„...when you're tired before you even start“

–Fatigue in paediatric oncology seen from different perspectives –

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Introduction

The term „fatigue“ is a word of French origin meaning „tiredness“. In medicine, this term, alongside other chronic diseases, is also used in oncology as so-called Cancer-Related-Fatigue (CRF). It refers to an especially agonizing form of tiredness, often leading to complete exhaustion [1]. Some definitions by German- and English-speaking authors describe fatigue as a phenomenon characterized by a continued, overwhelming feeling of exhaustion combined with a reduced physical and mental performance of the patient [2, 3, 4]. There is general consensus among researchers that this type of fatigue is not relieved or alleviated by rest and / or sleep [2,5]. In German-speaking paediatric oncology, this phenomenon has so far received but little attention [6].

An interview by Michael Jung (graduate health care scientist and physiotherapist) with Klaus Siegler, M.D., Physician in the Psychosocial Services Department at the Centre for Paediatric and Adolescent Medicine, Dept. III, Paediatric Oncology, Haematology and Blood Coagulation at the Johann Wolfgang Goethe University Hospital at Frankfurt (Main), Germany (Director Prof. Dr. Thomas Klingebiel) and himself a patient with a Hodgkin's lymphoma, revealed different perspectives on „Cancer-Related-Fatigue“.

Dr. Klaus Siegler is a paediatrician and has worked in paediatric oncology since 1988. Diagnosed with a Hodgkin's lymphoma himself, he experienced in person the problems related to cancer. Before his illness, he had hardly any experience with fatigue: „...only in theory, because taken from literature. I thought it was something that happens in adults, but not in children.“

But then he experienced fatigue himself, the hard way. During chemotherapy treatment, especially in the first third of it, he was suffering a lot and he realized that fatigue is less of a psychological or mental phenomenon, but rather a physical state. Since then, his attitude towards fatigue has changed considerably.

Fatigue is largely unknown and underestimated

Once he understood that it is really a physical state, which in some phases of chemotherapy treatment is hard to get out of, he also came to realize the ignorance of some of the staff members.

„Sometimes I get annoyed by the attitude of colleagues or the nursing staff who have never really concerned themselves with fatigue and misjudge it - also what needs to be done then.“

In paediatric oncology, Siegler judges the phenomenon of fatigue as a completely underestimated and still little known side effect of cancer: „People are really acting - just like I used to in the past - as if there were no such thing.“

Fatigue during chemotherapy treatment and in therapy-free intervals

He sees the biggest negative impacts on children mainly during chemotherapy treatment. A form of fatigue, of flaccidity, one can hardly defeat and which „is probably - but we know too little about it because we have so far not paid attention to it - also very much present during the intervals between therapies“. What fatigue compromises most are daily life activities and this even during the therapy-free intervals and after completion of the treatment.

Does this phenomenon also occur in radiation therapy?

Depending on the structure that is treated with radiation, diffuse impairment will also occur under radiation therapy. The apathy syndrome in children undergoing skull radiation, however, must be distinguished from this, as it is a direct consequence of the radiation of the brain.

Is it possible to counteract CRF?

Latest studies have shown that fatigue symptoms may be reduced through exercise therapy [7, 8, 9, 10, 11]. The main difficulty, however, lies in motivating oneself to physical exercise despite the severity of the illness.

From his own experience, Siegler can recommend to „force yourself into the tight corset that fits you, in other words, it's a question of discipline. There are people who can motivate themselves, who are well-disciplined and do something even when physical

strength is declining. Others, like me, need someone by their side or fixed appointments or such like. So, one should really force oneself to exercise at least three times a week, doing sports or some moderate regular physical activity”.

One should establish a certain level of regular physical activity as early as possibly, ideally at the beginning of the therapy, in a manner of speaking before the patient's physical constitution has gone downhill. In adult oncology, exercise and sports therapy programmes offered by physiotherapists or sports therapists have become common practice. Also during the intervals between chemotherapy blocks, one should not give this up. Patients in follow-up care still suffer from fatigue and also here exercise therapy is widely used in the respective follow-up care groups (e.g. after mastectomy). This approach shall now also find its way into paediatric oncology [12].

Changes due to new perspectives

In order to raise awareness among the staff on this very debilitating phenomenon, all members of the interdisciplinary team shall receive training on the subject of fatigue. This topic has already been implemented into the further training programme for oncology nurses and has long been known with regard to adults. In respect of children, it still needs to be intensified. It is necessary to develop treatment concepts for physical, occupational and sports therapists which are suitable for the specific situation in the hospital or at home [13]. One particularly important point to Siegler is to set it apart from other symptoms. Everybody working in paediatric oncology needs to „learn to see and to distinguish with a better trained eye, because we are making one big mistake: Many of my colleagues are inclined to think, when seeing children, adolescents, young adults, hence our patients who sit in their beds with a serious look on their face, that they are depressive. I can tell you that in light of the gravity of the situation, the degree of bother caused by chemotherapy, this facial expression is perfectly appropriate. And we must learn to differentiate depression from fatigue, because they result in completely different therapeutic consequences. In fact, I would even be so bold as to say that it's hardly ever a case of depression!”

The experienced paediatrician now understands his little patients better. He remembers how it was when he was ill: „it's not possible to motivate yourself to doing anything at all. You put everything off until tomorrow or whenever, just not today or even now. And you can spend a lot of time in a state like that.” The entire daily routine is affected by this debilitating exhaustion. Siegler describes: „It's actually quite simple: There were days, which I can still remember, where I got up and then I somehow just drank tea and read the newspaper and obviously didn't do anything else until my wife came home from work and I was completely taken

aback that the day was already over. You can actually spend many hours just staring in one direction, sometimes you have to negotiate hard with yourself that when the bladder is about to burst you should really get up now and go to the toilet, because you get almost nothing done anymore.”

Another approach is to arrange the surroundings and the activities for the children as well as the daily routine in the ward in a way that the sickbed is no longer the child's primary place to stay. Here, the conventional wisdom that a sick child belongs in bed is contradicted. The aim should be, as far as possible, to prevent additional difficulties caused by muscular atrophy.

One of Siegler's conclusions, or rather his own definition of Cancer-Related Fatigue based on these experiences, is: „Fatigue is when you're tired before you even start.”

Prospects

At the ward for children and adolescents with stem cell transplants at the University Hospital Frankfurt (Main), Germany, headed by Prof. Dr. Peter Bader, a feasibility study was conducted on the subject of „Exercise therapy in transplantation”. Klaus Siegler and the health care scientist Michael Jung are part of the team of experts working on this study. The fact that initial literature research and studies revealed that there are very few German publications on CRF [6] and that it occurs also in children [14], led to initial steps being taken. Subsequently, the department for stem cell transplantation initiated a study on the subject of sports therapy funded by the José Carreras Leukemia Foundation [12], which is already well advanced. First results are expected for 2013.

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