

# Transition of care in pediatric oncohematology: a systematic literature review

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**Abstract.** *Background:* The transition of medical care from a pediatric to an adult environment is a psychological change, a new orientation that requires a self-redefinition of the individual, to understand that changes are taking place in his life. Up to 60 percent of pediatric patients who transition to adult services will experience one or more disease or treatment-related complication as they become adults. A nurse who knows how to recognize potential barriers at an early stage can play a pivotal role in the educational plan for the transition process. *Materials and methods:* A literature search was undertaken of PUBMED, CINAHL and The Cochrane Library, with specific inclusion and exclusion criteria, including articles published in the last ten years. This literature review has been performed according to the PRISMA statement. *Results:* Using the keywords in different combination 38 articles were found in The Cochrane Library, 5877 in PUBMED, 274 in CINAHL. 88 articles were selected after the abstract screening. 31 after removing the duplicates and reading the full text. *Discussion:* The main themes surrounding transition of care that emerged from the synthesis are the organization of care within common models of transition, innovative clinical approaches to transition, and the experience of patients and caregivers. The transition from pediatric to adult care of cancer or SCD survivors is an emerging topic in pediatric nursing. The organization of care is affected by the lack of clear and well-structured organizational models. Further research is needed to deepen the understanding of some aspects of the transition. ([www.actabiomedica.it](http://www.actabiomedica.it))

**Key words:** oncology, sickle cell disease, pediatric, nurse, transition, review, models, organization, care, cancer

## Background

The transition of medical care from a pediatric to an adult environment is a psychological change, a new orientation that requires a self-redefinition of the individual, to understand that changes are taking place in his life (1). Transition is defined as a “purposeful, planned process with a goal of providing continuity of care and preparing young adults for greater independence” (2).

Transfer of care from pediatric to adult services may occur between 18 and 21 years of age (3,4). Young adults who make this transition from pediatric

oncology are usually long-term survivors, children who have survived cancer and need a follow-up period.

About 90% of young people with chronic health conditions survive and reach adulthood (5), and cancer survivors are a growing population (6). About 75% of survivors say they experience a chronic health condition, more than 40% still have serious health problems and 33% have multiple health problems (7). Many centers don't have a plan to prepare the survivors and their families for a successful transition (6), although a good plan can help young adults maintain optimal health outcomes, promote independence and empower them to manage their own health conditions (1,8).

Up to 60% of pediatric patients who transition to adult services will experience one or more disease or treatment-related complication as they become adults, including endocrine, cardiac, reproductive or psychological side effects, difficulty coping with adverse results of treatment, anxiety about the future, or an altered body image (9).

The same problems are experienced by patients with Sickle Cell Disease (SCD) (10). Almost 95% of patients with SCD live past the age of 18 and therefore require transition to an adult healthcare setting. For these patients, the period between 18 and 22 years of age is associated with an increased risk of mortality and morbidity due to poor adherence to therapy (11,12). As a consequence, pre-transition process measures are an important component of quality care in SCD (10).

Different transition models have been proposed to adapt to this difficult phase: generic models fit the traditional medical training models of pediatric, adolescent, and adult health care providers. In primary care models a family physician, or a primary care physician, is viewed as the care coordinator, and subspecialty consultants are used as needed. Single-site models are similar to generic models; the site of care remains constant as transition occurs from pediatric to adolescent to adult health care (3). Many patients have difficulty coping with this initial phase of the transition process, proved by an increase in access to the first aid, to emergency visits and re-hospitalizations.

Barriers to transition of care are most often classified into one of four groups: patient centered barriers, family centered barriers, pediatric caregiver barriers, and adult caregiver barriers (13,14).

A nurse who knows how to recognize potential barriers at an early stage can play a pivotal role in the educational plan for the transition process: this professional can identify the needs and limits of each young person, and must have a strong cultural background on this aspect (15).

## **Aim**

The present study aims at exploring, through a systematic literature review, the main topics of transition care in the pediatric hemo-oncological and oncological

setting, at identifying the strengths and weaknesses of this process, the different organizational phases, the models already tested, and at addressing the experiences lived by the main actors (patient and caregiver).

## **Materials and Methods**

A literature search was undertaken of PUBMED, CINAHL and The Cochrane Library, from March to April 2018.

The following keywords were used in combination to identify relevant publications: transition of care, oncology, cancer. The terms were combined using the Boolean operator AND. Limits for the search were: full text, publications in the last 10 years, articles in English or Italian, and any type of study design.

Inclusion criteria: articles about the transition process between pediatric and adult providers; articles about nursing topics related to the transition process, patient experiences of transition, caregivers experience of transition, facilitators, difficulties and barriers to transition; articles illustrating how handover between healthcare professionals is organized. Both articles exploring the transition process for patients with oncohematological, oncological disorders and sickle cell disease were all included as they share the same clinical environment and healthcare team.

Exclusion criteria: articles about the transition process between adult providers, articles about medical topics such as drug dosage, diagnosis, and costs related to the process, articles about transition processes for patients with a diagnosis other than cancer or sickle cell disease.

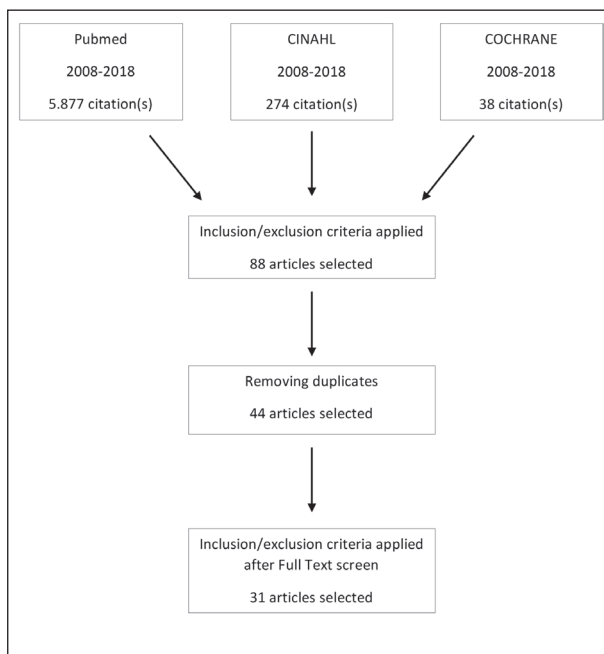
This literature review has been performed according to the PRISMA statement (16).

Using the keywords mentioned above, 38 articles were found in The Cochrane Library, but excluded because of lack of relevance. 5877 articles were found in PUBMED and 71 of these were selected, 274 articles were found in CINAHL and 17 of these were selected. A total of 88 articles were selected after the abstract screening. After removing the duplicates, 44 articles were considered.

After the reading of Full Text, 31 articles were selected, because the other fall in the exclusion criteria.

**Table 1.** Search strings and keywords.

Search number	Found articles	Selected articles	Keywords	Limits	Databases
1	4752	65	Transition of care AND oncology AND cancer	2008-2018, Full text, English and Italian	Pubmed, Cochrane Library
2	3351	42	Transition of care AND oncology	2008-2018, Full text, English and Italian	Pubmed, Cochrane Library
3	4053	46	Transition of care AND cancer	2008-2018, Full text, English and Italian	Pubmed, Cochrane Library
4	3	0	Transition AND cancer AND oncology	2008-2018, Full text, English and Italian	Cochrane Library
5	35	0	Transition AND oncology	2008-2018, Full text, English and Italian	Cochrane Library
6	15	0	Transition AND cancer	2008-2018, Full text, English and Italian	Cochrane Library
7	248	12	Transition of care AND cancer AND oncology	2008-2018, Full text, English and Italian	CINAHL
8	156	4	Transition of care AND cancer	2008-2018, Full text, English and Italian	CINAHL
9	162	8	Transition of care AND oncology	2008-2018, Full text, English and Italian	CINAHL

**Figure 1.** PRISMA Flow Diagram

Of these 6 were reviews of the literature, 1 policy statement, 14 descriptive studies in prospective/retrospective or cross-sectional design, 9 qualitative

studies with focus-groups, semi-structured interviews or Delphi studies, 1 qualitative socio-ecological study.

## Results

The main themes surrounding transition of care that emerged from the synthesis are the organization of care within common models of transition, innovative clinical approaches to transition, and the lived experience of patients and caregivers.

### Organization of care in transition

The definition of transition means the transfer experienced by adolescents and young adults from pediatric to adult care. This transition can be a period of major stress and unfavorable consequences especially for adolescents who have undergone treatment for a serious illness and must move from a sheltered pediatric environment to an independent adult-medicine environment. Adults who transitioned without a concrete plan reported feeling ill-prepared and that their

**Table 2.** Summary of results

<b>Study Author, Year</b>	<b>Design</b>	<b>Study Aim</b>	<b>Sample, setting</b>	<b>Findings</b>
Freyer et al., 2008	Literature review	To identify specific goals and action items in the following key areas: Models of Transitional Care, Survivor/Family Education, Post-Transitional Care Outcomes, Education of Health Care Professionals, and Health Care Policy and Advocacy.	Not applicable	Deficit in primary care assistance and long-term planning. Some centers use a team with a general adult physician and pediatrician. Pediatric oncologists should develop a plan for patients that accounts for the possible long-term effects that they may experience as adults. There is a need for increased family education, and additional education for care teams on the transition process.
McPherson et al., 2009	Descriptive cross-sectional study	Primary aim: to describe the preparation and knowledge of adolescents with Sickle Cell Disease during the transition process based on age, sex, degree of severity of the disease. Secondary aim: to identify adolescents' concerns about interfacing with transition process.	69 adolescents with Sickle Cell Disease, 30 females and 39 males, USA- Washington	Older children feel more prepared and have greater levels of knowledge about the process of transition of care. A positive attitude towards this process increases over the years, the difficulty of the process is inversely related to the severity of the disease. An insufficient knowledge and a late introduction to it emerges as the main barriers to the transition process.
Henderson et al., 2010	Literature review	To describe problems and obstacles to the success of transition programs dedicated to child cancer survivors.	Not applicable	Transition programs for child cancer survivors require the input from experts who can act as a bridge between pediatric oncology services and adult primary care services, in order to reduce risks associated with transition. The transition process must take place gradually and can be carried out optimally only by overcoming the concrete problems. The obstacles to the success of transition are put in place by those who should facilitate this process: the health system, the patients and those involved in providing care in the pediatric and adult fields.
Freyer, 2010	Literature review	To explore how the formal transition process can contribute to meeting the medical and psychosocial needs of child cancer survivors who usually have a lack of knowledge on health and health promotion.	Not applicable	Patients who survive childhood cancer are not compliant with the recommended follow-up in adulthood. The systematic transition process is the gold standard, even if there is no model that is ideal or better than others.

**Table 2.** Summary of results

Study Author, Year	Design	Study Aim	Sample, setting	Findings
Nathan et al., 2011	Literature review	To identify a systematic transition plan that considers diagnosis, initiation of therapy, completion of therapy, entry into long-term follow-up care, transfer from pediatric to adult medical providers, and exit from oncology care providers to primary health care providers.	Not applicable.	An appropriate care plan is essential to transfer the patient from a cancer clinic to the primary care setting. Many patients do not have a primary care provider, so the cancer clinic should help them find one. Some clinics accompany the patient during this phase, others discharge them at the end of the therapy without planning for the transition to the adult clinic.
Sobota et al., 2011	Survey, Descriptive cross-sectional study	To describe how the transition process takes place in pediatric hospitals with Sickle Cell Disease centers (logistic mode, identification of a physician in the adult area, patient preparation, program and transition assessment, demographic aspects).	Directors, or delegates, of 45 pediatric hospitals with Sickle Cell Disease centers. USA- Boston	The transition process is initially discussed when the patient is about 15 years old, and is initiated at around 19. 97% of the centers identify a referring physician in the adult area. Most professionals discuss it with the patient and the family, and prepare a plan that identifies needs. About half of the centers review the program annually, 39% measure patient satisfaction. The main obstacle is finding a referring physician in the adult service.
Schwartz et al., 2011	Qualitative study. Social-ecological model	To create a social-ecological model that describes the patient's preparation for the transition phenomenon.	Adolescent and young adult (AYA) with chronic health conditions, including patients with cancer and survivors.	Model divided into 3 parts (patient, parent, physician) that assesses the degree of preparation for transition by age, knowledge of the disease, and cognitive ability. This model considers the influence of health, culture, sociodemographic factors and health system on the style of coping that the patient and the family may develop. The model aims to be universal, therefore there is a need to validate it in specific populations.
Granek et al., 2012	Qualitative study. Grounded theory.	To identify psychological factors involved in the transition process.	Total: 38 patients. 10 patients still under the care of pediatric services. 28 patients who had undergone transition to adult services: 11 successfully transitioned, 17 failed the transition.	It is very important to take into account the psychological factors involved in the preparation of child cancer survivors who are transitioning to adult services. Identifying and addressing the individual psychological needs of these patients can contribute to a successful transition. Moreover, since the attitude towards one's own health is not always regulated by rationality, but is influenced by emotional drives, focusing on the psychological aspects, can help patients to address themselves in a positive way towards the treatment.

**Table 2.** Summary of results

Study Author, Year	Design	Study Aim	Sample, setting	Findings
McInally et al., 2012	Literature review	To explore the meaning of effective transition, highlight some of the challenges faced by young people with cancer, identify gaps in the research literature.	Not applicable	The care provided should be appropriate for the young adult; the patient's concerns must be heard by specialists; the transition of care should promote autonomy, independence and responsibility of the young person; the process must be flexible and planned with the family. There is no shared or emerging model to guide the process.
Sadak et al., 2013	Descriptive cross-sectional study	To generate hypotheses of facilitators of the transition process.	129 young adult (> 16 years old) cancer survivors that have not yet "passed" into the adult setting.	Young patients prefer a clinical team with a pediatric specialist and a clinical setting where there is good flexibility in planning the transition process. The possibility of using network to help the process is poorly considered. There is the necessity to clarify meaning of network, if included as a social network or network created by social media.
Schwartz et al., 2013	Qualitative forms: focus group e semi-structured interviews.	Further validation of the Socioecological Model of Adolescent and Young Adult Readiness to transition (SMART) through feedback from stakeholders: child cancer survivors, their parents and caregiver teams.	14 patients who survived childhood cancer. 18 parents. 10 health professionals specialized in the pediatric field.	Progress in the transition process is hampered by the lack of measurement instruments that could identify and improve current practices. SMART is a theoretical model, a comprehensive and empirically appropriate tool for assessing whether a child cancer survivor is ready for the transition process.
Klassen et al., 2014	Interview. Evaluation scales.	To develop and validate instruments that evaluate when a child cancer survivor is ready to transition from pediatric to adult care.	38 child cancer survivors: 10 still managed by pediatric care, 11 successfully transitioned, 17 failed transition process. 331 child cancer survivors, of these 250 completed the questionnaires.	There is limited knowledge about the experience of the transition process for child cancer survivors. Validated assessment tools can be used to investigate obstacles and / or facilitators to the transition process from pediatric to adult care. Creation of three evaluation scales: 1. Cancer Worry Scale 2. Self-management skills scale 3. Expectation scale
Fernandes et al., 2014	Descriptive study. Self-assessment survey: 30 multiple choice questions and 1 open-ended question.	To determine patient and parent attitudes and perceptions of the education provided during the transition process, and obstacles to transition .	155 patients with various chronic childhood illnesses, aged between 16 and 25.  104 parents or caregivers.	Most patients and parents say they have received information and training on the health condition. There are significant gaps in the educational process that takes place during the transition .  For example: lack of education regarding unprotected sex, birth control, pregnancy, drug abuse, and lack of job counseling. Some barriers to the transition process have been identified: emotional attachment to the pediatric team, and gaps in the provision of adult care. Most patients feel ready to complete the transition process at the age of 25.



**Table 2.** Summary of results

Study Author, Year	Design	Study Aim	Sample, setting	Findings
Andemariam et al., 2014	Descriptive retrospective study.	To describe risk factors for negative outcomes of the transition process.	47 patients with Sickle Cell Disease between the ages of 16 and 24 who experienced the transition process between 2007 and 2012.	The study shows that a transition with a negative outcome is not related to sex, race, episodes of “acute chest syndrome” or hospitalizations for episodes of vasocclusives. There is a correlation with the starting age of the transition (the most favorable outcome for those who start before the age of 21) and with the distance of the adult clinic compared to the pediatric setting.
Bryant et al., 2015	Policy statement	To define the process of preparing pediatric patients with Sickle Cell Disease for the transition of care	Not applicable	It appears necessary to start discussing transition at 12 years old, and start written planning from 14; to get help from organizations in the sector; to include in the plan a multi-professional team, and the family / caregiver; to make sure that parents leave the child alone only a part of the visit from the age of 13, and let completely alone visits from 18 years old. The process ends not in the transition to the adult setting, but when the whole team and the family are sure of the successful outcome of the transition.
Frederick et al., 2016	Qualitative study Focus group	To describe the commonalities and differences between experiences of patients with cancer.	16 patients recruited from a pediatric oncohaematological clinic, aged 21 to 39, who have completed therapy for at least 1 year.	Main themes emerged: education on “self-advocacy”, the worry about the future, the role of the family as an obstacle to autonomy, the dependence on parents to book visits and to make health decisions, the expectation of having a close relationship with the doctor, the problem of who to ask for support, the necessity of an individualized plan for the process, different expectations on primary care medical role.
Ganju et al., 2016	Descriptive cross-sectional study.	To evaluate the impact of the previous care, before the transition process, on patient knowledge and awareness of the disease. Identify any demographic or neurocognitive barriers to education.	110 patients enrolled. 93 of these completed the questionnaire.	Participation in patient care program plays an important role in the transmission of information regarding their pathological history and the perception of the risks of future health problems. Care programs for child cancer survivors must be developed and implemented to fill any gaps in the patients’ knowledge of self-management of health.
Svedberg et al., 2016	Cohort observational study. Mixed method.	To explore young adult cancer survivors experiences of support from health services during the transition process.	416 patients diagnosed with acute lymphoblastic leukemia between 1985 and 1997 enrolled in the Swedish Children’s Cancer registry. Of these, 144 completed the questionnaire.	Most participants received insufficient physical, mental and social support from health services. During the transition process it is necessary that health services adopt a personalized assistance plan. The approach used must be holistic and must support the patient in managing their life in the best possible way.

**Table 2.** Summary of results

Study Author, Year	Design	Study Aim	Sample, setting	Findings
Szalda et al., 2016	Descriptive cross-sectional study. Questionnaire.	To describe the patient perceptions of the involvement of adult services during follow up.	80 patients transferred from the Survivorship Cancer program at the Children's Hospital in Philadelphia to the adult-focused follow-up. 99 of these decided to participate in the study; 80 completed the questionnaire.	Young adults cancer survivors report a non-optimal involvement and communication during follow-up meetings for adults with cancer. Patients demonstrate a lack of understanding in the importance of follow-up.
Kenney et al., 2016	Descriptive cross-sectional study. Questionnaire.	To describe the current practices and models of transition process; to describe the perceived obstacles during the transition phase.	1586 medical specialists in pediatric oncohematology, members of the Children's Oncology Group. Of these, 507 replied to the electronic questionnaire. Of these, 347 possessed the eligibility criteria.	Systematic transposition practices do not seem to be widely used by pediatric oncologists. Specialists experience many barriers to the transition of patients to adult care. Medical specialists share the goal of providing patients with a systematic transition education to prepare them to manage their health needs independently.
Bashore et al., 2016	Pilot study	To examine the use of an interactive workbook as an educational method for patients facing the transition.	20 child cancer survivors, between 16 and 21 years old, who have completed therapy two years ago.	Those who are less ready to leave pediatric services are less likely to start the transition process. Patients experienced more anxiety at the start of the study than at the end. Those who finished the workbook reported they felt more ready for the transition. The workbook is recognized as an instrument, but more education and knowledge is needed on the process.
Margolis et al, 2017	Descriptive retrospective and cross-sectional study	To identify strengths and weaknesses in the management of transition from a pediatric to an adult clinical setting for patients with Chronic Granulomatous Disease	33 patients enrolled from 1 January 2011 to 28 February 2014, aged between 18 and 24.	The authors identified that introducing patients to the adult clinical setting before admission was a facilitator to transition. Main barriers identified included a lack of full understanding of the patient's disease and treatment regimen, lack of preparation and planning for the transition process, and missed opportunity for Advance Care Planning.
DiNofia et al, 2017	Descriptive cross-sectional study	To describe the wishes of parents of child cancer survivors in the transition process towards an adult setting.	138 enlisted parents, 123 enrolled, 41 responses collected. Parents of patients > 16 years of age who participated in the 3 years preceding the "LTFU Program at Children's National Medical Center"	Parents want complete involvement in the transition process. They consider it important to promote the independence and responsibility of their children, to be prepared for the transition process, and to maintain a point of contact at pediatric services.



**Table 2.** Summary of results

Study Author, Year	Design	Study Aim	Sample, setting	Findings
Sadak et al., 2017	Phenomenological qualitative study	To define the characteristics of a positive transition of care from the point of view of the patient's medical team, patient and parents, with semi-structured telephone interview.	29 professionals (10 doctors, 8 experienced nurses, 6 nurses, 2 psychologists, 1 social worker, 1 dietician, 1 administrative) of 3 institutions.	The study identified the following facilitators of transition: good communication between the pediatric and adult teams, multidisciplinary network of specialists, presence of several services within a structure (as happens mostly in Pediatrics), creating the figure of the "Patient navigator" (a bridge between the two settings), hold regular meetings between the pediatric and adult teams. The identified barrier is the lack of a home care team or primary care physician helping this process.
Quillen et al., 2017	Descriptive pilot study.	To identify and describe barriers that young adults encounter during the transition process within 5 years from the end of the pediatric therapeutic path.	48 young adults, aged between 20 and 25, who completed treatment in pediatrics and transitioned to adult services.	Barriers included a knowledge deficit in the transition process among young patients; lack of physicians' knowledge of the long-term effects; poor education on long-term follow-up. It could be useful to have a contact list of adult hospitals to create a transition plan.
Mouw et al., 2017	Qualitative approach: grounded theory. Interview.	To examine existing models of the transition process, emphasizing strengths and weaknesses. To optimize these models in order to maintain a connection with child cancer survivors who go through the transition process.	20 LTF experts (Long term Follow up): doctors, nurses, social workers, educators, psychologists from 10 institutions affiliated to the Pediatric Oncology group.	Most patients who survive childhood cancer develop physical and / or psychosocial sequelae; however, many subjects do not receive adequate long-term follow-up for screening, prevention and treatment of later complications. Patients benefit from transition models in which there is a greater and better connection between patient and specialist.
Nandakumar et al., 2018	Descriptive study: semi-structured telephone interviews	Describe the attitudes and experiences of child cancer survivors and their parents regarding barriers and facilitators to the transition process.	33 subjects interviewed: 18 patients who survived childhood cancer 15 parents of patients who survived childhood cancer	The obstacles to the transition process include: dependence on pediatric health services, low trust in general practitioners, inadequate communication and cognitive difficulties. Facilitators include trust of physicians, good communication, patient independence, and patient age when transition process is commenced.

transition was based on age rather than readiness or needs (17). These adult patients also reported that their follow-up care had declined since the transfer.

In addition, failure of transition and hence of appropriate surveillance for late effects may have potentially important medical consequences (6). Hence, a well-planned transition to adult care allows AYAs (adolescents and young adults) to optimize their health and ability to independently manage their disease and

assume adult roles and functioning (5). Thus, transition programs that prepare pediatric patients with SCD for the adult healthcare environment promote self-advocacy and self-management. Model transition programs use interdisciplinary teams to help adolescents develop this independence and knowledge.

While there is a body of literature on Advance Care Planning with AYA, this topic is often overlooked in the literature on transition (18). This is probably

due to the vast heterogeneity of situations that may be faced by caregivers dealing with this transition, so that the argument may have been considered as too broad. For instance, the pivotal focus in the transition programs for cancer and sickle cell disease (SCD) – one of the cases studied in this review – has so far been mostly focused on a very specific topic, the optimal age to deal with transition.

### Care Transition Models

Several models of care for adult survivors of childhood cancer were identified. According to Freyer et al., some institution-based programs transfer young adult survivors from the pediatric oncology clinic to an adult-oriented Long-Term Follow-Up (LTFU) team within the same medical campus, comprising both primary care physicians (e.g. family medicine or internal medicine) and pediatric oncology clinicians (e.g. physician or mid-level provider) (18). At the time of survivor transition (typically between 18–25 years old), the pediatric oncology team needs to prepare a detailed, comprehensive treatment summary to aid the new physician. This document should include a summary of the cancer diagnosis; prior treatment including significant clinical events; an assessment of current health status including a complete physical examination and list of active health problems and psychosocial issues; and potential late effects (with approximate risk estimate, if possible) that may result from the cancer, its treatment, genetic predispositions and any co-morbid conditions.

Freyer (19) classifies transitional care models under three headings. In the cancer center-based model transitional care is delivered within the same system as treatment was given and involves direct, on-site collaboration of the pediatric oncology team and adult care providers. In the community-based model, transition is located in the office or clinic of the care provider, typically a primary care clinician. With the hybrid model, care is also transferred to the office or clinic of the primary care provider but relies on an ongoing interaction with the cancer treatment center that includes bidirectional updates on patient status, assistance with clinical management, and provision of current survivorship

care guidelines. For all three models, the pre-transition phase relies on the pediatric long-term follow-up team (typically a pediatric oncologist, an advanced practice nurse, and a medical social worker).

A similar classification is proposed by Granek (20). In their work, some programs transition to a primary care practitioner, while others offer life-long care in specialized survivor clinics. An intermediate model distinguishes between survivors with high and low levels of morbidity. The former shall be included in specialized survivor programs, while the latter can be addressed to primary care practitioners.

The majority of pediatric cancer centers have a formal survivor program or clinic. The remaining centers do not have a specialized Long-Term Follow-Up (LTFU) program or clinic and provide follow-up to survivors in their acute care oncology clinics. Nathan (21) describes transition models for AYA cancer survivors in Canada. Once survivors reach adulthood, few centers have access to a formal program for adult survivors of childhood cancer, whereas the remaining centers discharge survivors to their primary care physician at some point after the completion of therapy. There are no formal survivor programs for adolescents/young adults who receive their acute cancer care in an adult hospital.

There are five core principles for transition arrangements of childhood cancer survivors to be successful (9):

1. The healthcare setting should be appropriate for the client's age and stage of development.
2. Common concerns associated with young adulthood should be addressed in addition to specialty care.
3. Transition should promote autonomy, personal responsibility and self-reliance in young adults.
4. Transition programmes should be flexible to meet the changing needs of young adults.
5. The designated process should be planned with the young adult and their family.

To describe transition practices and barriers to transfer, Kenney electronically surveyed 374 U.S. Children's Oncology Group members. Personal provision of transition education is delivered by the majority of pediatric oncologists, often with the help of other clinical staff. The majority of pediatric oncologists do not use a formal transition assessment tool such as

questionnaire, survey, or checklist to assess their patient's transition readiness (12).

Transition has been studied in depth also for SCD survivors. Andemariam defines the transition period for SCD patients as having three phases: preparatory, transitional, and completion. The preparatory phase is focused on patient education regarding SCD and patient-specific health issues and management (22). It lasts for 6–10 visits done every 4–6 months over a 3-year period. The transitional phase is dedicated to review health summaries, problem lists, and treatment plans with the family and the medical staff. It is focused on empowering the patient and promoting autonomous health management. The completion phase is focused on establishing effective patterns of health care in the adult setting.

Sobota carried out a survey of US pediatric providers and describes transition of SCD patients. Most clinics report having a transition program, although half have been in place for under 2 years (23). There is wide variation in specific transition practices. Close to all centers have an identified accepting adult provider, however, only slightly more than half routinely transfer their patients to an adult hematologist specializing in SCD. Although there has been a recent effort to establish transition programs in pediatric SCD clinics specific practices vary widely. Lack of an accepting adult hematologist with an interest in SCD emerged as a common barrier to transition. One-third of centers allow patients to remain in pediatric care past the cut-off age in cases of cognitive or developmental delay, or needing time to complete a transition program, graduate high school, or find an adult provider.

The majority of the aforementioned studies highlight that the transition age is a main determinant of success or failure of the entire process.

Bashore et al. (1) underlines that the American Academy of Pediatrics (AAP) has established guidelines for clinicians to begin transition as early as 12 years of age, to allow for acquisition of skills necessary for the independence required in adulthood. Not only should the chronological age of the adolescent be considered but also the developmental age of the adolescent.

Andemariam stresses that, in their study, older age at the time of initiation of the modified transition process was associated with poor transition success. The

preparatory and transition phases were changed such that both begin at age 16, and the definitive transfer to the adult SCD center is at the age 21. Ideally, patients schedule their first visit to the adult SCD center prior to reaching their 21st birthday, and prior to their last appointment at the pediatric SCD clinic (22).

In all three models proposed in Freyer's classification, the actual transition of care ordinarily takes place when the survivor reaches approximately 18 to 25 years of age and demonstrates transition readiness (19). The transition process needs to be initiated early—it is not too early to begin mentioning transition when the child is initially diagnosed with cancer—beginning at 18 years of age is almost certainly too late.

In another study the majority of respondents transferred childhood cancer survivors to adult care by age 25 years (12). The timing of transfer was most often determined by patients' chronologic age, diagnosis of adult comorbidities, and pregnancy.

According to Bryant et al. (10), a formal discussion about transition and the policy of the practice/institution should begin at age 12 (or when developmentally ready) with both parent and child. All patients should have a written transition plan by age 14. This plan should be developed together with the patient and their family and updated annually.

In a survey of transitioned patients, it has been demonstrated that most participants agreed that the transition should begin in early to mid-adolescence (24). This is needed to optimize education of disease history, current and future survivorship care needs, and medical risk.

In a survey of US pediatric providers, Sobota et al. (23) describes that just over half of the centers are in a system with a required age for transition due to "hospital policy," which ranges from 18–22 years. Transition is first discussed at a mean age of 15.7 years (range 13–18) and transfer occurs at a mean age of 19.6 years (range 18–25). Age and pregnancy are still the primary factors that determine time of transfer. Pregnancy in adolescents and young adults may not be planned, and therefore, using it as a trigger for transfer is unlikely to allow adequate time for preparation. Using age as a proxy for maturity may be particularly problematic for patients with SCD, who may have neurocognitive delay due to cerebrovascular injury.

According to Quillen (15) pediatric cancer survivors could start transition to adult health care at 21 years of age.

### **Innovative Approaches to Transitional Care**

As underlined by Ganju (25) a transitional clinic for young adult survivors (YAS) of childhood cancer is an evolving model and at present, there is little research evaluating the benefits, implementation, and efficacy of these clinics for pediatric cancer survivors.

Granek stresses that an important implication for practice is to empower teens' sense of identity as a cancer survivor by engaging with their peers and encouraging them to attend cancer-related groups and organizations that provide information and social support for survivors (20). This could be achieved through camps or organizations that involve peers as well as through peer mentor or 'buddy systems' within the health care context.

Freyer (19) propose an interactive online program called Passport for Care, which provides survivors and clinicians with a virtual resource center, where they can enter patient-specific history and receive individualized monitoring recommendations.

A pilot study examined the use of an interactive transition workbook as a method of educating survivors about their medical history, providing necessary information about the transition to adult care, and working with them to establish goals and plans for education and vocational success (1). Having the time to collate this information in an organized manner may have assisted them in processing the transition from pediatrics to adult care in the future.

Klassen et al. (26) developed three scales for childhood cancer survivors that measure concepts identified as barriers and/or facilitators to transitioning successfully to adult-orientated health care. They measure Cancer Worry (about cancer-related issues such as relapsing or getting a new type of cancer), self-management skills (investigating skills that adolescents need to acquire to be able to care for their health as adults, such as booking doctor's appointments and filling prescriptions) and expectations (delving into the nature of adult Long Term Follow Upcare, such as expecting to get a reminder call before an appointment).

Sobota, Shah and Mack (27) propose that sending a transfer summary ahead of the first visit in adult care should be part of best practice in transition. According to the results of an expert panel, adult SCD providers would also appreciate direct communication from the pediatric hematologist. Lack of time and reimbursement are often cited as barriers to providing comprehensive transition. To solve this problem, transition advocates have identified billing codes that allow reimbursement for transition activities such as updating a transfer summary (e.g. by billing for "care plan oversight").

A transition model called SMART – Socio-ecological Model of AYA Readiness for Transition was proposed by Schwartz et al. (5). This model of transition extends beyond patient age and patient knowledge and skills by identifying measureable social-ecological components of the transition process and highlighting the potential role of culture and socio-demographics in the transition process, a neglected issue.

Innovative approaches such as peer mentoring programs or web-based interventions may reach more patients compared to the traditional clinic approach (28). Important next steps include further education for patients and adult providers, ensuring adequate transition planning for youth and their families, and research to determine what factors have the most significant impact on transition quality.

### **The Patient experience**

The point of view of YAS is necessary to understand how to achieve a successful transition. To elicit this, patients aged from 16 to 39 years are often asked to complete a questionnaire by e-mail or during their annual survivor clinic visit. The most common questions concern barriers and facilitators to transition, how they received the relevant information, the relationship with their parents, and recommendations for a successful transition. Some studies have investigated gender differences (25,29); the psychological and social aspects of transition (20,21,30,31) and age differences (22,29).

Regarding gender differences, 30 females and 39 males (Median age was 16.7 years) responded to a survey on transition to adult services (29). Female patients reported a higher level of anticipated difficulty

than male patients. No significant differences were found between knowledge, thought, interest, and importance of transition. In the study by Ganju et al. (25) men were less likely than women to expect future health risks from their cancer treatment.

Regarding the psychological aspect, severity of disease and a high rate of hospitalization had a negative impact on patients' interest in learning about transition (18,22,29). Using the Childhood Cancer Survivor Study Neurocognitive Questionnaire (CCSS-NCQ), Ganju et al. (25) found that the patients are more likely to assess their health risks based on their current health states, as opposed to the intensity or duration of their treatment. The transitional period often takes place at a critical time during survivors' development into independent young adults. Many survivors view themselves as completely healthy or invincible and they do not recognize their risk of serious cancer-related health problems and do not adhere to recommended cancer-related follow-up care (21). Furthermore, childhood cancer survivors may experience psychological symptoms of depression, anticipatory anxiety prior to the transfer and posttraumatic stress (PTS) which can hinder their engagement with medical care and make the transfer of care to the adult system a difficult emotional process (30,31). In the study by Svedberg et al. on 213 YAS of pediatric cancer, they found that survivors would have appreciated more follow-up information based on their needs and on their psychosocial health (31). The participants reported they had not received the annual follow-up visit to control the risk of late effects of treatment, did not experience sufficient support for: depression, panic disorders, eating disorders, obsessions, hypochondria and did not receive treatment strategies for physical changes.

Patient age was significantly associated with interest in the transition. Older age at the time of initiation of the modified transition process was associated with poor transition success (22) but patients aged 17–20 years demonstrated significantly greater knowledge and interest in transition, greater self-management skills to make their own appointments and call for medication refills than 14–16 years old (10,29). A slightly older age at transfer may improve readiness for transfer but conversations about high-risk behaviors such as alcohol, tobacco, illicit drug use, sexual intercourse, need to begin in early adolescence (32).

In some studies, the relationship and attachment to the family and to the pediatric healthcare providers has been identified as a barrier. Patients recognize the importance of care received from parents and pediatric health care providers but report this has made them less prepared for autonomy in adult life. Therefore, parents still play a significant role in communication with the healthcare services even when the patients become adults (31,32). Dependence on parents or doctors could be necessary to compensate for cognitive difficulties that result from chemotherapy treatments, as these can negatively affect self-management ability (14). Several patients develop their self-management abilities and understand their disease only after transition experience (11,14). Also, pediatric oncologists find it difficult to transfer long-term patients into adult care because of their long-standing relationship with them (14,32).

Patients suggest that awareness of the differences in care between the pediatric world and the adult world could facilitate transition (28). About 63% of adolescents wanted their pediatric doctor to supply specific information about adult hospitals in the area, 59% requested written information about the transition process, 39% requested help in making the first appointment with an adult provider, 33% asked to be connected to someone who had already gone through the transition process (28), 23% requested help in visiting different adult hospitals, and 17% requested group meetings with other patients to discuss transition (29). Other information requests concern specific names of doctors, information on insurance coverage, ease of appointment scheduling and parking/ transportation (29). Good communication was perceived to enable successful transition and was associated with positive transition attitudes. Communication also provided comfort during transition (14). The most important information for patients with SCD, was concern about the modalities of pain management and planning re-entry for transfusions (22).

Key barriers to transition included dependence on pediatric healthcare providers, less confidence in primary care physicians (PCPs), inadequate communication, and cognitive difficulty (14). Less than half of patients (N=155) and parents (N=104) reported receiving any education regarding reproductive health (specifically, unprotected intercourse), impact of



disease on future offspring, birth control, risk of pregnancy, illicit drug use, and future career (32). Lack of knowledge about the disease and anticipatory guidance about the process were the major barriers in transition (29,33). Nearly a quarter of participants in Margolis' study (33 young adult participants, 19 - 27 years of age), reported that they did not feel included in planning the transfer of care or in the actual transition itself. One AYA said, "*There was no transition. It just kind of happened*" (33). Only in one study, a lower income was a demographic factor that correlates with less knowledge (25). Patients who have experienced a greater number of complications, like acute chest syndrome (ACS) episodes and hospitalization for vaso-occlusive crisis (VOC), are less likely to experience a positive transition (22).

In some cases participants expressed dissatisfaction about losing contact with healthcare services after the age of 18 or after being discharged from the pediatric oncology ward at the end of treatment (31), but the real problem is the perceived negative attitude and lack of trust in new adult care provider (18). Specifically in the Emergency Department and inpatient units, the staff were not well informed about SCD (28) or the PCPs did not demonstrate sufficient cancer-specific knowledge to provide the level of care that pediatric HCPs could (14). In particular, young adults with SCD have the perception that health care professionals in the adult world underestimate the degree of pain experienced (28). Some Adult Patients with SCD have reported "*these physicians did not have enough medical knowledge about sickle cell disease*" (11).

Non-clinical risk factors for unsuccessful transitioning were greater travel distance from the patient's home to the adult SCD center (22), or the inaccessibility of care due to distance (14) transfer to another city (11), and insufficient medical insurance (11,14).

According to the results of this literature review, patients demonstrated high levels of awareness about the importance of transition and showed interest in learning about the process. The transition is a time-consuming process and the goal is to become responsible for oneself (28). Svedberg et al. (31) and Frederick et al. (32) underline the need for a personalized, holistic care plan. Survivors desire a multidisciplinary care team that offers care across multiple specialties and

subspecialties but it is unclear which disciplines would be central to the clinical team (34,35). The major barriers in transition included dependence on pediatric HCPs, less confidence in PCPs, inadequate communication, and cognitive difficulty (14). The emotional components such as fear, anxiety, gratitude and gaining perspective acted as both facilitators and barriers to transition in different childhood cancer survivors (20). Improvements in the transition process could be made with more written information about local adult providers and the overall transition process through an appropriate medium "like a website or a booklet" (14,29). In some studies, group meetings and visits to adult hospitals were not highly rated (29), while in the qualitative study of Sobota et al. (28) the young adults with SCD suggested meeting the adult provider prior to transfer. During the transition process, patients also need comfort and support for coping with difficult thoughts and memories of traumatic experiences (31). To increase coping, the figures to be involved are: family, survivors, and adult health staff (1).

### The Caregiver Experience

The transition phase should assist parents or caregivers in accepting a new role, as they may no longer be directly responsible for the patients' care. Transition means not only a change in the place of care or a change in the referring physician, but also an increased responsibility for the young adult, who must learn to interface directly with the medical specialist and health services (34). Survivorship care plans are an important method for addressing the challenge of safe and effective transfer of care from cancer center to primary care. These documents should be created by the cancer team and shared with patients, families and primary care providers at the end of treatment (21).

While being the only point of reference in the care path creates a unique bond, at the same time it also creates an important barrier. Young patients identify the longstanding dependence on parents for healthcare management as an important barrier, including their reliance on parents to retain critical health information, coordinate appointments, and engage in critical health decisions (24).



A notable difference between survivor and parent point of view on transition emerges from the study of Frederick et al., where only 43% of survivors reported parental inclusion as “very important” in their decision to transition care compared to 83% of parents (24).

This discrepancy could mean that young adults experience a period of increasing independence.

There is also a subset of childhood cancer survivors that develop an unhealthy dependence on their parents for coordination of their health care.

On the other hand, while there are many possible reasons for this discrepancy between desired parental involvement, this difference in scores emphasizes the fact that all models of transitional care for child cancer survivors must allow adaptation to the new care setting to meet the individual needs of each survivor and his family, including parents

Sadak et al. report that parents feel “*worried because they feel like everyone in pediatrics knows exactly what happened [to their children]*” and may wonder if the team of adult-centered survivors “*really know*” and “*understand consequences of having received the treatments*”. It is important for parents to know that “*their child is moving to a team of specialists who focuses specifically on caring for the adult survivor [of child cancer]*” (34). The medical team in the adult area should make caregivers more involved in the care path by showing them the informative and teaching materials that they will give their children.

Fernandes et al. shows that 73% of parents support the allocation of resources and materials for more education and assessment prior to transitioning, and 95% of parents supported the allocation of resources to improve the transfer process of patients from pediatric- to adult- oriented care (32).

DiNofia, Shafer, Steacy, & Sadak showed that 100% of parents believed it was important to promote the independence of survivors. Sometimes, these desires can be conflicted. The achievement of autonomy for adolescents with chronic health conditions is often delayed compared to peers without these conditions (36).

However parents also have the opportunity to be proactively involved in supporting the path of their child towards the independence of healthcare (36).

Some parents suggested strategies that could help alleviate their fears, for example by using the resources

of a pediatric provider that could help / mediate part of the transition by working together with adult providers and building patients / parents support groups (32).

These two studies agree that additional studies are needed to determine if parental attitudes about transition of care to adult care settings and their inclusion in the transition process are determinants of successful transfers.

The perceived barriers to transition to adult care included deficits in: disease understanding, medication regimen understanding, knowledge about advance directives, and preparation, planning, and practice related to the transfer in care. In this sense, the participation of caregivers is intended as a facilitator and not a barrier (36).

The good preparation and skill of the adult team to succeed at this stage is fundamental: “*educating the families about the idea of transition and that is beneficial is critical*” (34). This literature review has illustrated that sufficient planning of transition is the main contributor to successful outcomes for survivors.

## Discussion

The organization of care is affected by the lack of clear and well-structured organizational models. The first problem that arises is the age of the patient when they start this process. The second is whether the care team is adequate for dealing with the transition and what are the professional figures that shall be involved in the process. The third is the active role given to the family. New innovative models to increase the patient’s awareness of this transition have been studied. However, emotional factors such as anxiety and fear are still considered as crucial from the perspective of patients, families, or caregivers. Active involvement of the whole family member is necessary to promote survivor autonomy.

This process has to start at an early age and reach the definitive phase with the full maturity of the young adult.

This review highlights how some non-organizational aspects, mainly related to the sphere of the subject’s experience, are essential for the success of the process. In fact, unlike studies that deal only with the issues of therapy, the ultimate goal of the transition is

achieved when the patient positively accepts the move into the adult environment and becomes independent and autonomous in dealing with the disease.

The phenomenon of transition faces multiple aspects and includes multiple actors. By dividing the review into these paragraphs, we tried to touch all those fundamental aspects to create a winning treatment plan in the near future.

## Conclusion

The transition from pediatric to adult care of cancer or SCD survivors is an emerging topic in pediatric nursing.

This systematic review is the first that includes a review of the transition of care for pediatric patients with cancer or SCD, in all aspects of care.

The review has some limitations: first, it was decided to take into consideration both patients, with oncohematological pathologies and with sickle cell disease, since in most international situations these two groups have in common the same care environment (same hospital unit). However, the two types of patients face different treatments, with treatment paths that can be differently structured, even at the age of taking charge.

Another limitation regards the different types of studies considered to carry out the review: the studies, both quantitative and qualitative, approach the different experiences from different points of view that are sometimes difficult to reconcile. As a result, conflicting results may sometimes emerge.

The strengths concern the originality of the study as the issue of transition, both in the medical and nursing fields, is increasingly prevalent. A review that builds bridges between the different realities can help to create a common care pathway between the two environments.

The review also sought to explore the experiences of both patients and caregivers, considering them both as important and fundamental actors, together with healthcare professionals.

Further research is needed to deepen the understanding of some aspects of the transition care, such as the training provided at university level regarding

this process and the possibility of creating an instrument that allows to act as a mediator in the transition process, “like a website or a booklet”.

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## References

1. Bashore L, Bender J. Evaluation of the Utility of a Transition Workbook in Preparing Adolescent and Young Adult Cancer Survivors for Transition to Adult Services: A Pilot Study. *J Pediatr Oncol Nurs* 2016; 33 (2): 111–8
2. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult healthcare systems for adolescents with chronic conditions. A position paper of the society for adolescent medicine. *J Adolesc Health* 1993; 14: 570–576
3. Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. *Pediatrics* 2010; 126 (1): 129–36
4. Jin YT, Chen CM, Chien WC. Factors influencing transitional care from adolescents to young adults with cancer in Taiwan: A population-based study. *BMC Pediatr* 2016; 16: 122
5. Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev* 2011; 37 (6): 883–95
6. Mulder RL, van der Pal HJH, Levitt GA, et al. Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. *Eur J Cancer* 2016; 54: 64–68
7. Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med* 2004; 2 (1): 61–70
8. Mouw MS, Wertman EA, Barrington C, Earp JA. Care Transitions in Childhood Cancer Survivorship: Providers' Perspectives. *J Adolesc Young Adul* 2017; 6 (1): 111–119
9. McNally W, Cruickshank S. Transition from child to adult services for young people with cancer. *Nurs Child Young People* 2013; 25 (1): 14–8

10. Bryant R, Porter JS, Sobota A, Association of Pediatric Hematology/Oncology Nurses, American Society of Pediatric Hematology Oncology. APHON/ASPHO Policy Statement for the Transition of Patients With Sickle Cell Disease From Pediatric to Adult Health Care. *J Pediatr Oncol Nurs* 2015; 32 (6): 355–9
11. Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD. Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. *Int J Hematol Ther* 2015; 1 (1)
12. Kenney LB, Melvin P, Fishman LN, et al. Transition and transfer of childhood cancer survivors to adult care: A national survey of pediatric oncologists. *Pediatr Blood Cancer* 2017; 64 (2): 346–352
13. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatr Blood Cancer* 2013; 60 (8): 1365–8
14. Nandakumar BS, Fardell JE, Wakefield CE, et al. Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care. *Support. Care Cancer* 2018; 26 (8): 2743–2750
15. Quillen J, Bradley H, Calamaro C. Identifying Barriers Among Childhood Cancer Survivors Transitioning to Adult Health Care. *J Pediatr Oncol Nurs* 2017; 34 (1): 20–27
16. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009; 3 (3): 123–130.
17. Kanter J, Kruse-Jarres R. Management of sickle cell disease from childhood through adulthood. *Blood Rev* 2013; 27 (6): 279–87
18. Freyer DR, Brugieres L. Adolescent and young adult oncology: transition of care. *Pediatr. Blood Cancer* 2008; 50 (5 Suppl): 1116–9
19. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol* 2010;28 (32): 4810–8
20. Granek L, Nathan PC, Rosenberg-Yunger ZR, et al. Psychological factors impacting transition from paediatric to adult care by childhood cancer survivors. *J Cancer Surviv* 2012; 6 (3): 260–9
21. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer* 2011; 117 (10 Suppl): 2335–41
22. Andemariam B, Owarish-Gross J, Grady J, Boruchov D, Thrall RS, Hagstrom JN. Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. *Pediatr Blood Cancer* 2014; 61 (4): 697–701
23. Sobota A, Neufeld EJ, Sprinz P, Heeney MM. Transition from pediatric to adult care for sickle cell disease: results of a survey of pediatric providers. *Am J Hematol* 2011; 86 (6): 512–5
24. Frederick NN, Bober SL, Berwick L, Tower M, Kenney LB. Preparing childhood cancer survivors for transition to adult care: The young adult perspective. *Pediatr Blood Cancer* 2017; 64 (10)
25. Ganju RG, Nanda RH, Esiashvili N, Switchenko JM, Wasilewski-Masker K, Marchak JG. The Effect of Transition Clinics on Knowledge of Diagnosis and Perception of Risk in Young Adult Survivors of Childhood Cancer. *J Pediatr Hematol Oncol* 2016; 38 (3): 197–201
26. Klassen AF, Rosenberg-Yunger ZR, D'Agostino NM, et al. The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults. *Health Expect* 2015; 18 (6): 1941–55
27. Sobota AE, Shah N, Mack JW. Development of quality indicators for transition from pediatric to adult care in sickle cell disease: A modified Delphi survey of adult providers. *Pediatr Blood Cancer* 2017; 64 (6)
28. Sobota AE, Umeh E, Mack JW. Young Adult Perspectives on a Successful Transition from Pediatric to Adult Care in Sickle Cell Disease. *J Hematol Res* 2015; 2 (1): 17–24
29. McPherson M, Thaniel L, Minniti CP. Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatr Blood Cancer* 2009; 52 (7): 838–41
30. Schwartz LA, Brumley LD, Tuchman LK, et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatr* 2013; 167 (10): 939–46
31. Svedberg P, Einberg EL, Wärnestål P, et al. Support from healthcare services during transition to adulthood - Experiences of young adult survivors of pediatric cancer. *Eur J Oncol Nurs* 2016; 21: 105–12
32. Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, et al. Transitioning and Transfer of Adolescents and Young Adults with Pediatric Onset Chronic Disease: The Patient and Parent Perspective. *J Pediatr Rehabil Med* 2014; 7 (1): 43–51.
33. Margolis R, Wiener L, Pao M, Malech HL, Holland SM, Driscoll P. Transition From Pediatric to Adult Care by Young Adults With Chronic Granulomatous Disease: The Patient's Viewpoint. *J Adolesc Health* 2017; 61 (6): 716–721
34. Sadak KT, Neglia JP, Freyer DR, Harwood E. Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers. *Pediatr Blood Cancer* 2017; 64 (11)
35. Szalda D, Pierce L, Hobbie W, et al. Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care. *J Cancer Surviv* 2016; 10 (2): 342–50
36. DiNofia A, Shafer K, Steacy K, Sadak KT. Parent-perceived Facilitators in the Transition of Care for Young Adult Survivors of Childhood Cancer. *J Pediatr Hematol Oncol* 2017; 39 (7): e377–e380

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