



IMPLEMENTATION OF PSYCHOSOCIAL CARE – SURVEY SUMMARY REPORT

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The issue in a nutshell

Why this survey? Collecting evidence and building the case for psychosocial care

Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs and have access to it throughout the cancer trajectory as needed.

As a Europe-wide umbrella organisation, CCI Europe observed over the past decade that there is still a great lack of adequate psychosocial care in numerous European countries in the field of childhood cancer: While children, adolescents and young adults with cancer require comprehensive psychosocial care, the provision thereof seems to vary significantly not only across European countries, but also within countries. CCI Europe member organisations across Europe as well as psychosocial health professionals in the field of paediatric oncology have discussed and exchanged about gaps in public funding of psychosocial care in paediatric oncology, and experience great challenges in advocating on their regional and national levels for implementation (and the necessary funding) of comprehensive psychosocial care in paediatric oncology treatment centres.

Despite the fact that there are psychosocial care guidelines and standards available^{1,2}, up to date, no such standards have been widely adopted and implemented in paediatric cancer care in Europe.

Therefore, CCI Europe has over the past decade worked towards inclusion of quality of life and psychosocial care related topics on the European level within numerous projects, initiatives and campaigns. However, in order for such project outcomes to be impactful on the national, regional and local levels, the respective health care systems need to have appropriate frameworks in place to allow systematic implementation of psychosocial care aspects.

In order to support future advocacy efforts to improve access to psychosocial care and improve psychosocial care provision in paediatric oncology across Europe, CCI Europe's Psychosocial Care Pillar, consisting of patient advocates and psychosocial health professionals, conducted a Europe-wide survey among CCI Europe member organisations to assess the status quo of psychosocial care provision.

The following report will give

- a brief introduction to the field of paediatric oncology and psychosocial care as integral part of treatment and follow-up care
- an overview on the methods used to collect and analyse the data as well as the interpretation of the results
- an outlook on the recommendations following the report as well as on the next steps to be taken in terms of advocacy

Introduction

Numbers, numbers, numbers: Some childhood cancer facts

Each year, more than 35.000 children and young people in Europe are newly diagnosed with cancer, approximately 80 % of the young patients survive. Therefore, currently there are approx. 500.000 survivors of paediatric cancer in Europe. As many as 60 % up to 75 % are confronted with cancer- and/or treatment-related physical and psychosocial late-effects.

Thanks to multimodal treatment methods and the progress in research, diagnosis, treatment and care in the past decades, most children and adolescents can be cured. However, there is a major difference in the survival rate between European countries because of unequal access to medical care. In Eastern European countries, the survival rate is 20% less compared to the rest of Europe.

Sadly, still more than 6.000 of the affected young patients die of the disease. So still, cancer remains the first cause of death in children by disease, and therefore poses a serious threat to the life of the affected patients. The young people must deal with the trauma of the disease, its psychosocial and socio-economic impacts on themselves as well as their whole family (1).

Treatment is more than just medical: BIO-PSYCHO-SOCIAL approach in paediatric oncology

By 2030, it is anticipated that there will be around 750,000 paediatric cancer survivors in Europe 3. The growing number of survivors makes us understand that curing cancer is a process, where also psychosocial consequences of the illness and its treatment as well as survivorship potentially constitute an enormous challenge, especially when a prolonged illness keeps the young patients away from their normal social and developmental context. These psychosocial consequences can be equally impacting everyday life as can physical late effects of the disease and its treatment.

At least two-thirds of survivors have early- or late-occurring complications (late-effects) due to their treatments, which can be severe or even life-threatening for 25% of them (1). This has a strong impact on survivors' daily lives as well as on their families.

Processing being diagnosed with and treated for cancer and all the emotional, social, economic and physical burden that comes with it does not automatically happen with medically being cured from the disease. When the young patient receives the information that their body is free from cancer cells, the process of healing doesn't stop. Psychosocial healing goes far beyond physical cure. Individual identities and social roles need to be redefined, which can be difficult when the family structure has been attuned for a long time to the 'sick child'. The burden of cancer disease is very complex and influences numerous aspects of young cancer patients' lives – it changes the way they see themselves, the way they shape their future, the way they enter relationships with others.

Even after cancer treatment is finished, stressors that were present during treatment, like threat to one's (or the child's) life, disruption of the developmental context, learning difficulties, anxiety about recurrence, financial burden or employment concerns often remain, yet the support offered by the public health institutions changes. It can become even more challenging when some treatment-related late effects like e.g., learning problems, fertility issues, psychological maladaptation, come to light many years after the end of treatment.

Cancer is not just about cells and drugs; in many cases it affects the psychosocial dimension and the physical dimension alike. The whole family is affected and changed, as childhood cancer threatens every aspect of the family's life and their possible future. Appropriately supporting the young

patients and their families through this pathway is a complex task, which is why optimal cancer treatment **must** include psychosocial care services **accessible for all**.

Speaking the same language: Definition of Psychosocial Care

What exactly do we mean when we speak about “psychosocial care”? As for their comprehensive understanding, this report adopts the definitions and framework proposed by Schroeder et al. (2019) (2) in their revision of the S3-Guideline “Psychosocial Care in Paediatric Oncology and Haematology”. The authors define psychosocial care as follows:

“(a) Psychosocial care in paediatric oncology and haematology encompasses all the clinical and scientific research activities concerning the evaluation and treatment of individual, psychological, familial, social and social welfare/entitlement issues relevant to the disease and their influence on coping. It also includes the development of concepts aimed at the ongoing improvement of treatment.

(b) Psychosocial care in paediatric oncology and haematology is conducted in cooperation with the medical and nursing treatment team. The emphasis is on promoting the resources of the patient and family during the course of the disease, during therapy, follow-up care and, if the need arises, during dying, death and (anticipatory) mourning. The basis for this is a supportive and informative relationship with the children, families and the social environment. It is oriented towards the physical, emotional, social and developmental potential of sick children and adolescents and their social environment, taking individual styles and ability to cope and adjust into account.” (p. 11)

More concretely, within these definitions, according to the authors psychosocial care covers support in coping with the disease, ensuring therapy and cooperation, treatment of specific symptoms, social counselling and support/organisation of follow-up care and prevention¹.

Main aims of the survey

The present survey aimed at

- Assessing the current implementation status of psychosocial care in Europe from the perspective of CCI Europe member organisations (parent-, survivor- and other childhood cancer organisations)²
 - How many childhood cancer organisations provide psychosocial care?
 - How many financially support psychosocial care in the hospitals?
 - For whom is psychosocial care provided and in which phases of the treatment (active/follow-up/palliative care/bereavement)?
 - Is the provided care sufficient according to the experience of CCI Europe member organisations?

¹ For a more detailed list of specific goals of psychosocial care see https://register.awmf.org/assets/guidelines/025_Ges_fuer_Paediatriische_Onkologie_und_Haematologie/025-002eng_S3_Psychosocial-Care-Paediatric-Oncology-Haematology_2020-02.pdf p. 10

² Further referred to as either “CCI Europe member organisations” or “childhood cancer organisations”

- Is the access to high-quality/state of the art psychosocial care equally country-wide?
- Assessing the need for a joint European psychosocial standard of care
 - Are there existing psychosocial care standards or guidelines in use in some countries?
 - Should there be a joint European psychosocial standard of care?
 - What are the challenges related to implementing a joint standard of psychosocial care in Europe?
 - What are the expected benefits of implementing a joint standard of psychosocial care in Europe?

Methods

In April 2021, CCI Europe's Psychosocial Care Pillar started developing the survey. Moving from the main question about the implementation status of psychosocial care provision, a questionnaire with a total of 63 questions was constructed, based on information retrieved from currently available psychosocial care guidelines and standards (2, 3).

The online questionnaire consisted of 7 sections:

1. About your organisation
2. Provision of psychosocial care
3. Collaboration with the hospital / the paediatric oncology unit
4. Psychosocial Care Provision for patients and families
5. Involvement in research
6. Impact of COVID
7. Towards European standards of psychosocial care

For the purpose of this report and to give insights on the main aims of survey (see p. 3), the results presented below focus on the replies received to the sections:

- Section 2 - Provision of psychosocial care
- Section 3 - Collaboration with the hospital / the paediatric oncology unit
- Section 4 - Psychosocial Care Provision for patients and families
- Section 7 - Towards European standards of psychosocial care

The survey was addressed to representatives of CCI Europe member organisations. Per member organisation, one representative should reply to the survey, responding to the questions to their best knowledge of the situation in their region or countries (depending on whether the organisation is a national umbrella organisation or a regional or local organisation).

The invitation to participate in the survey including the link to the online questionnaire was sent via email to all 67 CCI Europe member organisations, covering 34 European countries³. Organisation representatives were asked to fill in the survey, and in case the CCI Europe member organisation itself was a national umbrella organisation, they were asked to forward the survey to their regional /

³ Based on CCI Europe's membership status June 2022.

local member organisations, which resulted in varying numbers of participating organisations across countries. Several reminders were sent out, the final data collection was closed mid-July 2022.

The language of the survey was English. However, in order to maximise participation, the invitation letter (email) as well as the introductory text of the questionnaire were translated into 5 languages: French, Italian, Spanish, German and Bosnian/Croatian/Serbian.

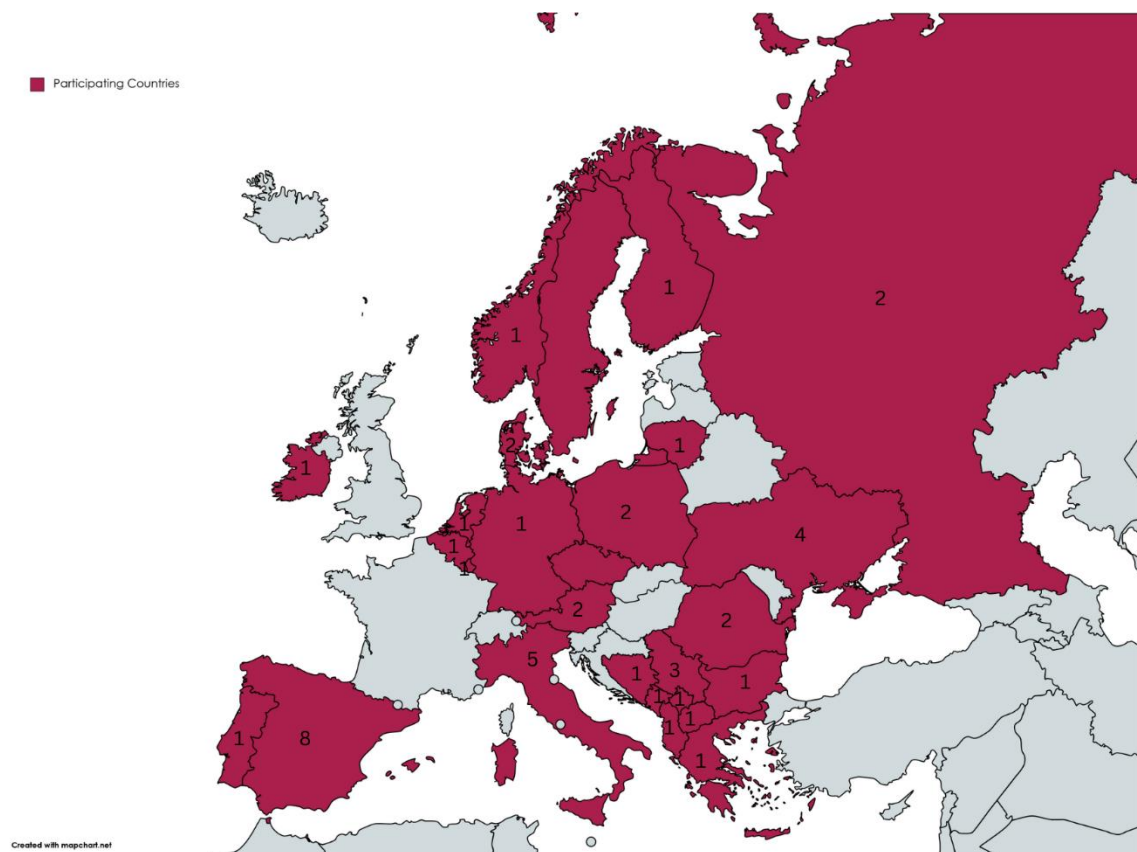
Data Analysis

All statistical analyses were conducted in SPSS. Descriptive statistics were applied for variables of interest. Data analysis included dependencies between different questions and the search for similarities or differences in replies between countries, but also within countries.

Sample

52 answers from 25 European countries were received. Due to multiple replies from the same organisations with differing answers, seven datasets had to be excluded from analysis, yielding a total of 45 data sets.

Graph 1. European countries covered by the survey. The respective numbers indicated in the countries reflect the exact number of childhood cancer organisations who replied to the survey.



Summary of results - very short answers to complex questions

Assessing the current implementation status of psychosocial care in Europe from the perspective of CCI Europe member organisations

- **How many childhood cancer organisations provide psychosocial care?**

In total, 42 out of 45 participating organisations stated to provide psychosocial care.

- **Is there collaboration between childhood cancer organisations and local hospitals regarding psychosocial care?**

In terms of collaboration with the local hospitals regarding psychosocial care, the majority of organisations (N=30 out of 45 in 18 countries) stated to collaborate with the psychosocial team of their local hospital. 12 of the respondents stated that they do not have a collaboration with the local hospital.

Moreover, 26 organisations from in total 14 countries detailed that they collaborate closely with the psychosocial team of the local hospital through case discussions and regular interdisciplinary meetings. Other respondents described the collaboration on a more national level, e.g. through establishing or being part of national working groups.

In addition to collaborating in such ways with the local teams, 11 organisations stated to finance various support services such as supervision for the interdisciplinary team at the local hospital.

- **How many financially support psychosocial care in the hospitals?**

According to the results, 20 participating organisations reported to fund psychosocial health professionals at local hospitals.

- **For whom is psychosocial care provided and in which phases of the treatment (active/follow-up/palliative care/bereavement)?**

While 38 participants indicated that in the local hospital psychosocial care was provided during active treatment, only 21 said that it was also provided during follow-up care.

Overall, the support provided seems to be inconsistent across the different target- and age-groups. There seems to be a decrease in care provision as the age of the patients increases (highest for children, lowest for young adults).

Siblings and survivors seem to receive significantly less support than patients and parents.

- **Is the provided care sufficient according to the experience of CCI Europe member organisations?**

According to the results of the survey, there seems to be the general perception among the participants that the provided psychosocial care is not sufficient: only 5 out of 45 organisations think that the available psychosocial care is sufficient. 25 think it's not sufficient, 5 organisations didn't answer, 10 stated they didn't know.

- ***Is the access to high-quality/state of the art psychosocial care equally country-wide?***

One important aspect of this survey was to find out whether there were indications to inequalities in psychosocial care provision also WITHIN countries (in addition to differences across countries).

According to numerous additional comments from respondents, (28 out of 45) access to high quality psychosocial care wasn't ensured country wide. In addition, in countries where multiple languages are spoken, respondents commented that access to care depends also on the patient's language.

In addition, we found for 10 questions that organisation-representatives from within the same countries reported different levels of care provision. Also, this finding indicates that inequalities in access to psychosocial care do exist within countries, regardless of whether the respondents were from high income or low/middle income countries.

This finding supports the experience of the respondents that in numerous cases access to psychosocial care is not equal within countries.

Assessing the need for a joint European psychosocial standard of care

- **Are there existing psychosocial care standards or guidelines in use in some countries?**
Psychosocial standards according to National Cancer Control Plans (NCCPs)?
Only 6 out of 40 participants who replied to this question stated that in their respective countries there were psychosocial standards according to their NCCP.
Psychosocial care aligned to existing standards/guidelines?
Only 7 out of 42 participants who replied to this question stated that the psychosocial care they provide in their organisation is specifically aligned with existing psychosocial standards of care.
- **Should there be a joint European standard?**
The majority (32 of 39) of participants stated that in their opinion there should be a Europe-wide psychosocial standard of care.
 - **What are the challenges related to implementing a joint standard of psychosocial care in Europe?**
The greatest challenges that were mentioned addressed:
 - funding
 - cultural differences and recognition of psychosocial care
 - adequate number and training of professionals
 - **What are the expected benefits of implementing a joint standard of psychosocial care in Europe?**
The greatest benefits that were mentioned addressed:
 - more attention, recognition and easier acceptance of psychosocial care
 - equal access & uniform approach as well as clear strategies for psychosocial care
 - better support, quality of life & wellbeing of patients, families and health workers

Conclusions

While it appears that in many countries there is a lack of psychosocial support provided by the public health care system to families affected by cancer, many local, regional and national parent-, patient, survivor- and other childhood cancer organisations offer psychosocial support services like e.g. parent houses or camps for children and adolescents. Many organisations support psychosocial services in local paediatric oncology centres by financing/financing employment of psychosocial professionals.

Moreover, the results indicate that there is regular collaboration between some of the childhood cancer organisations who replied to the survey and the respective local hospitals in terms of psychosocial care on a clinical level in their day-to-day practice.

In line with previous observations and exchanges with CCI Europe member organisations and psychosocial health professionals, the results of the survey indicate that the access to psychosocial care is not equal to all target groups (patients, families, survivors) and throughout the different phases throughout the paediatric oncological treatment trajectory.

According to the results of the survey, psychosocial care is:

- more accessible for younger patients and parents. It seems to be more difficult for young adults, survivors and siblings of the patients to access psychosocial care.
- more accessible at the beginning of treatment (during the phase of communication of the diagnosis), and least accessible during follow-up care

Given the reported inequalities in provision of and access to psychosocial care for the different target groups affected by paediatric cancer, the majority of respondents stated that in their opinion there should be a Europe-wide standard of psychosocial care implemented.

Challenges that should be considered in such an effort include standardisation between the different countries, in all hospitals in Europe, taking into account different cultures, languages, varying financial capacities and different views and opinions on the need for good psychosocial care and on the understanding of psychosocial care in general. Furthermore, raising awareness about the importance of psychosocial care among medical staff, health sector authorities as well as the general public is a great need in order to increase recognition and acceptance of psychosocial care, and that therefore respective public funding needs to be allocated.

The expected benefits of implementing a Europe-wide psychosocial standard of care on the other hand are increased recognition and consequently better understanding and acceptance of psychosocial care in paediatric cancer. Moreover, quality of life, wellbeing and health is expected to be improved - not only for patients and families, but also for health care professionals themselves. Importantly, one major expected benefit of the implementation of a Europe-wide standard is the levelling out of existing inequalities across as well as within countries.

Outlook/Recommendations

One concluding outcome of the present survey is a strong recommendation for establishing a Europe-wide psychosocial care standard in order to ensure high-quality psychosocial care throughout the whole paediatric oncological treatment trajectory, and to eliminate inequalities in access to care. State-of-the-art psychosocial care should be equally accessible for everyone who is immediately affected by paediatric cancer - patients, survivors, parents, siblings - no matter in which country they live, no matter in which hospital they are treated.

This standard should

- Be co-created in a joint effort between childhood cancer organisations (who reportedly cover a big part of psychosocial care) and psychosocial health professionals in the field of paediatric cancer
- Cover all phases of the paediatric cancer treatment trajectory, including diagnosis, treatment, palliative care, follow-up care, rehabilitation, bereavement counselling
- Cover both the care provided by the treatment centres and the care provided by childhood cancer organisations
- include a roadmap on how treatment centres and childhood cancer organisations should collaborate and together offer a continuous support network: What has to be offered in the treatment centre? What has to be offered by childhood cancer organisations? What should be offered "closed to home" (e.g. by extramural/ psychosocial professionals in private practice)
- Be translated in different languages. The language barrier across Europe poses great challenges and increases inequalities. Successful implementation of standards relies on broad dissemination to regional and local levels, and the acceptance of the standard as a useful tool. Accessibility of such tools can be increased significantly by providing translations of relevant information.

Another concluding outcome is the recommendation for a interdisciplinary, comprehensive mapping of psychosocial services across Europe: The current survey was specifically addressed to CCI Europe member organisations, consequently the results presented in this report reflect the experiences and professional opinions of the respective patient-organisation-representatives regarding psychosocial care provision in their countries and/or regions. Therefore, this report does not claim to give an all-encompassing assessment of psychosocial care across Europe. Furthermore, several of CCI Europe's member organisations themselves are national umbrella organisations with numerous regional and local member organisations who carry out patient-related work. An important step to pave the way for the development and implementation of a Europe-wide psychosocial care standard would be a parallel mapping of psychosocial services from the perspective of psychosocial health professionals working in the treatment centres across Europe.

As also on the side of the health care professionals, numerous psychosocial health professionals in the field of paediatric oncology have voiced the need for a top-down support in the national, regional and local implementation of standards for psychosocial care. Therefore, one of the next steps will be to share the results of the present survey with the recently launched Psychosocial Working Group within SIOP Europe in order to engage and define a common strategy.

Concluding remarks

The success history of medical treatments in the past decades showed clearly that the implementation of standardised treatment protocols significantly improved the overall survival. Therefore, developing and implementing a Europe-wide standard on how psychosocial care should be delivered throughout the whole trajectory in paediatric cancer would be a major development towards significantly improving the quality of life of those affected by paediatric cancers. This can only be done in a joint effort by childhood cancer organisations, health care professionals and health care systems. The present survey and respective results offer relevant insights in the current state of psychosocial care across Europe, and thus provide an important foundation for related upcoming initiatives.