

Fatigue in pediatric oncology patients

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Abstract



Fatigue, which is considered the most bothersome side effect of oncological diseases, has hardly been researched in German children. Studies from the USA and Great Britain demonstrate the existence of this phenomenon in pediatric oncology.

A possible reason for the deficiency in research may be that there is no validated assessment tool for children available in German language. Therefore, the author together with the developers of the PedsQL 3.0 Multidimensional Fatigue Scale have collaborated to translate the English language questionnaire. The translation has been conducted according to a universally accepted three stage process.

With the intention, to provide a primary impression of the standardized questionnaire, 66 children were examined by patient and parent questionnaires. As reference, the results of the cancer patients were compared to data from 240 healthy children.

The existence of fatigue in pediatric oncology was confirmed by low values in the dimensions 'general fatigue' and 'fatigue related to sleep / rest'. A significant correlation between age and fatigue related to sleep/rest ($p=0,028$) and close to significant correlation between age and general fatigue ($p=0,053$) were observed.

In the dimension cognitive fatigue no significant expression of this phenomenon could be observed.



Fatigue, als am die meisten störend empfundene Begleiterscheinung onkologischer Erkrankungen, ist bei Kindern in Deutschland noch wenig erforscht. Studien aus den USA und Großbritannien zeigen aber die Existenz dieses Phänomens in der pädiatrischen Onkologie auf. Ein möglicher Grund für den Forschungsrückstand in Deutschland kann darin bestehen, dass derzeit kein validiertes deutschsprachiges Assessmentinstrument für Kinder zur Verfügung steht. Aus diesem Grund hat sich der Autor zusammen mit dem Entwickler der PedsQL 3.0 Multidimensional Fatigue Skala um die Übersetzung dieses englischsprachigen Fragebogens bemüht. Die Übersetzung erfolgte nach einem allgemein anerkannten dreiphasigen Prozess.

Mit der daraufhin vorliegenden deutschen Version des Assessmentinstrumentes ist der Frage nachgegangen worden, ob die Existenz von Fatigue bei krebserkrankten Kindern nachgewiesen werden kann.

Es wurde eine explorative, nicht-interventionelle Vorstudie in der pädiatrischen Onkologie der Universitätsklinik Frankfurt am Main durchgeführt. Diese sollte einen ersten Eindruck von dem standardisierten Fragebogen vermitteln. In der durch die Ethikkommission genehmigten Untersuchung wurden mittels eines Patienten- und eines Elternfragebogens Daten zu 66 Kindern erhoben.

Um die Ergebnisse der krebserkrankten Kinder besser einordnen zu können, wurden zusätzlich Daten von 240 gesunden Kindern an drei Frankfurter Schulen erhoben und mit den Werten der krebserkrankten Kinder verglichen. Die Auswertung erfolgte anhand, der im aktuellen Forschungsstand mehrfach beschriebenen Dimensionen 'Allgemeine Fatigue', 'Fatigue bezogen auf Schlaf / Ruhe' und 'Kognitive Fatigue'.

Die Existenz von Fatigue in der pädiatrischen Onkologie konnte durch niedrige Skalenergebnisse in den Dimensionen Allgemeine Fatigue und Fatigue bezogen auf Schlaf / Ruhe bestätigt werden. Eine signifikante Korrelation zwischen Alter und Fatigue bezogen auf Schlaf/Ruhe ($p = 0,028$) sowie eine annähernd signifikante Korrelation zwischen Alter und Allgemeiner Fatigue ($p = 0,053$) wurden deutlich. In der Dimension Kognitive Fatigue wurde keine ausgeprägte Wahrnehmung des Phänomens nachgewiesen.

Results

The American authors explain that low values in the assessment (min. 0 / max. 100) are considered as indicators of fatigue and they compare their patient data with a healthy control group (table 1). On the basis of the international literature currently available and the data resulting from the clinical preliminary study, the presence of fatigue in paediatric oncology should also be recognized in Germany. It seems that German children with cancer and their parents perceive fatigue more distinctly than the comparison group in the US. Group comparisons carried out between the American and German patient groups respectively their parents must, however, be considered on the premise of different numbers of cases. The assumption that the low values result from the fact that German patients perceive fatigue more distinctly than American patients is deemed unlikely. More likely is the hypothesis that in America some things, even severe illnesses, are seen from a more positive perspective.

Tab.1

	N	General Fatigue	Sleep / Rest Fatigue	Cognitive Fatigue	Total Score
Patients Germany	50	68,5 (SD 20,2)	60,7 (SD 20,6)	76,7 (SD 20,6)	68,6 (SD 16,8)
Healthy Children Germany	238	78,4 (SD 15,3)	67,4 (SD 15,4)	78 (SD 15,8)	74,6 (SD 12,6)
Patients USA	220	74,9	67	70,9	70,9
Healthy Children USA	52	85,3	75	81,1	80,5

In the clinical preliminary study, German adolescents stated more distinct fatigue values in the dimensions "general fatigue" and "fatigue relating to sleep and calmness". In the dimension "cognitive fatigue", adolescents with cancer stated less distinct values. One reason for this might be that adolescents are more likely to show inhibitions in admitting mental problems on top of their obvious physical weakness. The frequency polygon (fig.2) illustrates an age trend. Drops in the progression of the frequency polygon arise from the fact that there were sometimes only one or two test persons per age-group. When these test persons indicated extreme values, the frequency polygon then shows sharp deflexions. In order to obtain substantiated results, it is necessary to recruit more test persons.

The age hypothesis made that "fatigue increases with advancing age" must always be looked at against the backdrop of the heterogeneity of the age groups. The activity level, the radius of activity and the interests of the age groups are so varied which makes comparison difficult. While small children make use of play possibilities offered on the ward, adolescents mostly stay in their rooms. A significant correlation between age and fatigue with regard to sleep and calmness and an approximate correlation between general fatigue and age are calculated according to Pearson.

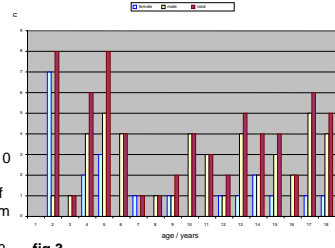


fig.3

The existence of fatigue and the simultaneous lack of an adequate assessment instrument has so far posed a dilemma to patients, the treatment team and research in Germany. Since there was no validated assessment instrument used in children yet, there were no reference values (tendencies) available for Germany. The German version of the PedsQL 3.0 Multidimensional Fatigue Scale is used to identify the existence and intensity of fatigue in children. Thanks to this work, it is now possible in Germany to measure fatigue in paediatric oncology.

The conclusion of this preliminary study is that the existence of fatigue in children with cancer can be seen as a clear tendency, but that it only has limited representative validity due to the low number of cases. Since the questionnaire shows good practicability and acceptance, it is predestined to be used in the following research project. Nursing staff and members of therapeutic professions can test fatigue without much effort and are able to evaluate treatment measures.

Once problem awareness for this phenomenon has been established, one practice-oriented aim can be to adapt the daily routine to this new knowledge. The Multidimensional Fatigue Scale can serve as a basis of decision-making for interventions. Medical doctors, nurses, physiotherapists and other professional groups involved are able to contribute to the reduction of fatigue through education and counselling, structuring the daily routine or systematic sporting activities. The integration of fatigue in the education of patients to develop coping strategies as well as into university studies and professional training may help to cope with this phenomenon.

Background

The American original of the questionnaire shows good reliability with a Cronbach alpha value of 0.89 for interviews with children and of 0.92 for interviews with parents. Validity was demonstrated using the "known-groups method" ("benchmarking with healthy populations"). The translation was performed in a three-phase process according to the EORTC-criteria: forward translation, backward translation (fig.1) and pre-test. No major translation difficulties occurred due to the child-friendly wording of the original.

The first version of the PedsQL 3.0 Multidimensional Fatigue Scale was available for a pre-test at the Centre for Paediatrics III, Paediatric Oncology, Haematology and Haemostaseology at the Johann Wolfgang Goethe University Hospital at Frankfurt / Main. The respective proposal was accepted by the ethics committee. For comparison of healthy children, one selected three Frankfurt schools and interviewed children between the ages of 8 and 18.

In the past ONE month, how much of a problem has this been for you

GENERAL FATIGUE (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I feel tired	0	1	2	3	4
2. I feel physically weak (not strong)	0	1	2	3	4
3. I feel too tired to do things that I like to do	0	1	2	3	4
4. I feel too tired to spend time with my friends	0	1	2	3	4
5. I have trouble finishing things	0	1	2	3	4
6. I have trouble starting things	0	1	2	3	4

SLEEP/REST FATIGUE (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I sleep a lot	0	1	2	3	4
2. It is hard for me to sleep through the night	0	1	2	3	4
3. I feel tired when I wake up in the morning	0	1	2	3	4
4. I rest a lot	0	1	2	3	4
5. I take a lot of naps	0	1	2	3	4
6. I spend a lot of time in bed	0	1	2	3	4

COGNITIVE FATIGUE (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4
6. I have trouble remembering more than one thing at a time	0	1	2	3	4

fig. 1

Wie häufig war dies ein Problem für Dich im letzten Monat:

ALLGEMEINE ERMÜDUNG (Probleme mit...)	Ne	Fair	Much	Very	Fat
1. Ich fühle mich müde	0	1	2	3	4
2. Ich fühle mich körperlich schwach	0	1	2	3	4
3. Ich fühle mich zu müde um Dinge zu tun, die ich mag	0	1	2	3	4
4. Ich fühle mich zu müde um Zeit mit Freunden zu verbringen	0	1	2	3	4
5. Ich habe Schwierigkeiten, Dinge zu beenden	0	1	2	3	4
6. Ich habe Schwierigkeiten, Dinge zu beginnen	0	1	2	3	4

ERMÜDUNG BEZUGS- O- SCHLAF/ RUHE (Probleme mit...)	Ne	Fair	Much	Very	Fat
1. Ich schlafe viel	0	1	2	3	4
2. Es ist mir schwer, durch die Nacht zu schlafen	0	1	2	3	4
3. Ich fühle mich müde, wenn ich morgens aufwache	0	1	2	3	4
4. Ich ruhe viel	0	1	2	3	4
5. Ich nehme viele Nickerchen	0	1	2	3	4
6. Ich verbringe viel Zeit im Bett	0	1	2	3	4

GEISTIGE ERMÜDUNG (Probleme mit...)	Ne	Fair	Much	Very	Fat
1. Es ist mir schwer, meine Aufmerksamkeit auf Dinge zu halten	0	1	2	3	4
2. Es ist mir schwer, mich an Dinge zu erinnern, die ich gerade gehört habe	0	1	2	3	4
3. Es ist mir schwer, mich an Dinge zu erinnern, die ich gerade gedacht habe	0	1	2	3	4
4. Es ist mir schwer, mich an Dinge zu erinnern, die ich gerade gemacht habe	0	1	2	3	4
5. Es ist mir schwer, mich an Dinge zu erinnern, die ich gerade gesehen habe	0	1	2	3	4
6. Es ist mir schwer, mich an Dinge zu erinnern, die ich gerade gemacht habe	0	1	2	3	4

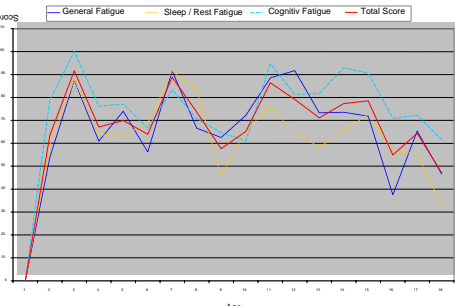


fig. 2

Discussion

A difference in the perception of fatigue between girls and boys could not be proven in the author's random test, which is dominated by boys (68% boys and 32% girls) (fig. 3). A gender-specific difference, as known in adult oncology due to specific kinds of tumours, could not be demonstrated in children. Intense fatigue in women with breast cancer and low perception of fatigue in men with prostate cancer are irrelevant in paediatrics.

Summary

With the first German version of the questionnaire, it was possible to show fatigue in children with cancer. Both parents and patients had no difficulties in completing it and it was widely accepted. An age trend towards increased fatigue in adolescents was observed in two dimensions. There was no discrepancy between boys and girls in this random test.

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