



Cancer in Children: What happens after the Cure? Progress in Therapy and Participation in School

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Ladies and Gentlemen:

"Every society honors its living conformists and its dead troublemakers" Mignon McLaughlin (1913-1983).

Speaking of troublemakers:

The good news is we can cure children with deadly diseases.

The bad news is because they recover, we must take care of them.



Children - Health - Future
Our Time Belongs to the Children

CHILDREN'S HOSPITAL

This is the motto of our hospital.

To clarify this, I would like to make a counterpoint first: Society that says farewell to our children, says farewell to the future.

Today, I am concerned with three challenges faced by the school for the sick:

1. Medical,
2. Psychological and
3. Social challenges.

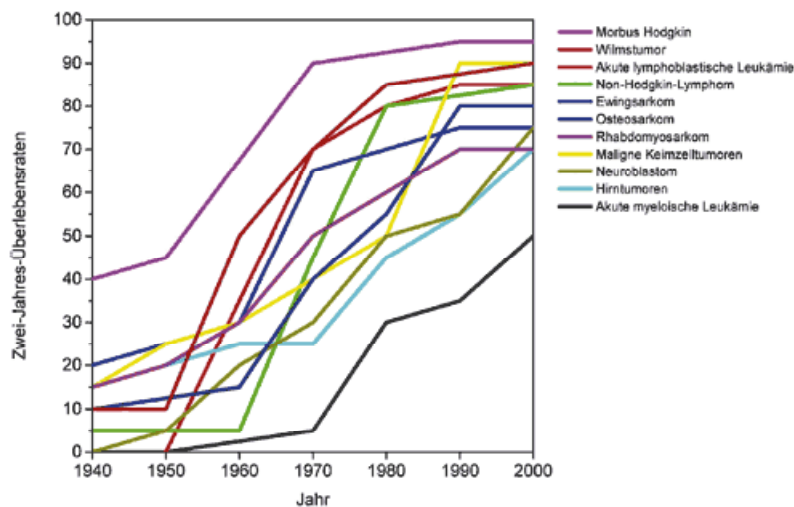
I would like to start with two theses to differentiate between pediatrics and adult medicine in order to define the framework conditions of the school for the sick:

1. pediatrics is a curative subject and
2. compared to adult medicine, which deals mostly with the symptomatic treatment of age and degenerative diseases and is a significant topic in our aging society, pediatric and adolescent medicine are mostly concerned with cure or at least long-term survival with chronic diseases.

In childhood cancer, the objective is a cure. Oftentimes, the question was about the advancement in medicine. Are we talking about technical progress or advancements that really lead to a cure of diseases? In this case, it is beneficial to take a look at pediatric and adolescent medicine. "Is cancer cured rarely?" This is still a widely believed prejudice, an overall opinion: It is a deadly diagnosis. Here are the results of the past 20 years based on approximately 26,000 children with cancer treated in Germany (Slide 13, MUC-HOPE 2010 after the cure101101stb). As you can see, you are able to cure four of five children with cancer. We have the best results with leukemia and lymphomas. In others, the rates for a cure are lower. "Cancer in children is mostly cured!" "Rarely cured" would be the wrong response. For individual diseases, the treatment successes are even more impressive. I would like to address one disease, which we study in particular, namely the Ewing sarcoma. This is a highly malignant bone tumor. While the survival rate was below 10% in 1940, it is currently more than 60%.



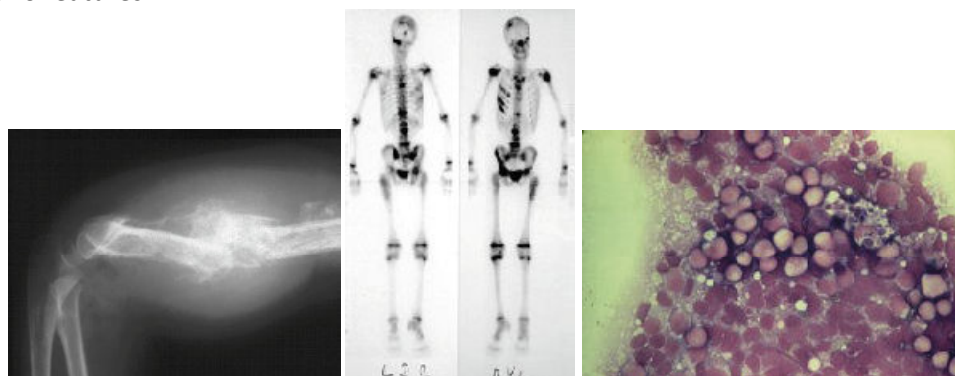
Cancer in children: increase in successful therapies



Another important disease in connection with the challenges posed in the school is brain tumors. Here, too, the survival rates have greatly increased. Therefore, cancer in children is mostly cured. This year, one in 250 adults between the ages of 15 and 45 years will be a survivor of childhood cancer. Now, there are politicians, of course outside of Bavaria, who say, "This could be a contribution to solve the demographic problem." This experience is not new to us as pediatricians. Our field becomes more interesting when politics notices that for example there is a lack of people paying into the retirement fund or other funding agencies which society deems as essential. I believe that this perspective of the future does not solve the future viability of our society. Only, if we take care of the children for the children's sake does it prove the sustainability of our society.

I would like to tell you briefly about Peter. Peter was barely 18 years old when he came to us in February of 2009. He suffered from Ewing sarcoma and had approximately 50 bone metastases. Maybe you have first-hand knowledge of breast cancer in your family or of prostate cancer with bone metastases and know that bone metastases in general are a death sentence. Metastases (disseminating cancer) are not good news because if the cancer metastasized into the bone it is in general a death sentence.

Multifocal Ewing Tumors (ET): Leukemia and Solid Tumor at once Primary multifocal bone metastatic disease in ET has two features:



(1) Local (multifocal) disease; (2) Systemic disease

The physicians at the Pediatric Hospital of Munich-Schwabing, who are specialized in this disease, have tried to revise this death sentence by subjecting Peter to a highly invasive therapy, which included five stem cell transplants. Peter had lost his mother one year prior to the diagnosis.



His mother died during labor with his little sister. A few months after his diagnosis, his much-loved grandmother died who was the most important parental figure in the family. Subsequently, Peter grew up at his aunts because both his father and he thought it better if Peter is raised by the aunts. In this family, he found an impressive and loving safety net. We were able to see this for ourselves during the course of the exhaustive treatment. In this year, during which he received treatment, he did not miss a single appointment despite the fact that he is from Lower Bavaria and had to be driven to the hospital every day more than 100 kilometers. One could think that with such tragedies there is something else besides school on someone's mind. However, immediately after his diagnosis, Beate Winkler, his teacher, contacted his school at home to find out his future career goals. He wanted to become a heating system technician. Subsequently, she set up a curriculum together with the school and worked with him. Today, Peter survived the disease and he wants to become an electronic salesperson. He is presently working on his 'qualifizierten Hauptschulabschluss.' I believe this is quite an impressive story that illustrates many issues, which I would like to discuss with you now.

However, one of our little patients has illustrated this connection in a different manner. And because a picture says more than 1000 words, I would like to show you this picture that Lisa Meixner-Mücke has given to us. It shows a bridge between the hospital and the school and this is the bridge to life (Slide 20). This is how little and older children see it - just like this artist or Peter.



Why schooling for the sick? Sick children have an intellectual need. They want to be taken seriously and this may apply even more so to sick children than to healthy children. School provides patients with perspectives and self-esteem. If children go to school with cancer in our hospital then the connection to life is not lost afterwards. Students, children, patients sense very keenly that they are given up as patient and as children if they are given up on as students.

However, the school for patients has a special pedagogic challenge. I would like to address this pedagogic challenge. It is not like, we are curing all children and they attend their own school again as healthy children. It is rather that the undesired long-term effects of cancer therapy are quite extensive.

Oeffinger and colleagues wrote about more than 10,000 adult survivors of childhood cancers. The work was published in 2006. This work demonstrates the so-called 'chronic health conditions' (that is an American euphemism, we rather say 'late effects') the late-toxicity of surviving cancer is extensive. Up to 40% of the patients have severe adverse effects 30 years later. In leukemia - the red curve shows the severe adverse effects, the other curve illustrates the more general ones. As you can see, the majority of the patients' restrictions are less severe. However, a significant percentage suffers severe restrictions that



impact the quality of day-today living. It is slightly lower in leukemias and it increases in solid tumors such as sarcomas and brain tumors similar to the survival rate.

Of course, as physicians and researchers we are trying to lower the toxicity of the therapy. For example, we are working on parents donating special cells that cure the children's cancer. Actually, we truly can establish a perspective how we can get tumor stem cells to behave benign so that they lose their malignancy.

This has two interesting implications - for you as well. We can teach these cells without changing their genetic makeup. We can train tumor cells, tumor stem cells to behave benign by changing their environmental conditions.

A second important implication that we have learned from this research is that this striving for eternal youth or this 'forever young' has its price, its pay off, and this can be malignancy.

These insights have led us actually to treat the first patients with the cells of their parents this year. The cells of the father can recognize characteristics of the mother on the tumor cells of the children and we hope to reduce some long-term toxicity through this - but that is in the future.

Currently, you still must deal with long-term effects of treatment in your pedagogic work. And these are significant. The treatment itself can cause cancers, there are late effects on the central nervous system, and hormonal imbalances that impact puberty. All this affects the students' quality of life and creates increased challenges for you as educators

secondary malignancies
cardiomyopathy
late effects to
central nervous system
hormonal imbalances -
puberty, fertility
kidney damage
skeletal / soft tissue
damage



These were the somatic problems you have to deal with. In addition, there are psychological late effects: Lonnie Seltzer conducted an excellent research about the psychological condition of survivors of childhood cancers, which was published last year. This research discovered - as expected - that survivors report of more symptoms and distress and a worse somatic condition; however, the emotional quality of life, HRQOL meaning, 'health-related quality of life' is the quality of life. The quality of life is emotionally excellent for the cancer survivors. They are highly content with their current life and they have high expectations for the future. Risk factors for psychological distress and a worse quality of life are lower educational attainment, low income, in other words, and therefore, inadequate successes in the professional life - to name just a few (Slides 31-33). Naturally, children with brain tumors pose a special challenge and these psychological distress factors have a significant impact on the further health prognosis. Unhealthy lifestyles are more frequently the result. Psychological distress leads to a lower compliance with medicine. The bottom line is that most survivors are psychologically healthy and report about being content with their life. In addition, it is a challenge for education to approach these risk factors for psychological distress and to find interventions for these risk factors. This means to think from day one about school and a school-leaving certificate. The consequences are that the survivors of a childhood cancer need special educational support and this educational support is entirely different from



the psychosocial care. This educational support may have a preventive effect in relation to the risk factors for psychological distress and a poor health-related quality of life. In addition, children with brain tumors pose a special challenge for schools.

Finally, I would like to address the social aspect. You see the participants of the 'Tour der Hoffnung' or 'Tour of Hope' in front of our hospital. The 'Tour of Hope' is a bicycle tour by childhood cancer survivors who take a 600-kilometer trip through Germany. I, who always has thought of himself as interested in sports, was highly impressed by these children when they visited our hospital. Moreover, they visit the children cancer hospital to encourage patients confronted with the diagnosis of cancer. To give them hope for the life after the diagnosis and hope for school for them to survive this life. For this reason, it is so important that from day one school must be considered. Only the success in school is the suitable condition to overcome the fight against these prejudices.

In closing, I would like to state:

The survival rate of children with chronic diseases increases. The survivors need longer stays as in- or outpatients in the hospital. Therefore, the need for schooling in the hospital setting increases. Without schools for patients, the children lose their fight in life despite a cure.

I would like to discharge you from my lecture with three theses.

First: The identity of a society is determined by the belief in its future and this future is its children.

Second: Today, when we can cure children of many diseases, which were deadly just yesterday, then it cannot be our desire for these children to get healthy but fail in life later and must be a burden as social failure to society.

Third: We must assure that they recover and in doing so, we must assure that they do not lose their connection with school and life.

Children – Health – Future. Our time belongs to the children and children who were torn from the grips of death cannot be neglected in school, in a society that believes in its future. Schooling does not follow the cure. This would be too late.

I would like to thank everyone, especially my colleagues who are educators, the psychosocial team, and the physicians for helping me prepare for this lecture. I would like to thank you for your attention!