents (receiving outpatient treatment). The themes related to communication about cancer were as follows: three at the intrapersonal level, three at the interpersonal level, two at the institutional level, and one at the community level. The communication patterns of ACCSs were identified through intrapersonal and interpersonal analysis. This study suggests that cancer communication among adolescents is influenced by psychosocial developmental factors as well as structural and contextual factors at the institutional and community levels. Fig. 2 presents a conceptual framework of cancer-related communication in adolescents, situated within the SEM.²⁷

Intrapersonal level

Factors associated with communication about cancer at the intrapersonal level comprised three themes: a) securing of social support, b) perceptions related to cancer communication (desire to be “normal,” altruistic perceptions, time since diagnosis, and future disclosure of cancer), and c) communication skills. The communication patterns comprised motivations, methods, and outcomes. Motivations for cancer communication included seeking social support and an altruistic perspective, and methods involved face-to-face interactions or social networking services. ACCSs actively seeking social support often received greater physical and emotional support in school.

ACCSs with persistent disabilities described various strategies for obtaining social support. Some ACCSs with residual disabilities were inclined to articulate their situations to peers to garner social support, whereas others chose not to actively engage in discussions about their cancer experience but instead sought spontaneous assistance from friends when required. Furthermore, older ACCSs sustained contact with their peers during school absences through social networking sites, in which they discussed school-related events and their personal circumstances.

I would explain my medical condition and situation first so they would understand to some extent. I sent pictures on line, pictures of my hair falling out, to my good friends, and from the beginning, I told them myself so that they would accept me when I went to school (participants in mid-adolescence).

When asked about the illness, I usually give a rough explanation like “this happened, so that’s why this is happening. I’ve had this conversation several times. When there’s something I need help with, I

immediately ask my friends or teachers for assistance” (participants in mid-adolescence).

Some ACCSs in mid-adolescence and beyond have reported that upon sharing their cancer experiences with close friends, they felt grateful both for their friends’ expressions of concern and for being treated as normal individuals.

Sometimes I bump into people coming from in front of me, but they totally understand that. And the kids in the club also understand, so they are considerate and help me out in various ways (participants in mid-adolescence).

Perceptions and thoughts regarding cancer communication significantly influenced their decision to disclose and the extent and depth of their disclosures. Some ACCSs limited the information they shared about their cancer experience because they feared being treated differently by their peers.

“I miss my physical education classes, why do you always miss them?” I was asked. I don’t talk much about specifics “Well, circumstances have come up ...” Yes (participants in mid-adolescence).

In contrast, ACCSs who, after fighting the disease, developed an altruistic belief in wanting to help others with the same experience and actively shared their cancer journey with their peers, expressing a desire for a better understanding of individuals facing similar challenges. For this purpose, the ACCSs carefully responded to their colleagues’ questions.

Let’s see, if I say I went to the hospital, they ask me what hospital, what did I do, what was the disease, when did it start, and I say, wait a minute, I’ll tell you one thing at a time, and I answer all the questions they ask me. I want them to know and help the sick persons, something like that (participants in mid-adolescence).

Several ACCSs stated that they did not think about or discuss their cancer experiences. ACCSs who had the disease in early childhood, several years after treatment ceased, and were leading normal lives with no restrictions were less likely to focus on their cancer experiences and did not feel the need to talk about it.

No, now, we don’t (talk about cancer) anymore. In high school most of my friends don’t know (about cancer), and even in secondary school the only ones who know are friends from the same primary

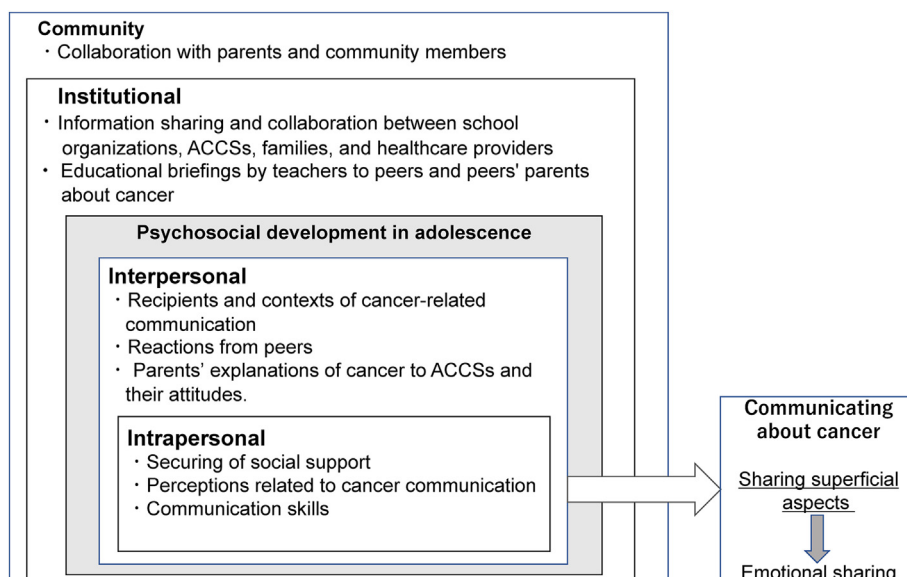


Fig. 2. Conceptual model of ACCSs' communication about cancer using the SEM. ACCSs, adolescent childhood cancer survivors; SEM, socioecological model.

school and not from other primary school (participants in mid-adolescence).

Regarding future disclosure of their cancer experiences, some ACCSs said that they would not discuss it, whereas most expressed willingness to talk about it if asked or if someone else had similar experiences, highlighting the possibility of disclosure.

From the middle of adolescence onward, when the ACCSs were asked by a friend about their diagnosis and treatment, they often provided logical and easy-to-understand information. However, the knowledge about cancer and communication skills that ACCSs possessed in early adolescence were insufficient to help their peers fully understand their situation. One ACCS was confused by the excessive support their peers gave him when their fitness improved, and they could do more things on his own. The ACCS sought advice on how to communicate with his peers to explain his situation without hurting them.

It's hard to say, "I can do this myself," so I wondered what I should do in such cases (participant in early adolescence).

Interpersonal level

The factors that influenced cancer-related communication at the interpersonal level encompassed three themes: (a) recipients and contexts of cancer-related communication, (b) reactions from peers, and, (c) parents' explanations of cancer to ACCSs and their attitudes. The communication patterns included the person and context to whom ACCS speaks.

ACCSs shared cancer-related information primarily with close friends and parents. Two-thirds of the ACCSs conveyed their illness experiences to close friends. They shared their daily lives at the hospital in the natural flow of conversations with their peers, sometimes incorporating humor. The cancer experiences of ACCSs were naturally shared in conversations among close friends, focusing on the everyday realities of hospital life rather than emotional expression. In the mid-adolescent period and beyond, when asked about their diagnosis or treatment by friends, ACCSs often conveyed information logically and comprehensibly. ACCSs expressed gratitude for their friends' concern and support. However, after communicating with friends about cancer-related experiences, ACCSs in the early- to mid-adolescent period reported that such communication did not affect their friendships or lead to any significant psychological changes.

I talked to two close friends. I told them about the surgery, going to the hospital school for a bit, and playing games" (participants in mid-adolescence who returned to school in early adolescence).

Hmm, there wasn't really any change afterward. I didn't really think much about the illness experience (three participants in mid-adolescence).

In contrast, one ACCS who returned to high school explained their diagnosis and treatment when asked about their illness by peers; however, they expressed discomfort with their peers' reactions.

They said things like, "That must have been tough," but it was like, "But you wouldn't know that from you guys (participant in late adolescence).

ACCSs without physical limitations rarely initiated conversations with their peers about cancer. However, changes in their appearance or behavior often sparked their peers' curiosity and questions, prompting them to share their cancer experiences when asked. Absences for hospital visits often provided opportunities for discussion regarding their cancer experiences. However, when teachers had explained the needs and considerations of ACCSs to classmates in advance, the participants were less likely to be asked about their illness or changes in their appearance by their peers.

Regarding wearing a wig, I think it was good that my classmates didn't ask me anything. They might have known, but no one said anything to me (participants in mid-adolescence).

Some participants experienced bullying or teasing related to hair loss or physical disabilities. ACCSs who experienced teasing or bullying sought support from close friends and resolved the issues with their friends' support. After treatment for a brain tumor, one ACCS, who experienced narrowing of the visual field and depressive tendencies, felt inconvenienced in school life as time passed since returning to school but was unable to communicate this to her peers.

Teachers cooperate with me, but my friends, not so much, I don't know if they do (participant in early adolescence).

ACCSs discussed their frustrations with restrictions on their lives because of illness, concerns about cancer, and their desire to know more about cancer with their parents. Sometimes their parents would listen to them, but other times they were overly sensitive.

During an outpatient visit ... we talked (with my mother) about what would happen in the future ... yes (participants in mid-adolescence).

Around junior high school, on the contrary, I became curious about what my illness looked like. I didn't care when I was in primary school (participants in mid-adolescence).

The perceptions of parents toward treatment and their explanations of cancer to ACCSs may influence the communication of cancer by ACCSs. For instance, one parent appeared to have clearly and understandably communicated the necessity of cancer diagnosis and treatment to an ACCS shortly after diagnosis, typically during their early elementary school years, and supported the ACCS with a positive attitude toward treatment. The ACCS of this parent developed an altruistic perception following their cancer experience and actively shared their cancer experience with peers. Conversely, ACCSs and their parents who chose not to discuss their cancer experiences with others perceived their hospital experiences as negative.

You have to take a lot of medicine, you might throw up a lot, you have to have a lot of blood taken. But you have to in order to get better. When I said that, she said, "All right" (mothers of mid-adolescence).

"I only have bad experiences" (mothers of mid-adolescence).

"I don't want to remember" (participants in mid-adolescence).

Institutional level

Relevant factors for communication about cancer in ACCSs at the institutional level included a) information sharing and collaboration between school organizations, ACCSs, families, and health care providers, and b) educational briefings by teachers to peers and their parents about cancer.

Since the time of cancer diagnosis, parents and returning school-teachers have maintained regular communication, with information regarding the reasons for ACCSs' school absences and considerations for their return to school being predominantly conveyed from teachers to their peers within the school. Before the discharge of ACCSs, meetings were held involving parents, schoolteachers, education committees, and attending physicians. The primary focus of these meetings was on the considerations of ACCSs in various aspects of school life. Information about the illness of ACCSs to be communicated to school peers was discussed among ACCSs, family members, and faculty to determine the content and scope of communication. For example, in some cases, the principal informed all students, whereas, in other cases, homeroom teachers informed their classmates, occasionally informing peers' parents. In many cases, the name of the disease, cancer, is not communicated. However, to discourage ill guesses, the strategy of daring to tell the

name of the disease to peers was sometimes employed. In contrast, some ACCSs who developed the disease in middle school voluntarily decided not to communicate the disease name to their peers. After returning to school, most ACCSs received compassionate support from their peers and teachers. However, prereturn discussions between parents and teachers of ACCSs who experienced teasing and bullying failed to address explanations of the illness to their peers.

The teachers were worried because if they didn't tell the students why, the students would be even more concerned. So, the principal explained in simple terms to all students in front of the whole school that the children would be absent from school because they were receiving hospital treatment, and that they needed to be a little careful, for example, not to run in the hallway or bump into things, explained within the children's understanding range (mother of a participant in early adolescence, participants who returned to school at age 8).

One participant who had returned to junior high school was confused because their homeroom teacher had not communicated any information about their return to school to other teachers or classmates. ACCSs emphasized the importance of information dissemination regarding their return to school to school staff and peers from their assigned teachers.

(The day I returned to school) they were surprised, and they were like, oh, it's been a long time, so I thought they knew (that I was returning to school), everyone knew. So I thought, huh, Why didn't the teacher tell them about me? If you tell everyone in advance, everyone will know when I return, so you won't have to explain to them, and yes, it will be easier to return (participants in mid-adolescence).

After returning to school, communication between the school and parents regarding ACCSs' situation occurred when necessary. When homeroom teachers were changed due to promotion, some ACCSs and their parents repeated the explanations each time. Peers and school-teachers had forgotten about ACCSs' invisible disabilities (e.g., narrowing of vision and persistent physical weakness) due to the passage of time since their return to school. Therefore, ACCSs were forced to live without consideration at school and experienced psychological distress.

This child seems to be the only one paying attention. Everyone else has already forgotten, so they almost bump into them (mother of participant in early adolescence).

Community level

Factors related to the communication of the cancer experiences of ACCSs at the community level included collaboration with parents and community members. In particular, the parents of the ACCSs shared information about their children not only with school teachers but also with the parents of their children's friends and those involved in sports teams and parent-teacher associations to gain their understanding and cooperation. When the ACCSs were temporarily discharged from the hospital, efforts were made to arrange opportunities for them to meet their friends.

When they were in elementary school, they played softball, and their best friend in class also played on the same team. We made sure to communicate with the mothers of the other children on the team about these matters, so I think the parents likely informed their children, which meant that my child was probably never directly asked about the illness (mother of participant in early adolescence).

Discussion

Socioecological approach helped us identify the multilevel factors influencing communication about cancer experiences in this age group.

To the best of our knowledge, this is the first report to use the SEM method to examine factors associated with cancer communication regarding ACCS experiences. The results of this study indicate that ACCSs' communication with friends involves sharing cancer information across multiple levels, including parents, teachers, school organizations, and community members, with these levels being interrelated in a complex and reciprocal manner. Furthermore, the study indicates that ACCS communication patterns evolve from superficial aspects sharing in early adolescence to seeking deeper emotional connections in late adolescence, as depicted in Fig. 3. This finding provides further evidence for research on communication involving ACCSs.

Communication among adolescent and young adult (AYA) cancer survivors is often initiated by the motivation to seek understanding and acceptance from others.^{13–15} In this study, ACCSs with physical limitations engaged in cancer communication driven by the motivation to gain social support. In contrast, ACCSs in early to mid-adolescence without physical limitations tended to share only superficial aspects about their experiences. In early adolescence, interactions with friends involve spending a significant amount of time in conversation, with a tendency to prefer superficial sharing of personal information.^{33–35} This tendency has been suggested to be possibly related to the increased risk of embarrassment or rejection during early adolescence.^{36,37} Therefore, sharing superficial aspects about their cancer experiences with close friends can be considered a unique form of self-disclosure characteristic of early adolescence and may contribute to the developmental task of forming intimate relationships during adolescence.^{38,39} In contrast, some ACCSs who returned to high school expressed dissatisfaction with the reactions of their friends after communicating their cancer experiences. Adolescents, as they undergo psychological maturity, desire to share emotions with close friends.⁴⁰ This tendency is exemplified by a study by Larsen et al.,¹⁷ which found that ACCSs felt a sense of satisfaction when their friends, after hearing about their cancer experiences, responded with admiration or were deeply moved. This suggests a shift in the purpose of ACCSs' self-disclosure from sharing superficial aspects to sharing emotions as they transition from early to late adolescence in their psychosocial development. Understanding the changes in the rapid psychological development process during adolescence can contribute to the development of communication intervention programs tailored to ACCSs' cancer-related developmental processes.

Enhancing the understanding and effective information-sharing of ACCS' cancer experiences at each SEM level is crucial for alleviating prejudice against ACCS, improving communication, and fostering a supportive environment.⁴¹ Consistent with studies reporting challenges in communication between adolescent childhood cancer survivors and their healthy peers,¹⁸ our findings indicate the necessity of providing age-appropriate cancer education for ACCSs and support for their communication skills at the intrapersonal level. At the interpersonal level, interventions promoting peer understanding of ACCSs and online interactions during school absences contributed to fostering positive peer engagement and responses. These findings support previous research and indicate the need for continued interventions as effective approaches for peers.^{23,42,43} Moreover, by providing appropriate information about ACCSs' cancer experiences at the institutional and community levels, educators and community members can enhance their understanding of cancer and support the promotion of peer awareness regarding illness.^{3,23} In this study, there were opportunities for sharing cancer-related information with peers' parents, which is rarely observed in previous research. Moreover, sharing information with peers' parents may provide an opportunity for this information to be discussed within the family. Collaboration among parents, teachers, and health care professionals is crucial to address educational challenges faced by ACCS.^{4,44} When cancer information was not adequately conveyed to schoolmates, ACCSs experienced bullying or teasing. Therefore, this study emphasizes that appropriately sharing information with peers to foster an understanding of ACCSs' cancer experiences is a crucial factor for the prevention of bullying or teasing after their return to school.

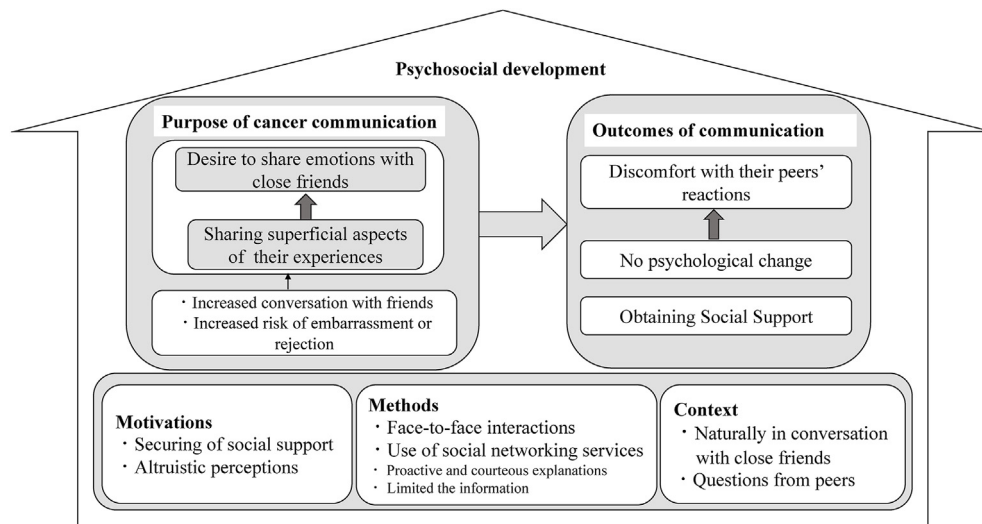


Fig. 3. Cancer communication patterns of adolescent childhood cancer survivors.

Consistent with studies on self-disclosure among AYA cancer survivors' and school reintegration among of school-aged childhood cancer survivors, changes in an individual's appearance or behavior after being diagnosed with cancer were frequently reported as motivating factors influencing the initiation of cancer-related communication between the individual and their peers.^{45,46} However, attention toward ACCSs tends to diminish over time,¹² leading to a corresponding decline in consideration for ACCSs.^{2,25} For survivors of childhood cancer, long-term physical disabilities and the potential development of late-onset complications necessitate ongoing collaboration and support from relevant organizations to help them cope and socialize.²⁵

Communication between ACCSs and their parents may significantly influence ACCSs' perception of cancer and their ability to communicate with others about cancer.⁴⁷ Families are suggested to play a significant role as the primary emotional support for cancer survivors, and the study participants also appeared to engage in emotional self-regulation by disclosing their feelings and concerns about cancer to their parents.^{48–50} However, for parents experiencing psychological distress due to their child's cancer diagnosis,^{51–53} communicating with the ACCS about cancer can be a challenging task.^{16,45} If obstacles in communication with parents are present, ACCSs may experience an increase in psychological issues, such as anxiety and depression,^{54,55} and their knowledge of cancer may become limited, which could affect their communication with others. Another study suggested that accurate understanding of cancer among childhood cancer survivors may lead to appropriate coping strategies.^{47,56,57} Therefore, to improve communication between parents and ACCSs regarding their cancer experiences, strengthening psychological support for parents and providing tools and guidelines for communication are necessary.⁵⁸ Although the development of these guidelines has been ongoing, there are few studies on their evaluation.

Most participants indicated the possibility of discussing future information about cancer with others. Rabin¹⁹ noted that the experience of cancer disclosure may influence the perception of future disclosures. This may be associated with the fact that only a few participants had negative experiences regarding communication about cancer in this study. The onset of late complications from childhood cancer may create a need for ACCSs to discuss their cancer experiences in society in the future. Positive communication experiences during childhood may contribute to ACCSs' ability to create a supportive social environment through cancer communication.

Future directions

Further research is recommended to establish programs to support communication about cancer between ACCSs and their peers and

between ACCSs and their parents and to enable long-term collaboration between parents, school organizations, and health care providers.

Strengths and limitations

Data were collected from a single medical institution in Japan, with each participant undergoing only one interview. In Japan, cancer treatment and care systems are well established on a nationwide scale, ensuring that patients can receive treatment with confidence. The cure rate of pediatric cancer is > 80%,⁵⁹ showing no significant difference compared with Western countries. However, to obtain richer and more comprehensive data, research involving multiple institutions across broader geographic regions is necessary. ACCSs and their families often experience psychological distress,^{60,61} necessitating careful selection of wording during interviews to avoid psychological intrusion. Conducting multiple interviews can help strengthen the researcher–participant trust, potentially enabling a deeper understanding of the experiences. In cases in which a parent participated in the interview, the participants' responses may have been limited because of their deference to their parent. Furthermore, interviews during the free time of follow-up outpatient visits were sometimes limited by tests and other factors. These factors may have affected the results. Considering the qualitative research design, the results cannot be generalized. However, by recruiting survivors from diverse cancer types, we were able to capture a broad spectrum of ACCS experiences, along with the context and motivations underlying their cancer-related discussions.

Conclusions

Communication about cancer between ACCSs and their peers was associated with self-disclosure to form close relationships as part of psychosocial development, and the purpose of communication varied according to the course of psychological development. Some ACCSs experienced difficulties in communication with their peers and families. This study highlights the necessity of a multilevel approach that involves ACCS individuals, parents, educators, school peers, and communities to enhance communication about cancer within this population.

CRedit authorship contribution statement

Naoko Honda: Conceptualization, Methodology, Validation, Software, Investigation, Formal Analysis, Funding Acquisition, Writing – Original Draft, Review and Editing. **Yasutomo Funakoshi:** Methodology, Validation, Investigation, Review and Editing. **Yuki Matuishi:**

Validation, Investigation, Formal Analysis, Review and Editing. **Kanako Morifuji**: Methodology, Formal Analysis, Review and Editing. **Kazuteru Tanabe**: Writing – Original Draft, Review and Editing, Supervision. All authors have read and approved the final manuscript. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Ethics statement

The study was approved by the Institutional Review Board of Nagasaki University Hospital (IRB No.19081921-4) and was conducted in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. All participants provided written informed consent.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author, NH. The data are not publicly available due to privacy and ethical restrictions.

Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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Declaration of competing interest

The authors declare no conflicts of interest.

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