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**This is the author's manuscript**

*Original Citation:*

*Availability:*

This version is available <http://hdl.handle.net/2318/1896254> since 2023-03-20T14:46:56Z

*Published version:*

DOI:10.1089/jayao.2022.0166

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# Emotional Distress, Self-Management Skills, and Expectations Among Adolescents and Young Adult Childhood Cancer Survivors in Transition from Pediatric to Adult Care: A Brief Report

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**AU3 ▶** The transition from pediatric to adult care poses several emotional and personal challenges to adolescents and young adult (AYA) childhood cancer survivors (CCSs), which need attention to avoid the risk of nonadherence and medical dropout. This brief report describes the condition of AYA-CCSs at the moment of transition in terms of emotional state, personal autonomy, and expectations regarding future care. The results provide insights for clinicians dealing with survivorship care, to enhance AYA-CCSs emotional resilience and to support them in being in charge of their health, thus facilitating their transition to adulthood.

**AU4 ▶** **Keywords:** adolescent and young adult, cancer survivors, transition, pediatric oncology

## Introduction

**P**ROGRESSIVE IMPROVEMENTS IN pediatric oncological care imply that the growing population of adolescents and young adult (AYA)-childhood cancer survivors (CCSs) survivors will join long-term follow-up (LTFU) for the prevention and early detection of possible late effects caused by oncological treatments. Besides physical complications, at transition and during other phases of LTFU, health care providers (HCPs) should monitor also psychological sequelae that can affect AYA-CCSs' population.<sup>1,2</sup> AYA-CCSs, in fact, should be considered as a target population from psychological point of view. Most of them report good psychosocial functioning, comparable with their healthy peers.

However, some AYA-CCSs are at risk of developing psychological discomfort,<sup>3</sup> body disaffection,<sup>4</sup> social and relational impairment, difficulties in work placement, and job

satisfaction.<sup>5</sup> The current literature also highlights that the transition from pediatric to adult LTFU is a crucial moment for AYA-CCSs.<sup>1</sup> Factors that can improve the transition process are early introduction to transition, independence, good communication between health care professionals, provision of adequate and comprehensive information, and trust in the doctors at the adult center. In contrast, dependence on HCPs, inadequate communication, lack of trust in new LTFU physicians and cognitive difficulty can be barriers to a successful transition.<sup>2</sup>

Emotional stability and personal autonomy are some of the essential components to a successful transition, able to influence the adherence, and the evolution of the follow-up.<sup>6-8</sup> Moreover, to avoid possible barriers to a successful transition, exploring expectations about the nature of LTFU might help to identify those adolescents who need education about what is most likely to happen in an adult-oriented health care setting.<sup>9-11</sup>

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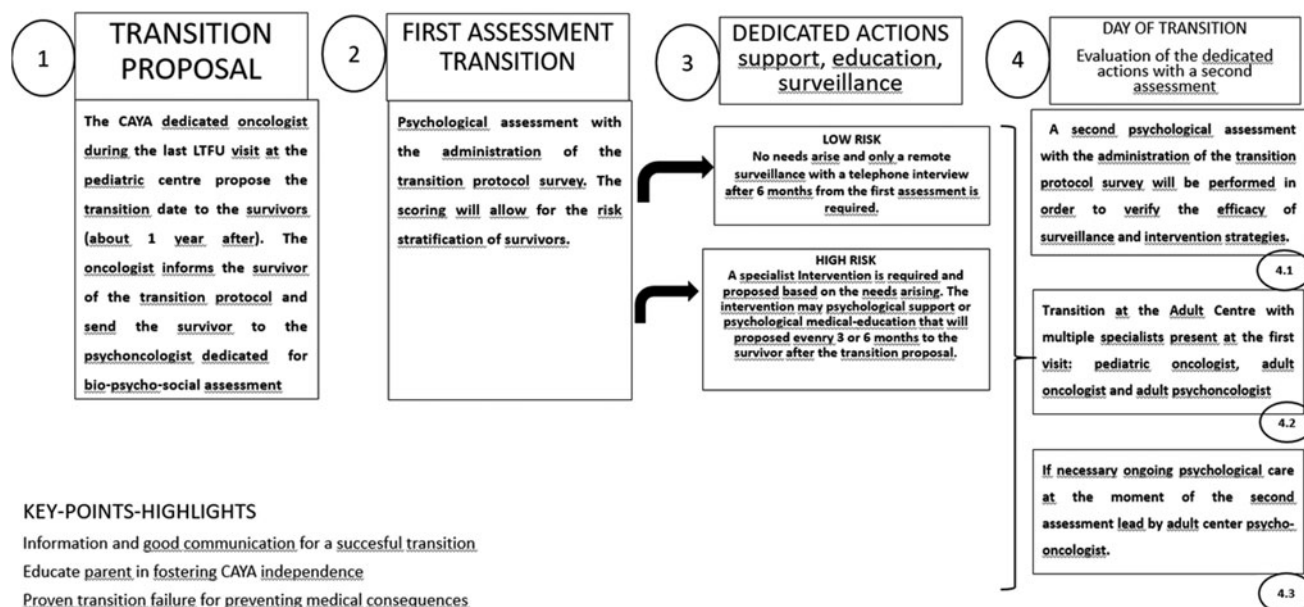
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MODEL OF CAYA SURVIVORS TRANSITION PROTOCOL

Transition: Promoting individualized transition adapted to the needs of each CAYA (children, adolescents and young adults) survivors



KEY-POINTS-HIGHLIGHTS

- Information and good communication for a successful transition
- Educate parent in fostering CAYA independence
- Proven transition failure for preventing medical consequences

FIG. 1. Transition protocol.<sup>7</sup>

Recently in our institution an AYA-CCSs Protocol<sup>12</sup> (Fig. 1) has been developed, to identify and address the individual psychological needs youths to improve the likelihood of their successful transition to adult care.

The aim of this brief report, therefore, is to address the condition of AYA-CCSs at the time of their transition in terms of emotional state, subjective perception of self-management skills, and expectations for transition.

Methods and Materials

Between June 2021 and October 2022, this study was performed at the Pediatric Oncohematology Department of the Regina Margherita Children’s Hospital in Italy, a referral center of the Italian Association of Pediatric Hematology Oncology<sup>13</sup> (AIEOP). The administration of the questionnaires was approved by the Ethics Committee of the hospital.

The youths were invited to complete the questionnaire during the last clinical visits before the planned transition. In the center, about five AYA-CCSs transitions each month are planned. A psychologist gave each AYA-CCSs a printed copy of the questionnaire in person and explained the aims of the study. Thanks to this approach it was possible to obtain the willingness of filling the questionnaire by all the AYA-CCSs involved. The questionnaire was administered in an anonymous format, thus ensuring the confidentiality of all the data collected. AYA-CCSs >18 years old and who have finished cancer therapies for at least 5 years were eligible. No incentive was given for participation.

The survey has three questionnaires (AYA Cancer Distress Scale,<sup>14</sup> Transition-Q,<sup>15</sup> and Expectation Scale<sup>16</sup>) developed

at the Canchild Institute of the Mc Master University in Canada, translated into Italian after a language and cognitive validation process.<sup>12</sup>

The AYA Cancer Distress Scale (AYA-CDS) is a valid and reliable screening tool that measures distress across biopsychosocial and educational domains. Each item comprises four response options (from None=1 to Severe=4). In this report, we presented significant results in the emotional sphere from AYA-CDS: the patient is asked to indicate the degree of emotional distress due to the cancer.<sup>14</sup>

Transition-Q scale has 11 items and evaluates the skills acquired by the AYA-CCSs in the management of its health. Each item includes three response options (from Never=1 to Always=3). This scale is widely used by clinicians to evaluate the survivor’s readiness for transition.<sup>15</sup>

TABLE 1. CHARACTERISTICS OF THE SAMPLE

Whole sample	60
Gender	
Female	77%
Male	33%
Age	
Mean age at diagnosis	9 (5–17)
Mean age at transition	20 (18–29)
Cancer type	
Leukemia and lymphoma	79%
Solid tumors	18%
Brain tumors	3%
Treatment modality	
Chemotherapy only	60%
Chemotherapy and radiotherapy	22%
Chemotherapy and surgery	18%

◀AU8

CONDITIONS OF AYA-CCS IN TRANSITION

TABLE 2. ADOLESCENTS AND YOUNG ADULT-CANCER DISTRESS SCALE

<i>Emotional distress</i>	<i>None</i>	<i>Light</i>	<i>Moderate</i>	<i>Severe</i>
1. Feeling helpless?	62%	22%	8%	8%
2. Feeling hopeless?	70%	20%	6%	4%
3. Feeling guilty?	63%	25%	8%	4%
4. Feeling grief or loss?	65%	21%	12%	2%
5. Feeling everything is an effort?	57%	21%	18%	4%
6. Feeling afraid?	64%	20%	13%	3%
7. Feeling moody or irritable?	44%	24%	23%	9%
8. Feeling sad?	44%	32%	13%	11%
9. Feeling angry or frustrated?	45%	31%	10%	14%
10. Feeling worried?	38%	38%	15%	9%
11. Feeling anxious?	37%	41%	16%	6%
12. Having thoughts of suicide or harming myself?	87%	9%	3%	1%
13. Trouble learning new things?	69%	23%	3%	5%
14. Feeling confused?	60%	26%	12%	2%
15. Trouble putting my thoughts into words?	63%	27%	4%	6%
16. Feeling disorganized?	68%	26%	4%	2%
17. Feeling like I am living in a ‘fog’ (e.g., brain fog)?	80%	12%	6%	2%
18. Taking a long time to finish things?	57%	16%	23%	4%
19. Trouble remembering?	60%	6%	30%	4%
20. Difficulty paying attention or concentrating?	49%	12%	35%	4%

The Expectation Scale<sup>16</sup> includes 11 items and investigates the expectations that survivors have toward the moment of transition from the pediatric hospital to the adult center. Each item includes a possible expectation with four response options (from Strongly agree = 1 to Strongly disagree = 4).

Results

Sixty survivors completed the survey, most of them are female AYA-CCSs (77%) and they have been diagnosed with leukemia and lymphoma (79%) followed by solid tumors (18%) and brain tumors (3%). The median age at diagnosis was 9 years (range 5–17) and at the transition was about 20 years (range 18–29).

T1 ► Considering their emotional state (Table 1), most of participants reported feelings of moodiness and irritation (23% moderate; 9% severe), sadness (13% moderate; 11% severe),

anger and frustration (10% moderate; 14% severe). More than 60% of participants also reported worries (15% moderate; 9% severe) and anxiety (16% moderate; 6% severe). More than 30% of the survivors declared to have moderate difficulty in paying attention or concentration (35% moderate; 4% severe).

Concerning self-management skills (Table 2), the majority of participants reported to feeling able to summarize their clinical history (58%) and to look for an answer about questions related to their health (63%). Nonetheless, only about 20% declared that they prefer speaking to the doctor instead of the caregiver and 10% always travel on their own to the doctor’s appointment. ◀T2

From the Expectation Scale (Table 3), most of survivors agree to share their clinical history with HCPs (65% completely agree about “expect the doctor know my cancer story”) and expect to be punctual (42% completely agree ◀T3

TABLE 3. SELF-MANAGEMENT SKILLS

<i>Self-management skills</i>	<i>Always</i>	<i>Sometimes</i>	<i>Never</i>
1. I answer a doctor’s or nurse’s questions	36%	49%	15%
2. I look for an answer when I have a question about my health	63%	32%	5%
3. I talk about my health condition to people when I need to	51%	41%	8%
4. I ask the doctor or nurse questions	36%	49%	15%
5. I speak to the doctor instead of my parent(s) speaking for me	19%	61%	20%
6. I summarize my medical history when I am asked to	58%	37%	5%
7. I contact a doctor when I need to	44%	42%	14%
8. I see the doctor or nurse on my own during an appointment	34%	42%	24%
9. I drop off or pick up my prescriptions when I need medicine	32%	32%	36%
10. I travel on my own to a doctor’s appointment	10%	44%	46%
11. I book my own doctor’s appointments	14%	36%	50%

TABLE 4. EXPECTATION SCALE

<i>Expectations scale</i>	<i>Completely agree</i>	<i>Agree</i>	<i>Disagree</i>
1. I expect the doctor to know my cancer history	32%	65%	3%
2. I expect my appointment will start on time	42%	52%	6%
3. I expect to be called if I miss my appointment	13%	66%	21%
4. I expect to be seen by the same doctor each time I visit	7%	61%	32%
5. I expect to get a reminder call before my appointment	19%	73%	8%
6. I expect to be able to call the doctor any time I need to (e.g., if I have questions about late effects)	18%	72%	10%
7. I expect other appointments related to my cancer will be booked for the same day	13%	68%	19%
8. I expect my parent(s) will be able to see the doctor with me	21%	62%	17%
9. I expect the doctor will look after all my health care needs	5%	57%	38%
10. I expect the doctor will become like a friend	3%	38%	59%
11. I expect the doctor will spend a lot of time with me	17%	60%	23%

about “I expected my appointment will start on time”) and remember their appointments consistently. Furthermore, 90% of participants expect to be able to contact the doctor at any time they deem necessary. Only 3% of the sample do not expect their doctor to know their disease history (Table 4).

**Conclusions and Practical Implications**

This brief report aims to describe the condition of AYA-CCSs at the moment of transition to adult follow-up care in terms of emotional state, autonomy, and expectations.

Regarding their emotional state, some AYA-CCSs reported emotions ranging from sadness, anger, and frustration at the moment of transition. Also, a small percentage of participants referred to suicidal and self-defeating thoughts.

Although moderate, this detected psychological discomfort could be related to the presence of serious late effects due to previous cancer treatments,<sup>1,2</sup> to an unexpressed or uncontained fear about the possible cancer recurrence or to a difficulty in getting back to their normal life.<sup>17</sup>

In any case, it is necessary for HCPs to surveillance survivors to relieve their moderate emotional fatigue and to identify the most clinically vulnerable subgroup. However, factors associated with emotional discomfort should be investigated in future studies.

For this reason, the surveillance of psychological sequelae should be a regular and formalized practice during LTFU visits to offer dedicated support to AYA-CCSs for improving the quality of transition.<sup>18</sup>

Therefore, it is important that institutions agree that physicians, psychologists, and HCPs are “treating AYA with cancer” both during their treatment phase and beyond at survivorship stage. In the latter case, the presence of dedicated HCPs should help survivors in fighting the stigma of cancer and any subsequent negative consequences.<sup>19</sup>

Furthermore, in terms of self-management skills, the majority of AYA-CCSs claim to know their illness and to not have problems asking for advice or answering questions about their medical history. This attitude could be due to a previous establishment of trust between survivors and the pediatric center.<sup>2</sup> In fact in our center since from the cancer

diagnosis is promoted patient empowerment, emotional stress reduction and self-management through routinary parent-HCPs communications with a health education purpose and targeted psychological support pathways adjusted for age and stage of treatment.<sup>20</sup> However, further studies should investigate the self-management attitude directly with AYA-CCSs through the use of appropriate and validated measure to disseminate clinical practice strategies to other professionals involved in the management of this population.

Furthermore, a great percentage of our sample still depends on parents during medical visits. The parent-caregiver regularly works in collaboration with the clinicians throughout the care process, and for this reason it is necessary to work together toward the autonomy of these young adults right away. To find a balance between parent involvement and AYA-CCSs autonomy from different perspectives: physical, emotional, practical, cognitive, it is necessary to pursue this goal from the onset of the cancer diagnosis.<sup>18,19</sup>

When considering adult follow-up care, AYA-CCSs have high expectations. Most of them expect the doctors of the adult center to know about their cancer history and as a result they can become a reference point for them in the same way as the doctors of the pediatric center. Transition is partly experienced as a loss of reference points, such as the doctors at the pediatric center; therefore, they all hope to find a new point of reference in the doctors at the adult center.<sup>21</sup>

In conclusion, to make sure AYA-CCSs are in good condition at the time of transition, it is necessary to promote their psychological well-being and augment their decision-making autonomy from the moment of diagnosis or at least from the beginning of follow-up, to reduce negative emotions as far as possible and lessen their difficulty in dealing with new situations. Health care professionals, however, remain important points of reference for survivors. Therefore, it is necessary that even in adult care they are prepared to face some of the common issues AYA-CCS experience by offering to listen to them and provide empathy while remaining in their role as clinician.

Deep collaboration among pediatricians, follow-up care physicians, and psychologists can be the key to ensuring optimal and functional transition and to prepare survivors to

face the developmental tasks of adult life. Also, collaborations, psychosocial support, and interventions, guaranteed for every patient and family, should be adapted and extend to stressful events that may occur externally over the cancer trajectory, such as Covid-19 pandemic that has caused several emotional difficulties among AYA-CCSs.<sup>22</sup>

The identified worries and expectations will help to improve the LTFU care of AYA-CCSs who are in transition to adult care by educating health care professionals of other countries with a similar health care system about the possible individual needs of survivors.<sup>23</sup>

This study reports preliminary data about AYA-CCSs at the moment of the transition. The main limitation is the small size of our sample, which did not allow us to conduct more sophisticated statistical analyses to evaluate any differences in our results based on gender or tumor type.

However, the sample included in this study is broadly representative of the AYA-CCSs in transition to adult center in Italy even if compared with other significative study,<sup>9</sup> and the study presentation modality allows us to have a total participation rate and an avoidance of missing data in the answer of questions. Also, the Emotional Distress tool did not provide an evaluation of positive emotions among AYA survivors. These data would be informative for HCPs in the management of their follow-up, and thus it needs to be investigated in future studies.

Despite these limitations, our evidence allows us to contribute to the topic of AYA-CCSs follow-up care, particularly of the transition process by highlighting factors (psychological status, self-management competence, and thoughts regarding follow-up) that pediatric clinician should consider to improve the process of transition.

#### Acknowledgments

Authors thank UGI ODV and ADISCO Sezione Piemonte for the support.

#### Author Disclosure Statement

No competing financial interests exist.

#### AU6► Funding Information

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