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LIFE AFTER CHILDHOOD CANCER

"Childhood cancer survivors are just as likely as anyone else to have healthy children."

**Professor
Jeanette Falck
Winther,
SALiCCS**

The number of cancer survivors among children and young people in the Nordic region has never been greater, but little is known about the challenges this patient group faces in the aftermath of cancer treatment. Survivors of childhood cancer may experience difficulty concentrating, fatigue or depression due to various late effects from the disease and the treatment, and also have an increased risk for a wide array of other diseases. More knowledge is needed about the impacts of childhood cancer on subsequent education, working life and family life. With the help of Nordic health registries, the NordForsk-funded SALiCCS project is taking steps to learn more.

Written by: Tor Martin Nilsen

"We do not know enough about the adult lives of those who survive serious cancers as children," says Professor Jeanette Falck Winther of the Danish Cancer Society Research Center in Copenhagen and Aarhus University. "Do they have a harder time in life than other people? Do they pursue education, find their place in the labour market, start a family? The registries found in the Nordic region can provide unique insights, and this will enable us to determine where to implement measures to improve their quality of life." Professor Winther heads the research project "Adult Life after Childhood Cancer in Scandinavia (SALiCCS): Socioeconomic consequences of long-term survival", which in 2015 was allocated NOK 10 million under NordForsk's Nordic Programme on Health and Welfare.

Fortunately, children comprise only a very small percentage of people diagnosed with cancer in the Nordic region, but the toll on those who experience it is great. Leukaemia, brain tumours and lymphoma are the main paediatric cancer types, and over 80 percent of children survive cancer. Since childhood cancer is relatively rare, it is a difficult field to study

at a national level. Using data from several Nordic countries expands the number of cases exponentially, however, and increases the likelihood of drawing solid conclusions.

"The SALiCCS project," continues Professor Winther, "is an extension of the Adult Life after Childhood Cancer in Scandinavia (ALiCCS) project launched in 2010, which studied nearly 44 000 Nordic childhood cancer patients diagnosed from the 1940s until 2008. That project primarily focused on somatic late effects in childhood cancer survivors, but the SALiCCS project adds socioeconomic data as well. It is exceptional to be able to consider both somatic and psychiatric disease burdens when looking at how these patients cope in life. If, for example, someone has a heart problem or suffers from depression when young, it affects their education and subsequently their ability to work"

Challenges in research using registry data

Originally, Professor Winther hoped the project would include registry data from the five Nordic countries. However, the number of technical, organisational and

ethical obstacles connected to the exchange of data across national boundaries was such that only three countries are participating.

"The legislation in the Nordic countries is not in itself a problem, but problems arise when those who are responsible for the registries in the different countries interpret the legislation differently. In some Nordic countries, certain types of data, such as data related to mental illness, are considered particularly sensitive personal information that cannot be shared across national borders. Such differences between the countries, along with the degree of data accessibility needed to address the research questions posed in the SALiCCS project, are what determined which countries were included in the project. SALiCCS ended up as a collaboration between Finland, Sweden and Denmark, but is nonetheless the largest population-based study in childhood cancer within this research field."

"Research at the Nordic level takes time," adds Professor Winther, "and it takes an especially long time to obtain permission to transfer data between the countries. There are many parties involved, often within each country, and we appreciate NordForsk's efforts over many years to draw attention to the challenges related to data exchange in the Nordic region. Currently, for instance, the SALiCCS project is waiting to see what Statistics Denmark decides in relation to our project and the ability to collect and analyse data from three Nordic countries under one roof. We just have to be patient."

The Nordic region is a unique platform for research

Professor Winther believes the SALiCCS project is a good example of research collaboration with potentially great Nordic added value.

"The use of personal identity numbers and the many registries give us fantastic research opportunities in the Nordic region. This unsurpassed level of detail enables us to track the population from cradle to grave, and merging the data from the Nordic countries gives the analysis statistical strength. This combination creates a platform for research envied by the rest of the world. In addition, Nordic researchers' access to the registries makes us attractive as partners in international studies. I have no doubt that SALiCCS and other projects that make use of Nordic registries generate the highest grade of Nordic added value – because no one else can do what we can," she says with enthusiasm.

High expectations

Although the SALiCCS project is still waiting for data, the researchers have prepared themselves for the time ahead. Variables between the countries have been compared, a review article has been drawn up and published, and Professor Winther reports that the entire team is eager to begin analysing. Expectations are high.

"The results from the SALiCCS project will be worth waiting for since they will be the most wide-ranging and detailed in their field. We hope our research will make a difference for survivors of childhood cancer as it should help us to identify specifically where measures are needed, such as special education at the primary and lower secondary school level, or steps to prevent depression. The entire team believes that the results of this largest and most comprehensive study to date will lead to international recognition in the field of childhood cancer."

At the same time, Professor Winther then adds, "it is important for me to stress that there is no catch-all solution. Cancer types such as leukaemia and brain tumours require different treatments and cause different late effects so the needs for follow-up will differ. First we will look at all childhood cancer survivors before we go deeper into the data and carry out specific studies of the most common childhood cancers. It is also important to remember that very many childhood cancer survivors cope perfectly well and do not need special help in subsequent years. This is something we always want to emphasise."

The way forward

Jeanette Falck Winther is optimistic about the continued activities under the SALiCCS project and recognises the importance of NordForsk's activities to highlight Nordic registry-based research.

"It was a big day for us when we found out about the NordForsk call under the Nordic Programme on Health and Welfare. It is fantastic to have an organisation that helps scientists and clinical researchers at an overall level and facilitates Nordic research cooperation. Being able to help children affected by cancer and their families is close to my heart, and I am thankful that NordForsk has helped make that possible."

"The research and results are important," she goes on to explain, "but what that research can lead to is even more important. The knowledge we generate benefits those who survive cancer, their families, physicians and the health care community. One of the most valuable things research can do is help to raise awareness about an issue and dispel prejudices or ease concerns. For example, it is important that physicians can tell childhood cancer survivors that they are just as likely as anyone else to have healthy children – which is vital knowledge documented in one of my previous international projects. I hope the results from the SALiCCS project can help in similar ways," concludes Professor Winther. "If we can produce results that really matter to someone, then we will have truly succeeded."

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Professor Jeanette Falck Winther, Project Leader for the SALiCCS project, hopes the research results will determine where to implement measures to improve the quality of life of childhood cancer survivors.

Photo: Trine Bukh

