“...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 be-
ginning 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
come become common practice. Also during the in-
tervals 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 mastec-
tomy). 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 sub-
ject of fatigue. This topic has already been implemen-
ted 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 pa-
ediatric oncology needs to „learn to see and to distin-
guish 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,
however 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 diffe-
renti ate 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 under-
stands his little patients better. He remembers how it
was when he was ill, „it’s not possible to motivate your-
self to doing anything at all. You put everything off until
tomorrow or whenever, not just not today or even now.
And you can spend a lot of time in a state like that.” The en-
tire daily routine is affected by this debilitating exhaus-
tion. 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 news-
spaper 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, someti-
mes 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 surround-
ings 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 atro-
phy.

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 Frank-
furt (Main), Germany, headed by Prof. Dr. Peter Bader, a
feasibility study was conducted on the subject of „Exer-
cise 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 litera-
ture research and studies revealed that there a very few
German publications on CRF [6] and that it occurs also
in children [14], led to initial steps being taken. Sub-
sequently, 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.

References
[In German]
2. Carpenito, IJ. Nursing Diagnosis. Application
to clinical practice. 7th ed., Lippincott: Philadelphia,
1997.
3. Johnson M, Bulachek G, McCloskey Doch-
termann J, Maas M, Moorhead S. Nursing Diagnosis,
Outcomes & Interventions - NANDA, NOC and NIC
4. Stefan H, Allmer F, Eber J. Praxis der Pflege-
diagnosen (Nursing diagnoses in practice). Springer
Verlag Vienna, New York, 2003. [In German]
5. Glaus, A. Das Konzept Fatigue in der Onko-
logie: Definitionen, Hintergründe (The concept of fati-
gue in oncology: Definitions, backgrounds) In Fatigue
bei Tumorpatienten (Fatigue in tumor patients), Weis J,
Bartsch HH (ed.). Karger Verlag: Basel, 2000;1-13. [In German]

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