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Cure is not enough! Why it is time to act and close the gap

Survivors speaking up

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Summary
Purpose Good news: Survival rates in childhood cancer have increased from 20% up to over 80% in Europe, depending on cancer type and country. Not so good news: This great success comes with the price that up to 60 to 70% of childhood cancer survivors suffer from cancer- and treatment-related long-term effects that need life-long follow-up care. Bad news: transition from paediatric health care to adult health care still poses a great problem for childhood cancer survivors due to the lack of adequate long-term care structures for adult survivors of childhood cancer.
Patients and methods Ongoing initiatives and projects driven forward jointly by survivors, parents and health care professionals tackle this gap: Childhood Cancer International Europe (CCI-E) and its Survivors Network (CCI-ESN), the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) and the European Society for Paediatric Oncology (SIOP Europe) are working on and advocating for better long-term follow-up care structures across Europe.
Results Three ongoing best practice projects are presented—each reflecting one important element in the delivery and provision of comprehensive long-term follow-up care: The PanCareFollowUp Project, the Survivorship-Passport and the ZONE-project.
Conclusion The Childhood Cancer International Europe Survivors Network call for action: We need the support of politicians and our health care systems to make sure that every single survivor gets the long-term care that they need. So #RaiseYourHands4Survivors and help us close the gap!

Keywords Childhood cancer survivors · Long-term follow-up care · Late-effects · Transition · Patient advocacy

Take home message

- Survivors of childhood cancer need comprehensive, medical and psychosocial long-term follow-up care. To build adequate long-term follow-up care we need the support of our health care systems: #RaiseYourHands4Survivors

Introduction

Many publications on optimization of treatments in paediatric oncology are introduced by the good news that in Europe survival rates of paediatric cancers have increased enormously over the past decades, from 20% up to over 80%, depending on cancer type and country [1]. Survivors' overall quality of life seems to be good [2].

However, this success comes with a price: Up to 60 to 75% of childhood cancer survivors (CCS) suffer

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from long-term effects of their cancer and its treatment [3, 4].

Why is that? Exposure to highly toxic medication, radiation and surgery at a young age can lead to damage which may accompany the young survivors for the rest of their—hopefully long and prosperous—lives. So, the question for our community, survivors of childhood cancer, is: What kind of damage do we have to expect? How will that affect our lives? And: What can we do about it?

Late-effects: It's not over when it's over

Depending on the type of cancer we had, depending on what age we had it, depending on the treatments we underwent, we might be facing cardiac problems, fertility impairment, musculoskeletal issues, endocrine insufficiencies, hearing impairment, orthopaedic problems, second malignancies, neuropsychological problems like attention and memory deficits [3–8]—to name a few. Having said that, we have not even talked about psychosocial late-effects like depression, anxiety, fatigue or post-traumatic stress disorder [5, 9, 10]. Some of these long-term effects may need short-term treatment, some may need life-long treatment and monitoring, some may even lead to death [11].

These are certainly not the best news, but as long as survivors are enrolled in a follow-up regimen that takes into account their individual late-effect risk and meets their needs for medical and psychosocial issues—no complaints. The crucial terms in the above section, however, are "life-long" and "long-term". Not only are these terms crucial, but they also imply a problem for most of us—those who are at late-effects risk and need monitoring and treatment that goes beyond the follow-up care provided by paediatric-oncological treatment centres: The problem called *transition*. Transition from the paediatric health care system to the adult health care system. Now, why is this a problem?

Missing: transition and long-term follow-up care

One of the problems that paediatric oncology faces is the following: more and more childhood cancer patients survive (which is not the problem, but the great accomplishment, of course) with long-term effects that are very diverse and complex. According to current research, long-term effects can occur decades after the end of therapy [3], when survivors have left childhood and adolescence far behind. Entering adulthood is accompanied by the problem that paediatrics is no longer the place to go with your health conditions. That is: Mostly, as soon as you turn 18 or have had between 5 and 10 years of follow-up care, your paediatric treatment centre can no longer be responsible for your long-term sequelae—even though they might want to be. They can't, because they are paediatricians and you are an adult. So, who is responsible for your long-term care (besides you yourself)? Adult health care is. So, what's the problem then? The problem is that mostly adult health care systems are not equipped for the diverse, complex health conditions, the psychological and social problems that adult survivors of childhood cancers are confronted with: Many survivors do not know their individual late-effects risk, but neither do their general practitioners. Searching for medical advice and psychosocial support, survivors race from one health care professional (HCP) to the next and the next, too often without receiving the advice, examinations let alone the treatments that they would need according to their risk. In the best case, survivors then bounce back to their paediatric treatment centres to seek help. In the worst case, they give up, believing that their condition is so special that no one can do anything about it. One can imagine what consequences this can have when it comes to undetected or too late detected second malignancies, for instance.

One important facilitator that would bridge the gap are transition programs that help HCPs and to-be-transitioned patients alike to make the way from paediatric into adult health care [12–14]. But even when the paediatric oncological centre has implemented such a transition program, for many survivors in different countries the big question then is: Where exactly will I be transitioned to as long as there are no systematic structures foreseen for my long-term care in my country's health care system?

Time to act!

This lack of adequate long-term care for survivors of childhood cancer has been recognized and pointed at by the childhood cancer community—medical and psychosocial professionals as well as parents' and survivors' organizations—continually over the last decade [15, 16]. The call for action now is growing louder than ever—it is growing louder with the ever-growing population of CCS: The issue of lacking long-term care is global—it is lacking in high-income countries and middle and low-income countries alike. And survivors' organizations from all over the world have formulated their need and the consequent request for comprehensive information and long-term care [17].

Even across Europe there are only some exceptions where life-long follow-up (LTFU) care has become a standard in paediatric oncology already: the Netherlands, e.g., have been delivering age-appropriate, risk-adapted, individual long-term care for adult survivors of childhood cancer in special late-effects clinics for many years.

In order to close the gaps and make sure that survivors across Europe, no matter where, can get access to the long-term care that they need, Childhood Cancer International Europe (CCI-E) and its Survivors Network (CCI-ESN), the Pan-European Network for

Care of Survivors after Childhood and Adolescent Cancer (PanCare) and the European Society for Paediatric Oncology (SIOPE) have been putting the topic of survivorship and its challenges into the spotlight.

Ongoing initiatives

In the PanCareFollowUp project medical and psychosocial professionals, parent- and survivor-advocates from CCI-E, CCI-ESN, SIOPE and PanCare are working together to develop a best-practice model for optimal, person-centred long-term care, which will be piloted in four late-effects clinics in Europe. Another important outcome of the project is the development of a replication manual to make sure that a standard of long-term follow-up care is developed that can be used across Europe in different long-term follow-up structures [18, 19].

An important facilitator with regards to self-management of survivors will be the Survivorship-Passport (SurPass), an e-health tool that provides survivors and HCPs alike with cancer-related information—including cumulative doses and expected late-effects and resulting follow-up recommendations based on international guidelines. The SurPass is currently being piloted in Italy and will hopefully be soon ready to be implemented across Europe [20].

In Austria, the Austrian Childhood Cancer Organization (ÖKKH), together with the Austrian Survivors group and the paediatric oncological treatment centres in Graz, Linz, Innsbruck and Vienna are working together in the ZONE-project[1] [21, 22]. The aim is to implement regional long-term follow-up centres for adult survivors of childhood cancer. Survivors will be transitioned from follow-up care in paediatric oncology to these centres, where they will find a multidisciplinary team consisting of case managers, doctors (internists, endocrinologists or oncologists), clinical psychologists and social workers who they can turn to for medical and/or psychosocial care following their individual late-effects risk profile. Also here the SurPass will be an important facilitator. Representatives of the nation-wide experts-network consisting of the paediatric oncological treatment centres, the ÖKKH and the Survivors group are involved in the PanCare-FollowUp project as well and will ensure the exchange of expertise within the projects.

#RaiseYourHands4Survivors

This hashtag has become synonymous for the call for action and the consequent movement that the CCI-ESN has set in motion: It is the call towards our politicians and health care systems to act and support the childhood cancer community in finally closing the gap and making sure that every single survivor of childhood cancer gets the long-term care that they need. We have fought for our lives, many of us willingly paid the price and we are glad to have won our lives back. But we also want to live our lives in the best quality possible—and for that we need the support of our health care systems. And we need it *now*.

So #RaiseYourHands4Survivors and make a difference!

For more information visit us at:

- https://ccieurope.eu
- https://www.survivors.at
- http://www.kinderkrebshilfe.at
- https://www.pancare.eu
- https://www.siope.eu

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[1] ZONE is the German acronym for the project "Centre for oncological follow-up of adult Survivors (of childhood cancer)".

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