

# The Role of the Certified Child Life Specialist with Adolescent and Young Adult Patients in Japanese Hospitals

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## ABSTRACT

A child life specialist is the health care professional dedicated to providing psychosocial interventions for adolescent and young adult (AYA) patients. The purpose of this exploratory study was to understand the role of the child life specialist in providing psychosocial interventions for AYA patients in Japanese hospitals. Participants ( $n = 5$ ) consisted of Japanese child life specialists who were clinically trained in North America and work in Japan. Participants completed a 30-minute online survey created specifically for this study. Child life specialists most frequently reported providing developmentally appropriate play, emotional support, and family/sibling support for AYA patients in Japan. Child life specialists encountered several challenges to providing interventions for AYA patients in Japan, including the promotion of emotional expression, lack of developmentally appropriate resources, and low child life prioritization due to the limited number of child life specialists in Japan. Future research is needed to understand the full scope of psychosocial interventions provided for AYA patients in Japan by child life specialists.

*Keywords:* child life specialist, Japan, adolescent, young adult, psychosocial intervention

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It is well known that adolescent and young adult (AYA) patients need psychosocial support in the hospital due to their unique developmental level (Carter, 2014; Gusella et al., 1998; Kirchenbauer, 2013). In a growing number of countries, a Certified Child Life Specialist is the health care professional dedicated to providing psychosocial interventions and support to youth (Association of Child Life Professionals [ACLP], 2018c). Several studies have explored the psychosocial interventions provided by child life specialists for the AYA patient population in the hospital setting in the United States (e.g., Carter, 2014, and Kirchenbauer, 2013); however, there is a dearth of research on the psychosocial interventions provided for the AYA patient population in countries outside of the United States, specifically Japan (Carter, 2014; Hagiwara, 2015; Ishizuka, 2017; Nishimoto, 2012).

Due to cultural differences, psychosocial interventions for the AYA patient population may vary based on the country of origin. As part of their core values, the child life specialist must consider the cultural upbringing of the patients and families to whom they provide psychosocial interventions (ACLP, 2018c). Therefore, the purpose of this exploratory study was to better understand the role of child life specialists in providing psychosocial interventions for AYA patients in Japanese hospitals. First, the history and professional role of the child life specialist will be discussed, followed by the characteristics of pediatric hospitalization in Japan. Next, typical psychosocial development for adolescents and young adults will be covered. Then, psychosocial interventions provided by child life specialists for AYA patients in North America and Japan will be reviewed before discussing the current study.

## History and Professional Role of the Child Life Specialist

The underpinnings of the child life profession began in the 1920s when several pediatric hospitals in the United States created play programs for children (Turner & Grissim, 2014). In 1955, Emma Plank, who was a leading authority on the psychosocial care of children in hospitals, created an educational support program for children in the Cleveland City Hospital, which led to the development of the child life profession (ACLP, 2018a; Rubin, 2014). The Child Life Council was formed in the United States in 1982 and was later renamed the Association of Child Life Professionals (ACLP, 2018a). Currently, there are 5,908 Certified Child Life Specialists in the United States, 337 in Canada, 54 in Japan, and 69 in various countries throughout the world (Child Life Certification Commission, electronic communication, May 1, 2019). In fact, the American Academy of Pediatrics Committee on Hospital Care and Child Life Council (2014) published a policy statement in which child life specialists are considered the standard of care in pediatric hospitals.

In Japan, the child life profession has developed as an allied health profession. In 1999, the first Certified Child Life Specialist started to work in a Japanese hospital (Japanese Association of Certified Child Life Specialists [JACCLS], 2018). By 2000, the JACCLS was established in relationship with the ACLP in the United States (ACLP, 2018b; JACCLS, 2018). Currently, there are 42 Japanese Certified Child Life Specialists registered with JACCLS and working in 31 hospitals in Japan (JACCLS, 2018).

A child life specialist is an expert in supporting children and their families during challenging experiences related to illness, injury, trauma, and hospitalization (Gaynard et al., 1998). A child life specialist provides psychosocial interventions to reduce fear and anxiety for children and their family members in health care settings; these interventions include emotional support, coping techniques, preparation for health care procedures, developmentally appropriate and therapeutic play, bereavement care, sibling and family support, and developmentally appropriate diagnosis education (Gaynard et al., 1998). The child life specialist role is to help improve the socioemotional experiences of children, adolescents, young adults, and their families in the medical environment (ACLP, 2018c).

## Characteristics of Pediatric Hospitalization in Japan

The Japanese culture consists of a high-context communication style, defined as a communication style in which the nonverbal behavior is richer than what is expressed verbally (Hall, 1989). Japanese culture is modest, in that people do not show negative facial expressions directly (Nishimura et al., 2008). During conversations, Japanese people understand experiences, common sense, and values without hearing about them (Hall, 1989). In addition, Japanese people demonstrate a cultural sympathy, where they perceive an individual's feelings inseparably from others because of their modest culture (Nishimura et al., 2008). Thus, Japanese people prefer the use of euphemism and indirect expression rather than direct expression (Hall, 1989).

Partially due to Japanese culture, pediatric hospitalizations in Japan differ from pediatric hospitalizations in the United States in several ways: In Japan, there is limited visitation from siblings and peers, serious diagnoses are revealed only to parents or caregivers, parental/familial participation during medical procedures is restricted, and the length of hospitalization is typically longer (Hagiwara, 2015). In addition, it is less common for patients and families in Japan to regularly interact with child life specialists in the hospital because of the low number of child life specialists in each hospital and the high number of pediatric patients, compared to the United States (JACCLS, 2018).

Japanese child life specialists have reported strict sibling visitation in Japanese hospitals compared with North American hospitals due to infection control practices and individual physician authority (Nishimoto, 2012). For example, even healthy siblings who are under age 13 are not typically allowed to visit the patient because they have not completed their pediatric vaccinations (Nishimoto, 2012). However, if the patient is at end of life, individual physicians may allow sibling visitation after determining the sibling(s) do not have symptoms of infection, such as fever, coughing, or vomiting (Nishimoto, 2012). In addition, some neonatal and pediatric intensive care units regularly allow sibling visitation (Nishimoto, 2012).

Telling the truth to children is a controversial issue in Japan. Parsons et al. (2007) found that 96% of physicians in the United States reported "always" or "most of the time" telling a child about their cancer diagnosis, while only 38% of Japanese physicians reported

doing the same. Furthermore, Japanese pediatricians have been reported to pessimistically evaluate the effect of truth telling and try to protect children from emotional distress by not telling them the truth about a diagnosis (Hagiwara, 2015; Miyawaki, 2016). Both of these studies indicate a limitation in understanding the impact of disclosing a diagnosis to pediatric patients.

There has been a lack of parental participation during medical procedures in Japanese hospitals (Hagiwara, 2015). Each hospital, physician, and nurse may have a different opinion about parental involvement in procedures. Hagiwara (2015) has discussed the importance for child life specialists to advocate for parental involvement during medical procedures in Japan. Increasingly, parental involvement is acceptable in the U.S. pediatric hospital settings (Boles, 2016).

Japanese pediatric hospitalizations tend to last longer than pediatric hospitalizations in the United States, specifically for patients with leukemia (Hagiwara, 2015). In Japan, children with leukemia typically need inpatient hospitalization for a few years (Hagiwara, 2015), whereas children in North America mostly receive their treatment in outpatient oncology clinics (Johnston et al., 2017).

Psychosocial interventions by child life specialists in Japan are slowly expanding (JACCLS, 2018); however, child life specialists are still not common in pediatric hospitals in Japan for two reasons: administrative budgeting for the cost of child life specialists and medical professionals' questioning of the need for the child life role (Hagiwara, 2015). Child life services are not eligible for medical service fees, which require hospitals to create room for child life specialists in their budget (Hagiwara, 2015; Kitagawa, 2009). In addition, culturally, it is less common to donate money to hospitals in Japan compared with the donations received by pediatric hospitals in the United States (Adachi, 2010; Hagiwara, 2015). For example, some hospitals in the United States have full-time child life specialist positions sustained solely by donations or private funding (e.g., MemorialCare Miller Children's and Women's Hospital Long Beach, 2012). In Japan, there are fewer monetary donations to pediatric hospitals, so child life positions, among other resources needed for children in the hospital, are not supported by donations.

Another reason child life specialists are not common in Japan is due to medical professionals' questioning

of the need for the child life role. As part of their education, Japanese pediatric nurses receive training to provide psychosocial interventions for pediatric patients and their families, especially diagnostic education and psychological preparation, more so than pediatric nurses in the United States (Hagiwara, 2015; Matsudaira, 2010), where child life specialists provide most psychosocial interventions for pediatric patients and their families (ACLP, 2018c). Therefore, Japanese child life specialists have to redefine their professional role in collaboration with Japanese pediatric nurses because both Japanese pediatric nurses and Japanese child life specialists provide psychosocial interventions for patients and families. For example, if a pediatric primary nurse were to provide diagnostic education and psychological preparation for a patient's procedure, the child life specialist would focus on providing therapeutic play or developmentally appropriate diversion for the patient during the procedure. As a result, this view of the child life role influences the expansion of child life services in Japan.

### **Adolescent and Young Adult Psychosocial Development**

In the pediatric medical setting, the AYA population includes patients between the ages of 12 and 25 (Johnson et al., 2018; Kullgren et al., 2018; Rosenberg et al., 2018). Adolescence is defined by the dramatic physical, cognitive, and psychosocial changes that occur in human development between the ages of 12 and 18 years (Erikson, 1968; Johnson et al., 2018; Kullgren et al., 2018). It is characterized by a developing capacity to think logically and abstractly (Piaget, 1950). Adolescent cognitive development allows adolescents to consider theoretical and abstract reasoning, such as morality, philosophy, ethics, and politics (Piaget, 1950). In his lifespan theory of psychosocial development, Erikson (1968) identified the developmental crisis of adolescence to be identity versus role confusion. In this stage, adolescents experiment with different identities (i.e., occupational, social, religious, and sexual) before settling on their identities within society (Steinberg, 2002). Successful resolution of the identity versus role confusion developmental crisis culminates in a "sense of well-being" and "knowing where one is going" (Steinberg, 2002, p. 274).

Young adulthood is characterized by the transition from adolescence to adulthood and is typically defined as ages 18 to 25 years (Berg et al., 2016; Scales et al., 2016). Some of the transitions experienced in

young adulthood include living away from home for the first time; taking on new roles and responsibilities as college students, employees, spouses, and parents; and entering intimate sexual and emotional relationships (Scales et al., 2016). Erikson (1968) identified the stage of intimacy versus isolation as the crisis of early adulthood. In this stage, young adults develop intimate emotional relationships with others, or they fear intimacy with others and become isolated (Erikson, 1968). In addition, young adults in the medical setting face stressors specific to their situation; for example, young adult cancer survivors experience other issues, such as barriers due to a lack of or limited insurance or transportation, major life changes, anxiety, and difficulty transitioning from pediatric to adult care (Berg et al., 2016). Berg and colleagues (2016) found that young adults need technology-based educational and psychosocial resources. Hence, for young adult patients, there are psychosocial interventions that can support their specific developmental needs.

There are cultural differences between AYA in Japan and the United States. For instance, it is typical for AYA in Japan to have strong and stable relationships with their parents, whereas it is typical for AYA in the United States to form strong relationships with their peers during this period of development (Rothbaum et al., 2000; Triandis, 1989). Japanese culture emphasizes collectivism and symbiotic harmony, which is “characterized by a continual pull toward adapting the self to fit the needs of others” (Rothbaum et al., 2000, p. 1123). Thus, AYA in Japan maintain emotional closeness, proximity, and harmony with their parents during adolescence and young adulthood (Rothbaum et al., 2000). American culture emphasizes individual autonomy and generative tension, which is characterized by a “struggle between the desire for closeness and the desire for separation” from parents during the adolescent years (Rothbaum et al., 2000, p. 1121). Thus, AYA in America are encouraged to be autonomous from a young age, and learn to transfer their emotional attachment from their parents to their peers during adolescence and young adulthood (Rothbaum et al., 2000). These differences demonstrate that psychosocial development must be viewed through a cultural lens (Rothbaum et al., 2000).

### **Influence of Hospitalization on Adolescents and Young Adults in North America**

It is difficult for children, adolescents, and young adults, who are still developing, to cope with hospi-

tal stressors (ACLP, 2018c; Al-Yateem et al., 2015; Gaynard et al., 1998). Two types of stressors for the AYA patient population are reviewed: general hospital stressors and stressors due to chronic and life-threatening diseases.

#### **General Hospital Stressors**

General hospital stressors for AYA patients include dependence on adults, separation from family and peers, lack of privacy and need for more time to be alone, fear of bodily injury and pain, fear of loss of identity, concerns regarding body image and sexuality, and concerns about peer group status after hospitalization (Carter, 2014; Kirchenbauer, 2013; Rollins et al., 2018). Frequent and long hospitalizations result in loss of independence and control, which lead to feelings of anger and frustration (Rollins et al., 2018). Isolation from peers can be especially difficult during adolescence (Rollins et al., 2018; Vera et al., 2012). Attention to privacy and confidentiality is an essential principal to facilitate adolescent trust and participation in their own medical treatment planning (Rollins et al., 2018).

#### **Stressors due to Chronic and/or Life-Threatening Diseases**

Many researchers have found that children and adolescents with chronic diseases tend to have more psychological problems when compared with healthy children and adolescents (Carter, 2014; Doka, 1996; Litt et al., 1982; Parvin & Dickinson, 2010). Rollins and colleagues (2018) found that the potential effects of chronic illness or disabilities for adolescents increase their sense of feeling different from their peers, limit job or career opportunities, increase concern about why they have the disorder, limit opportunities for heterosexual friendships, decrease their abilities to master their medical self-care, and lead to difficulty with the transition from the pediatric to adult unit. Specifically, studies have found that medical self-care (e.g., maintenance of their own physical health) presents serious stressors for adolescents (Carter, 2014; Costa Flora & Henriques Gameiro, 2016; Hattori et al., 2016).

Transition from caregiver-directed care as adolescents to self-care as young adults is a significant process for adolescents who have chronic or life-threatening diseases (Hattori et al., 2016; Rollins et al., 2018). This transition has received attention from many pediatric departments; however, one issue is the scarcity of institutions that provide appropriate support for AYA

patients (Hattori et al., 2016; Rollins et al., 2018). For example, Hattori et al. (2016) found that only four out of 101 Japanese institutions had transition programs for their AYA patients with childhood onset chronic kidney disease.

Another issue for AYA patients is medical non-compliance. Litt and colleagues (1982) found that adolescents with juvenile rheumatoid arthritis and medical non-compliance reported a poorly developed self-concept because of the long duration of the disease and the symptoms present at onset. These findings demonstrate the importance of psychosocial interventions for AYA patients to facilitate their transition to adult care while supporting their medical self-compliance.

Pediatric patients with life-threatening diseases, along with their families, struggle to live with the problems of ongoing illness due to the symptoms of the illness and effect of medical treatments (Doka, 1996). Specifically, pediatric patients with chronic disease respond to strict treatment regimens with regressive and dependent reactions, aggressive nonadherence, and impaired self-esteem (Doka, 1996; Rollins et al., 2018). In addition, adolescents may begin to fear that their life span could be limited by chronic disease or death (Parvin & Dickinson, 2010; Rollins et al., 2018).

### **Influence of Hospitalization on Adolescents and Young Adults in Japan**

There is a dearth of research on the influence of hospitalization on the AYA patient population in Japan; however, two studies have explored this issue. Maeda (2012) uncovered seven problems recognized by adolescents with chronic illness during hospitalization: resistance toward opposite sex nurses, physical and emotional pain from symptoms and treatment, anxiety about their future life, restrictions on their daily life due to hospital rules, loneliness, development and maintenance of human relationships, and difficulty with nurses who were not empathic. In addition, Matsuo and colleagues (2004) found that adolescents with chronic illness were able to recognize their disease stages, ultimately establishing an identity that incorporates their disease.

### **Psychosocial Interventions for Adolescent and Young Adults in North America**

There are many types of psychosocial interventions that child life specialists provide adolescent patients

in the pediatric hospital setting in the United States, including encouragement of socialization with peers, respect for independence and privacy, provision of therapeutic activities to promote emotional expression, education for medical procedures/diagnoses, continuation of academic goals, and support for the transition from pediatric to adult health care services (Rollins et al., 2018). While Rollins and colleagues (2018) discuss these psychosocial interventions for hospitalized adolescents, there is a dearth of empirical literature on this topic. However, several psychosocial interventions have been studied with the hospitalized adolescent population: encouragement of medical compliance by collaborating with family and various health care professionals, support for adolescents during the transition from pediatric to adult care, and support for end-of-life care.

Several studies have investigated medical non-compliance in adolescence. It is important for those supporting medical compliance of adolescents to collaborate with adolescents, their family members, multidisciplinary health care professionals, and educational professionals; to provide a comprehensive intervention that includes consideration of biological and psychosocial factors; to establish therapeutic relationships with the adolescent and their parents; to support their coping; and to encourage their motivation toward medical compliance (Carter, 2014; Lask, 2003).

Several studies have discussed supporting adolescents in the transition from pediatric to adult care (Hattori et al., 2016; Rollins et al., 2018). Effective interventions should include consideration of adolescents' understanding of the conditions, related treatments, medications, and precautions, and should inspire adolescents' abilities to verbalize health care concerns and needs, become compliant with medical regimens, and demonstrate their interest in the transfer to adult care (Carter, 2014; Hattori et al., 2016; Rollins et al., 2018).

One of the essential roles for child life specialists in the hospital setting is supporting children and their families with issues related to death, dying, and bereavement (ACLP, 2018c). Most child life programs in the United States offer interventions for pediatric patients and their families at end of life, specifically child life education programs about death and dying (Parvin & Dickinson, 2010; ACLP, 2018c). Child life specialists have an understanding of all aspects of death, dying, and bereavement and are prepared for

psychosocial crises or end-of-life events in the hospital (ACLP, 2018c).

### Psychosocial Interventions for Adolescent and Young Adults in Japan

There has been limited empirical research about psychosocial interventions for AYA patients in Japan. However, Maeda (2012) reported several communication and information-gathering needs of AYA patients in Japan with chronic illness: interaction with peers of the same sex and age, communication with the same generation, information provided by experienced people with the same disease, information provided by medical staff, information from same-sex medical professionals, information from non-medical professionals, and family communication (Maeda, 2012).

### Present Study

A child life specialist is the health care professional dedicated to providing psychosocial interventions for AYA patients in health care facilities. The child life profession has existed in North America for almost a century (Turner & Grissim, 2014); however, the child life specialist profession is still developing in Japan. There is a dearth of research on the similarities and differences in the child life specialist role in countries and cultures outside of North America (Carter, 2014; Hagiwara, 2015; Ishizuka, 2017; Nishimoto, 2012). The purpose of this exploratory study was to better understand the role of the child life specialist in providing psychosocial interventions for AYA patients in Japanese hospitals. An additional aim of this study was to understand the challenges that child life specialists in Japan face when providing psychosocial interventions for the AYA patient population. Therefore, this study explored three research questions:

1. What types of psychosocial interventions do child life specialists provide for AYA patients in Japan?
2. What do child life specialists perceive as the most effective psychosocial interventions for AYA patients in Japan?
3. What challenges do child life specialists encounter when providing psychosocial interventions for AYA patients in Japan?

## Method

### Participants

Forty-two Japanese child life specialists were invited to participate in the study; the overall response rate for the survey was 12%. Participants ( $n = 5$ ) consisted of Japanese child life specialists ( $M_{age} = 31.2$ ,  $SD = 4.9$ ) who worked in Japan and were clinically trained in North America. Participants were female ( $n = 5$ ), never married ( $n = 3$ ), and had earned graduate degrees ( $n = 3$ ). Four participants had worked as child life specialists in Japan for 5 to 7 years, and one participant had worked as a child life specialist for less than one year. No participants had worked as a paid child life specialist in North America prior to their work as a child life specialist in Japan. All participants were full-time day shift employees who worked more than 36 hours per week. Four participants worked at Japanese national hospitals and one worked at a Japanese private hospital.

Three participants reported the existence of psychosocial support teams within their hospital, which included the child life specialist and a social care worker as common team members. Other team members included clinical psychologists ( $n = 2$ ), child health nurses/pediatric emergency nurses ( $n = 2$ ), a child care worker ( $n = 1$ ), and a professional providing canine-assisted therapy ( $n = 1$ ). Four participants reported spending 25% of their time with the AYA population, whereas one reported spending 75% of their time with the AYA population. Hospital units and departments where participants worked are listed in Table 1.

### Procedure

This study was approved by the Institutional Review Boards of both authors' institutions. The researcher emailed the study invitation and survey link to the JACCLS forum. Child life specialists who were members of JACCLS (approximately 42 child life specialists) received the study invitation and survey link via the JACCLS forum email. The survey data was collected using Qualtrics, an online survey management system. Informed consent was obtained on the first page of the electronic survey. The online survey took approximately 30 minutes to complete. Once participants completed the online survey, they were eligible to receive a ¥1,000 (\$10 U.S. equivalent) gift card to Amazon.co.jp. The consent form included both Japanese and English translations, and the survey was in

**Table 1**

*Hospital Units/Departments Where Certified Child Life Specialists Worked*

Hospital Unit/Department	Frequency	%
General pediatric	3	60.0
Medical/surgery	1	20.0
Hematology/oncology	2	40.0
Pulmonary	1	20.0
Neurology/psychiatry	2	40.0
Intermediate care	4	80.0
Pediatric intensive care unit (PICU)	3	60.0
Neonatal intensive care unit (NICU)	3	60.0
Imaging/radiology	3	60.0
Surgery	4	80.0
Emergency room	4	80.0
Outpatient clinics	1	20.0
Special events	1	20.0
Other: 総合周産期病棟 (Maternal and perinatal care unit)	1	20.0
Other: がんセンター小児科(血液疾患は扱っていない) (Pediatric unit at the cancer center)	1	20.0
Other: 成人患者のこども支援 (Support for children whose family are patients in the hospital)	1	20.0

*Note.*  $n = 5$ .

Japanese. Participants were free to type their responses in Japanese or English.

## Measure

A 21-item mixed-method survey was created specifically for this study, titled A Survey of Japanese Child Life Specialists' Perspectives about Psychosocial Interventions for the AYA Patient Population in Japan. (See Appendix). This survey was divided into three sections: demographic questions, questions about the experiences child life specialists had with the AYA patient population in Japan, and open-ended questions about child life specialists' personal opinions and experiences of culture and child life practices with the AYA patient population in Japan and North America. Questions for this survey were developed based on relevant literature and adapted from previous surveys: Question numbers 8, 13, 14, and 18 were adapted from Kirchenbauer's (2013) survey, where peer review

was used to establish the content validity. Question numbers 15, 16, and 17 were adapted from Carter's (2014) survey, Survey Questions for Professionals Working with Adolescents, where initial data and analysis were reviewed by faculty for content validity and reliability. Additional questions were included in this survey that were not used for this paper.

## Data Analysis

Frequency analyses were used to answer the first two research questions with corresponding survey items 14 and 15, respectively. For question 15, response rankings were coded for the presence or absence of the response choice. For example, if a participant's response ranked the "emotional support" intervention at any ranking (1 to 5), then the researchers coded this as 1, denoting the presence of the response choice. If a participant's response did not rank the "emotional support" intervention, then the researchers coded this as 0, denoting the absence of the response choice. All participant transcripts were translated from Japanese to English, blind reviewed by the two authors, and item 17 was coded for themes. The codes were formed based on the emergent themes. The final codes were decided by the two researchers who reviewed the participant transcripts.

## Results

### Psychosocial Interventions Provided for AYA Patients by Child Life Specialists in Japanese Hospitals

One purpose of this research study was to identify the types of interventions child life specialists provided for their AYA patients in Japan. All child life specialists ( $n = 5$ ) reported that the most common psychosocial interventions provided for AYA patients in Japan were individual therapeutic/developmentally appropriate play activities, emotional support, and family and/or sibling support. Four child life specialists reported providing preparation for medical procedures, distraction/coping support during medical procedures, interventions for changes in body image, encouragement for patients' academic career in collaboration with school teachers, and bereavement support for AYA patients in Japan. All psychosocial interventions provided for the AYA patient population by child life specialists in Japan are listed in Table 2.

Table 2

*Types of Child Life Interventions Provided for Adolescent and Young Adult Patients in Japan*

Child life intervention	Frequency	%
Individual therapeutic/developmentally appropriate play activities	5	100.0
Group therapeutic/developmentally appropriate play activities	3	60.0
Preparation for medical procedures	4	80.0
Distraction/coping support during medical procedures	4	80.0
Emotional support	5	100.0
Providing educational resources	3	60.0
Providing opportunities to encourage their peer relationships	2	40.0
Intervention for changes of their body image	4	80.0
Encouraging their medical compliance	2	40.0
Encouraging their transition to adult unit	2	40.0
Encouraging their academic career with school teachers	4	80.0
Bereavement support	4	80.0
Pain management	3	60.0
Family and/or sibling support	5	100.0
Other: ピアサポートの提供 (Providing opportunities to encourage their peer relationships)	1	20.0

Note.  $n = 5$ .

### Child Life Specialist-Perceived Effective Psychosocial Interventions for AYA Patients in Japanese Hospitals

Out of the 14 possible choices of child life interventions, including a choice where participants could type in an “Other” child life intervention, child life specialists ( $n = 3$ ) perceived providing emotional support for the patient and providing family and/or sibling support as the most effective psychosocial interventions for AYA patients. Child life specialists ( $n = 2$ ) perceived that encouraging transition to the adult unit, encouraging the patient’s academic career with school teachers, and providing bereavement support as the next most effective psychosocial interventions for AYA patients in Japan. A complete list of child life specialist-perceived effective psychosocial interventions provided for the AYA patient population are listed in Table 3.

### Challenges to Child Life Specialists’ Provision of Psychosocial Interventions for the AYA Patient Population in Japan

Results indicated that child life specialists perceived the biggest challenges to providing psychosocial interventions for AYA patients in Japan were the (a) promotion of emotional expression in individual and group settings (e.g., “Prompting emotional expression,” translated from a participant response of “感情表出を促すこと。”); (b) lack of developmentally appropriate resources for adolescents, including privacy from younger children (e.g., “Differences in resources and environments. America has a lot of donated toys, but Japan does not. Also, although there is a play room, there is not a teen room, [so that is why there is difficulty to protect teen’s privacy appropriately],” translated from a participant response of “資源や環境の違い。アメリカはおもちゃの寄付などがたくさんあったが日本はな

Table 3

*Certified Child Life Specialists’ Perceptions on the Most Effective Child Life Interventions Provided for Adolescent and Young Adult Patients in Japan*

Child life intervention	Frequency	%
Individual therapeutic/developmentally appropriate play activities	1	25.0
Group therapeutic/developmentally appropriate play activities	1	25.0
Preparation for medical procedures	1	25.0
Distraction/coping support during medical procedures	1	25.0
Emotional support	3	75.0
Providing educational resources	1	25.0
Providing opportunities to encourage their peer relationships	1	25.0
Intervention for changes of their body image	1	25.0
Encouraging their medical compliance	0	0.0
Encouraging their transition to adult unit	2	50.0
Encouraging their academic career with school teachers	2	50.0
Bereavement support	2	50.0
Pain management	1	25.0
Family and/or sibling support	3	75.0

Note.  $n = 4$ .



い。また、ブレイルームはあるが、ティーンルームなどの環境は整っておらず、部屋を確保することが難しい。[なので、ティーンに対して]プライバシーへの配慮 [の難しさがある。]”); and (c) low child life prioritization of AYA patients due to the limited number of child life specialists in Japanese hospitals (e.g., “Because of the small number of child life specialists, the priority of support for adolescents at outpatient clinics and AYA generation during treatments and examinations is lower” translated from a participant response of “CLSの人数が少ないため、外来での思春期、AYA世代への処置、検査サポートの優先順位が低くなってしまうこと” and “A child life specialist does not consider the priority of the intervention, so nurses deal with the prioritizing and tell it to the child life specialist,” translated from a participant response of “CLS自身が介入優先度を検討するのではなく、看護師によってスクリーニングされた方への対応をしている。”).

In addition, there was a belief that providing psychosocial interventions for AYA patients was given higher priority by child life specialists in North America compared with child life specialists in Japan (e.g., “I think understanding/recognition of the importance to support adolescents and AYA generation is higher in the United States,” translated from a participant response of “思春期やAYA世代へのサポートの重要性に対する認識はアメリカの方が高い印象があります。”). Also, participants reported that, due to the number of child life specialists in Japan compared to North America, the role and duties of the child life specialist in Japan are still developing, whereas the role and duties of the child life specialist are more defined in North America.

## Discussion

### Types of Psychosocial Interventions for AYA Patients in Japan

The most common psychosocial interventions provided by child life specialists for AYA patients in Japan were individual therapeutic/developmentally appropriate play activities, emotional support, and family and/or sibling support. Similar to literature on psychosocial interventions for AYA patients in North America (Rollins et al., 2018), psychosocial interventions, including emotional support, medical procedure/illness education, support for changes in body image, bereavement support, and encouragement of transition to adult units were also provided for AYA patients in Japan.

As expected, our findings align with the literature in regards to child life specialists commonly providing individual therapeutic/developmentally appropriate play activities and emotional support for AYA patients (Gaynard et al., 1998; ACLP, 2018c), as well as consideration for the developmental needs of AYA patients in the hospital (Maeda, 2012). In addition, the common provision of emotional support and expressive activities by child life specialists in Japan could reflect the need for child life specialists to mitigate the high-context communication style of Japanese culture so that AYA patients may feel emotionally supported and free to express their feelings regarding hospitalization, illness, and development.

### Child Life Specialists' Perceptions of Effective Psychosocial Interventions for AYA Patients in Japan

The top two psychosocial interventions that child life specialists perceived as most effective for AYA patients in Japan were providing emotional support to the AYA patient and providing family and/or sibling support. Providing emotional support for the AYA patient in Japan aligned with the literature for the AYA patient in North America, which stated that providing emotional support for adolescents is helpful for immediate hospital stressors and typical developmental stressors (Rollins et al., 2018; ACLP, 2018c). However, the second child life specialist-perceived effective intervention, family and/or sibling support, did not align with the U.S. literature (Rollins et al., 2018; ACLP, 2018c). Perhaps this discrepancy was observed because Japanese youth tend to find relating to their parents important, whereas youth in North America tend to view relationships with peers as significant (Rothbaum et al., 2000; Triandis, 1989). In addition, it is interesting that family and/or sibling support was included as one of the most effective psychosocial interventions provided by Japanese child life specialists because of the limited sibling visitation practices in Japan. Perhaps these findings indicate that sibling visitation in Japan is occurring more frequently in practice than Nishimoto (2012) described, and that there is a changing culture regarding sibling visitation in Japanese pediatric hospitals. Alternatively, perhaps sibling support is seen as important precisely because siblings are not allowed to visit. Thus, family and sibling support may include providing parents with information on supporting siblings at home or helping the family maintain connections while the siblings are separated.

## **Challenges to Providing Psychosocial Interventions for AYA Patients in Japan**

The challenges to providing interventions for AYA patients in Japan were (a) the promotion of emotional expression for AYA patients in individual and group settings, (b) the lack of developmentally appropriate resources for AYA patients, and (c) low child life prioritization of AYA patients due to the limited number of child life specialists in Japanese hospitals.

### **Promotion of Emotional Expression in Individual and Group Settings**

Child life specialists in Japan reported the challenge of promoting emotional expression for AYA patients in individual and group settings. This could be due to the high-context communication style of Japanese culture. Japanese people prefer nonverbal, indirect emotional expression rather than direct emotional expression, and prioritize the group's feelings over individual feelings (Hall, 1989; Nishimura et al., 2008). Therefore, it may be expected that facilitating AYA emotional expression would be challenging for Japanese child life specialists in individual and group settings. Using nonverbal communicative and assessment tools, such as the Wong-Baker FACES Pain Rating Scale (Wong & Baker, 1988), a feelings chart, and/or expressive art may be beneficial to encourage AYA patients' emotional expression in Japan.

### **Lack of Developmentally Appropriate Resources for Adolescents**

In Japan and the United States, child life services are not eligible for medical service or reimbursement fees (Minami, 2017; Seo, 2018). Therefore, hospitals must create room for child life specialists in their budget or support child life programs through grant funding (Hagiwara, 2015; Kitagawa, 2009). Culturally, it is less common to donate money to hospitals in Japan compared with the donations received at pediatric hospitals in the United States (Hagiwara, 2015), which include monetary and resource donations (Snipes & Oswald, 2010). For example, during the winter holidays in the United States, an abundance of new toys; games, including electronic game systems and tablets; and movies are donated to children's hospitals. These donations help to restock child life playrooms and teen rooms throughout the entire year (until the next winter holiday). Monetary donations can help pay for grant-funded child life positions, electronic game system carts, tablets, and playroom and teen room updates or renovations. The

lack of monetary and resource donations to pediatric hospitals in Japan may be the reason behind the lack of developmentally appropriate activities for AYA patients in Japan. For instance, even though adolescent privacy is important, there are no teen rooms or adolescent spaces in the pediatric units in Japan. Therefore, AYA patients are grouped with young children in the playroom, which does not provide the privacy needed. However, child life specialists use the limited amount of developmentally appropriate resources for AYA patients for distraction and pain management during medical procedures.

### **Low Child Life Prioritization of AYA Patients**

An additional challenge listed by child life specialists in Japan was the low prioritization of AYA patients in their daily workload. Because there is a minimal budget for child life specialists in Japanese hospitals, child life specialists must prioritize patients to whom they provide interventions. Child life specialists use stress potential assessments, including the child's developmental level, the child's temperament, parental anxiety, family characteristics, chronic versus acute illness or injury, and past medical experiences to assist with patient prioritization (Gaynard et al., 1998; Koller, 2008; Staab et al., 2013). Younger children are especially vulnerable to anxiety and stress from a traumatic medical experience, so these children are often prioritized by child life specialists (Staab et al., 2013). Therefore, due to the limited number of child life specialists in Japanese hospitals, there is a pattern of low prioritization of AYA patients seen by child life specialists.

In addition, the other possible reason for the lack of child life specialists is that medical professionals in Japan often question the need for the child life role (Hagiwara, 2015). Japanese pediatric nurses receive training to provide psychosocial interventions for pediatric patients and their families, especially diagnostic education and psychological preparation, more so than pediatric nurses in the United States (Hagiwara, 2015; Matsudaira, 2010). Because pediatric nurses have training in psychosocial interventions, the separate role of the child life specialist may still be questioned in Japan and influence the slow expansion of child life services in Japan. Encouraging hospital staff recognition of the child life role and educational background may be beneficial. For example, similar to child life programs in the United States, a presentation about the child life role in new hospital employee orientation, a poster or business card explaining when

medical professionals should call child life specialists, and a training about child-friendly language or positioning during medical procedures can be used to advocate for the role of the child life specialist in Japanese hospitals. Child life specialists may gather information about existing psychosocial interventions provided by Japanese nurses through observation, review of nursing chart notes, or verbal communication. Then, distinguishing roles to divide psychosocial interventions between Japanese pediatric nurses and child life specialists may be beneficial, enabling the expansion of child life services and increasing the number of hired child life specialists in Japan.

### Limitations

There are several limitations to this study. The small number of participants limits the generalization of the results because participants were approximately 12% ( $n = 5$ ) of all child life specialists invited to participate. Due to the small number of participant responses, the qualitative analysis was not as rigorous as originally planned. For future studies, it would be beneficial for researchers to invite Japanese child life specialists to participate in research in months other than April and May. In Japan, April is the month when school starts, and child life specialists might have been too busy to answer this survey during the beginning of the school year.

An additional limitation of this study was the questionnaire, specifically the response option of “family and/or sibling support” in items 14, 15, and 16. Future studies should revise this questionnaire and separate “family support” and “sibling support” in the response option to further specify the types of interventions provided by Japanese child life specialists.

Another limitation was that this study focused on child life specialists’ experiences with AYA patients in general, so it did not separate child life specialists’ experiences with AYA patients with chronic or acute illnesses, specific diagnoses (e.g., leukemia), or special needs. Future research could explore child life interventions for AYA patients in Japan with specific disease diagnoses or special needs to better understand how child life specialists address their nuanced psychosocial needs. Also, future research is necessary in understanding the child life specialist role in Japan for children of all ages, especially to help mitigate the challenges child life specialists experience when providing interventions to AYA patients.

### Implications for Practice

This research study is relevant to child life practice because the results offer new information about the psychosocial interventions provided for AYA patients in Japan, as well as the challenges that child life specialists face when providing psychosocial interventions for AYA patients in Japan. The information discovered about the challenges that child life specialists face can be explored in future research so that solutions to the challenges can be considered.

This research study is especially relevant for Japanese child life specialists and child life internship supervisors in North America who mentor international student interns who plan to return to Japan and practice child life. The results of this study could assist child life students in better understanding how to serve and support AYA patients in Japan. Nishimoto (2012) stated that cultural differences in child life services should be explored in each country in order to help child life specialists work more effectively with children and their families in the health care environment. Because Japan has the largest population of child life specialists outside of the United States and Canada, future research is needed to provide more detailed information about the interventions implemented by child life specialists for AYA patients in Japan. Child life specialists working in Japan are typically trained in North America and must translate their practice for the Japanese hospital setting once they leave North America. Additional information is needed to determine whether this is the most effective way to train child life specialists for Japanese practice, and how the differences in the North American and Japanese cultures may affect training and practice.

### Conclusion

This study adds to the scant literature on the child life specialist role in Japan and the psychosocial interventions that child life specialists provide for AYA patients in Japan. The most common psychosocial interventions provided for AYA patients in Japan were individual therapeutic/developmentally appropriate play activities, emotional support, and family and/or sibling support. The latter two were perceived as the most effective interventions for AYA patients in Japan by child life specialists. In addition, child life specialists in Japan encounter several challenges to providing psychosocial interventions for the AYA patient population in Japan, including the promotion of emotional expression, lack of developmentally appropriate

resources, and low child life prioritization due to the limited number of child life specialists in Japan. Future research is needed to understand the full scope of psychosocial interventions provided for AYA patients in Japan by child life specialists.

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## Appendix

### A Survey of Japanese Child Life Specialists' Perspectives about Psychosocial Interventions for Japanese Adolescents

Item Number	Survey Item
1 – 11	Demographic questions and questions about work history and current work
12	<p>Do you have a psychosocial support team? (In this survey, a psychosocial support team is defined by a team that provides psychosocial support, such as child life specialists, social workers, music therapists, and/or chaplains/spiritual supports.)</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul> <p>If “Yes,” who is a part of your psychosocial support team? (Choose all that apply).</p> <ul style="list-style-type: none"> <li>• Child Life Specialist</li> <li>• Child Care Worker</li> <li>• Hospital Play Specialist</li> <li>• Child Care Specialist</li> <li>• Clinical Psychologist</li> <li>• Psychological Physician</li> <li>• Child Health Nursing/ Pediatric Emergency Nursing</li> <li>• Social Care Worker</li> <li>• Music Therapist</li> <li>• Hospital Pastoral Service</li> <li>• School Teachers</li> <li>• Hospital Dog therapy</li> <li>• Hospital Clown Service</li> <li>• Other (please specify): (type in)</li> </ul>
13	<p>On a typical workday, what percent of your time is spent working with the adolescent population in Japan?</p> <ul style="list-style-type: none"> <li>• 0% of your time</li> <li>• 25% of your time</li> <li>• 50% of your time</li> <li>• 75% of your time</li> <li>• 100% of your time</li> </ul>
14	<p>What kind of child life interventions do you provide for adolescents in Japan? (Choose all that apply).</p> <ul style="list-style-type: none"> <li>• Individual effective therapeutic/developmentally appropriate play activities</li> <li>• Group effective therapeutic/developmentally appropriate play activities</li> <li>• Preparation for medical procedures</li> <li>• Distraction/coping support during medical procedures</li> <li>• Emotional support</li> <li>• Providing educational resources</li> <li>• Providing opportunities to encourage their peer relationships</li> <li>• Intervention for changes of their body image</li> <li>• Encouraging their medical compliance</li> <li>• Encouraging their transition to adult unit</li> <li>• Encouraging their academic career with school teachers</li> <li>• Bereavement support</li> <li>• Pain management</li> <li>• Family and/or sibling support</li> <li>• Other: (type in)</li> </ul>

Item Number	Survey Item
15	<p>In your opinion, which child life interventions are the most effective for adolescents in Japan? Please rank the top five interventions in level of effectiveness: 1-5. One being the most effective and 5 being the least effective.</p> <ul style="list-style-type: none"> <li>• Individual effective therapeutic/developmentally appropriate play activities</li> <li>• Group effective therapeutic/developmentally appropriate play activities</li> <li>• Preparation for medical procedures</li> <li>• Distraction/coping support during medical procedures</li> <li>• Emotional support</li> <li>• Providing educational resources</li> <li>• Providing opportunities to encourage their peer relationships</li> <li>• Intervention for changes of their body image</li> <li>• Encouraging their medical compliance</li> <li>• Encouraging their transition to adult unit</li> <li>• Encouraging their academic career with school teachers</li> <li>• Bereavement support</li> <li>• Pain management</li> <li>• Family and/or sibling support</li> <li>• Other: (type in)</li> </ul>
16	<p>In your opinion, which child life interventions might not be necessary for adolescents in Japan? (Choose all that apply).</p> <ul style="list-style-type: none"> <li>• Individual effective therapeutic/developmentally appropriate play activities</li> <li>• Group effective therapeutic/developmentally appropriate play activities</li> <li>• Preparation for medical procedures</li> <li>• Distraction/coping support during medical procedures</li> <li>• Emotional support</li> <li>• Providing educational resources</li> <li>• Providing opportunities to encourage their peer relationships</li> <li>• Intervention for changes of their body image</li> <li>• Encouraging their medical compliance</li> <li>• Encouraging their transition to adult unit</li> <li>• Encouraging their academic career with school teachers</li> <li>• Bereavement support</li> <li>• Pain management</li> <li>• Family and/or sibling support</li> <li>• Other: (type in)</li> <li>• None</li> </ul>
17	(Short answer) What is most challenging about providing child life interventions for adolescents in Japan?
18	(Short answer) From your experience, what are specific interventions, techniques, or skills that are helpful for child life specialists to know when working with adolescents in Japan?
19	In your opinion, what are the differences in child life interventions for adolescents in Japan and adolescents in North America?
20	In your opinion, what are the differences in healthcare workers' understanding of the child life specialist role and job duties in Japan and North America?
21	What recommendation(s) would you give for Japanese child life students in North America to provide effective psychosocial interventions for Japanese adolescents in the future?