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Long-term follow-up after childhood cancer in Switzerland: a position statement from the pediatric Swiss LTFU working group

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Summary

With better risk assessments, improvements in treatments and optimized supportive care more than 87% of the children with cancer become long-term survivors in Switzerland. Many studies have demonstrated that this enlarging population has a lifelong increased risk of morbidity and mortality associated with the underlying disease and the therapies received. Altogether, two thirds of the survivors will present at least one chronic health condition during their life and for one-third of them, the condition will be severe or life threatening as late effect of their treatment. In this context, a structured long-term follow-up is needed. The aim of this article is to give a global vision of the current situation in Switzerland concerning the different care models proposed to childhood cancer survivors and to provide recommendations for appropriate transition and long-term follow-up care.

Introduction

Until two decades ago, the focus in pediatric oncology was almost exclusively on curing the diseases. Today 87% of all childhood cancer patients are cured and there are about 5'700 childhood cancer survivors (CCS) with completed treatment living in Switzerland [1]. In the last 20 years, it was shown that a large proportion of the survivors suffer from late effects of their oncological treatment and that the number of patients affected by late effects rises with age. The Childhood Cancer Survivor Study, conducted in the USA and Canada, has shown, that two thirds of survivors with cancer diagnosed between 1970 and 1986 have at least one chronic health condition and one third have a severe or life threatening health condition as late effects of the treatment they received [2-6]. We hope that modern treatments will have fewer late effects, as we try to adapt the treatment to the growing knowledge about chronic health issues. Late effects are multifaceted. They can affect all organs. Particularly endocrine, cardiac and pulmonary as frequently occurring late effects as well as psychosocial challenges can lower the quality of life significantly if untreated [7]. Furthermore, it was also demonstrated that CCS have a significantly increased risk of mortality compared to the rest of the population [4]. These results underline the importance of a lifelong specific and structured long-term follow-up (LTFU) to improve the quality of life and diagnose treatable late effects early enough to prevent further deterioration of health and early death [8]. In other - especially English speaking - countries, specialized survivorship clinics providing LTFU in a highly effective manner exist for some time [9].

This publication is a position paper of the Swiss LTFU working group aimed to have a global vision of the current situation in Switzerland concerning CCS medical care models, and to provide recommendations for appropriate survivorship transition and LTFU care. The LFTU working group of Childhood Cancer Switzerland consists of health care professionals, researchers, survivors and parent representatives.

Long-term follow-up care in Switzerland: current state

Until about ten years ago most Swiss survivors were closely followed-up in their treatment centers for at least 5-10 years (mostly longer) and then transferred to general practitioners or clinical oncologists most commonly without detailed evidence-based information and instruction about LTFU care. Many of these older survivors do not have any specific follow-up (FU) care after transition [10].

Currently, all nine SPOG (Swiss Pediatric Oncology group) centers in Switzerland offer a FU in the first years after the end of treatment and most have a transition model into adult care (**Tab. 1**). Additionally, four centers offer LTFU clinics for adult survivors (Aarau, Bern, Geneva and Kantonsspital Baselland in Liestal as a non SPOG center) interdisciplinary with pediatric oncology. Many of these adult clinics are open to survivors from across Switzerland. Most of the survivors attending LTFU clinic at the Kantonsspital Baselland so far are in their thirties or older and have been lost to FU previously.

Recommendations of the working group

For CCS, there are two different steps of transition. One concerns the transition from the initial disease-directed FU to the LTFU, usually 2 to 5 years after the end of treatment (EOT) depending on the disease; and the second one is related to the transition from child to adult-focused care, usually at age of 18 to 20. While the first step is usually carried out in the same clinic, it is the responsibility of the treating pediatric cancer team to provide a written health-care summary including minimal information set (**Tab. 2**) to the survivor and his family. The risk-based monitoring for late complications (LTFU recommendations) and preventive recommendations (like no smoking, less or no alcohol, physical activities, healthy weight, sun protection and consumption of fruits/vegetables) has to be provided to the survivor, both orally and in written, by the LTFU team. There are different models for transition from child to adult-focused care [11-13]. The chosen model will depend on the local resources and organization, but for most of the CCS a multidisciplinary approach based on the individual patient-risk is necessary. The LTFU programs have to be tailored to the needs of the CCS in respect to the treatment they received and the late effects they suffer [14, 15] as well as their mental level and maturity. This is especially relevant for survivors of neuro-oncological diseases who need specialized LTFU. The LTFU program must be coordinated and provided by physicians with expertise in childhood cancer survivorship who are aware of the last updated LTFU guidelines. The LTFU clinic should also include a pediatric oncologist or a close collaboration with the pediatric oncology clinic. The transition process to an adequate adult-focused LTFU care is a very important step which must be formal and well prepared. Because CCS are considered cured, but remain at risk for late effects, the question why continued medical care is necessary has to be discussed with CCS to encourage them to participate in the LTFU and to take responsibility for their health. As many late effects can be asymptomatic at the beginning risk tailored and frequent examinations are mandatory.

The patient-tailored LTFU recommendations have to be built on evidence-based late effects guidelines. Currently, different LTFU-guidelines exist and there is an international effort to harmonize them. The most complete and established guidelines currently available are the Long-Term Follow-Up Guidelines of the Children's Oncology Group (COG) (http://www.survivorshipguidelines.org/pdf/2018/COG_LTFU_Guidelines_v5.pdf). In those, the necessary clinical examinations are specified. This risk stratification based on the treatment received is currently investigated internationally. Based on the COG-LTFU-Guidelines, there are tools helping clinicians to summarize the treatment and individualize the recommendations («Passport for Care®», St. Jude's survivorship care plan). In Europe, a Survivorship Pass is under development. The tools should not only help the medical professional, but also the survivors to better understand the treatment they received and the recommendations for follow up and organs at risk.

In conclusion, we see a need to use the same guidelines and unified tools in Switzerland. These should be adapted to the resources and to the different types of local organization. A health care summary including the precise cancer treatment received and a personalized LTFU plan must be available for all Swiss CCS or their legal representative in survivors with cognitive impairment. The LTFU plan must be continuously adapted to the survivor, to the treatments received and to the updated current recommendations. A formal transition process to adult LTFU providers is essential to avoid loss to FU. At age 18 to 20 survivors who are at least two years after end of treatment or four years after initial diagnosis should be transitioned to an adequate adult LTFU - service. This harmonization approach meets the initiatives of active survivors and patient advocates and is therefore strongly endorsed by the community on national and international level, ensuring equal access to a high-quality LTFU services for all CCS.

Swiss LTFU working group perspectives

Currently there is a general lack of funding and human resources to tackle the problems of optimal LTFU-care. Especially psychosocial support and academic/vocational counselling are missing at many sites. We are fighting for adequate reimbursement of the work needed and have had some success so that the preparation of the minimal treatment summary including individual and evidence-based LTFU guidelines can now be billed based on TarMed rates system.

Optimizing LTFU care for all Swiss CSS and solving further specific problems of survivors, especially psychosocial issues (academic and vocational issues, fatigue etc.) or work related problems will have health economic relevance as well.

Tab. 1.

	LTFU program			Documents provided to the patient		Transition	
	Specific LTFU clinic	Disease specific LTFU clinic	LTFU Guidelines used	Treatment summary	Specific FU recommendation	Transition/ Follow up model	Age at transition/ Survivor-Population
Aarau	Yes	Yes (oncology , neurooncology, ortho-oncology, endo-oncology – both pediatrics and adult)	COG-LTFU Guidelines	Yes (St. Jude's survivorship care plan)	Yes	Interdisciplinary clinic coordinated by pediatric oncology	From 18 years onwards and at least 2 years after EOT
Basel	No	Yes (neurooncology)	Mainly COG-LTFU Guidelines	Yes, but not systematically (transition letter)	Yes, but not systematically	Adult oncologist or hematologist	18-20 years
Bellinzona	No	No	Treatment protocol based recommendations	Yes (Transition letter)	Yes	Not systematic	18 years, at least 3-5 years after EOT
Bern	Yes	Yes (oncology and neurooncology in childhood, specialties as needed in adulthood)	COG-LTFU Guidelines	Yes (COG passport for care)	Yes	Interdisciplinary; coordinated by internal medicine	18-20 years
Geneva	Yes	Yes (oncology and BMT)	Adapted COG-LTFU Guidelines and literature, and specific guidelines for post BMT patients	Yes (not for post BMT patient)	Yes	Interdisciplinary, coordinated by a pediatric and adult oncologist; or hematologist	20 years and at least 5 years after EOT. 18-20 years for post BMT
Lausanne	Yes	Yes (oncology and neurooncology)	Adapted COG-LTFU Guidelines and literature	Yes (transition letter)	Yes	Adult oncologist/ hematologist or GP/ internal medicine for selected patients	18-20 years
Liestal	Yes	Yes (specialties as needed)	COG-LTFU Guidelines	Yes (COG passport for care)	Yes	Interdisciplinary clinic coordinated by internal medicine/ endocrinology	>18 years, survivors without systematic FU
Lucerne	No	No	Protocol based and GPOH recommendations	Yes (transition letter)	Yes	Not systematic	Individualized
St Gallen	Yes	No	GPOH recommandations	Most (transition letter)	Yes	Only for neurooncology and some endocrinology patients	18 years
Zürich	No	No	GPOH recommandations and literature	Yes (transition letter)	Yes	Not systematic, network with adult oncologists and local Cancer League	Individualized

COG: Children's Oncology Group; EOT: End of treatment; BMT: Bone Marrow Transplantation; GPOH: Gesellschaft für pädiatrische Onkologie und Hämatologie; GP: General Practioner.

Tab. 2.

Cancer diagnosis

- Age at diagnosis
- Exact diagnosis (morphologic and molecular subgrouping), stage
- Date of diagnosis

Minimal Treatment Summary Information

- Name of the protocol, risk group and specific treatment arm, start and end date of treatment
- Cumulative dosages by body surface area of all relevant chemotherapeutics, separately calculated according to the application way (IV, PO, SQ, IT, IM, intra-peritoneal) and dosing (high dose, low dose, myeloablative)
- Cumulative dose of anthracyclines (doxorubicine equivalent dose) (important to determine the frequency of a cardiological follow up)
- List of biologicals and other additional drugs directed at oncological disease (for example ATRA)
- List of other therapeutic treatments (for example therapeutical MIBG treatment)
- Details of radiotherapy: radiation field, modality, duration, dose of single fractions, boost region and dose, total dose
- Surgeries due to oncological treatment including central venous catheters placement with date and details (examples: sacrifice of organs, laparotomy, neurosurgery affecting pituitary, limb sparing surgeries, amputation)
- Details of autologous and allogeneic stem cell transplantation (conditioning regime, source, acute and/or chronic GVHD, serious side effects, donor, date of transplantation)
- List of important and relevant treatment complications

Conclusions

Survivors of Childhood Cancer are a growing population with specific problems and vulnerabilities. The aim of the Swiss LTFU working group is to improve the health-related situation for all Swiss survivors by following international LTFU guidelines, by responding to their information needs and by creating more resources for psychosocial or vocational needs.

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