

DOI: 10.4455/eu.2016.011

Improving Nutritional Care for Cancer Patients in Germany

Joint Position Paper from the German Cancer Society's (GCS) Working Group on Prevention and Integrative Oncology (PRIO), in collaboration with other associations

Working Group on Prevention and Integrative Oncology (PRIO) (ed.), Berlin

Each and every individual has the right to food. This is indispensable for life and therefore a generally accepted good in our society. In cancer patients, nutritional deficiency can exacerbate the course of the disease. However, as the majority of us are overfed, deterioration in nutritional status is mostly overlooked. But a loss in weight rapidly leads to a change in body composition. This in turn can cause a "metabolic risk", which may influence cancer patients' tolerance, prognosis and quality of life.

Thus it is essential that any treatment plan for cancer patients must be supported by adequate nutrition. This is why we are under an ethical obligation to pay attention to nutritional status and to accept that nutritional therapy is an essential part of cancer treatment [1].

Cancer patients in Germany often have to submit to restrictions in their nutrition, caused by both their disease and their therapy. They suffer from nutritional deficiency, without being provided with appropriate nutritional therapy. However, providing cancer patients with adequate nutrition is an important part of their treatment. It is a component of any comprehensive therapeutic concept and is just as important as other types of supportive therapy. Deficient nutrition is not only a violation of patients' fundamental rights; it causes suffering and shortens survival. One of its con-

Citation:

Please refer to the correct mode of citation on p. M92.

Joint Position Paper from:

German Cancer Society's Working Groups on:

- Prevention and Integrative Oncology (PRIO)
[Arbeitsgemeinschaft Prävention und integrative Onkologie]
- Social Work in Oncology (ASO)
- Palliative Medicine (APM)
- Conference of Oncology Nurses and Paediatric Oncology Nurses (KOK)

other associations:

- German Professional Association of Nutritional Science and Home Economics (VDOE)
- German Society for Nutritional Medicine (BDEM)
- Professional Association of Practicing Gynaecological Oncologists in Germany (BNGO)
- German Nutrition Society (DGE)
- German Dietitian Association (VDD)
- Association for Nutrition and Dietetics (VFED)

self-help organisations:

- House of Cancer Self-Help – Federal Association (HKSH)
- The House of Life [Lebenshaus]
- Head and Neck Cancer Foundation
- Self-Help Network Head-Neck-Mouth

sequences is an irresponsible burden on the health system.

For this reason, the undersigned associations and institutions are of the opinion that technical experts, politicians and society have the common duty to ensure that all cancer patients enjoy access to appropriate nutritional therapy [1].

Good and appropriate nutrition is essential for both cancer patients and their families, as it:

- is a precondition for participation in life,
- reduces the symptoms and side effects of the therapy,
- helps to avoid complications,
- enhances patient safety,
- leads to better quality of life,
- raises adherence,
- supports the efficacy of the therapy,
- improves survival,
- is economically advantageous for the health system.

Data and facts

In 2011, about 255,000 men and 228,000 women in Germany fell ill from cancer. In the same year in Germany, there were 804,000 men and 786,000 women who had been diagnosed as having cancer in the previous five years [2].

Nutrition has an important influence on the therapy and successful treatment of all these patients. It has been shown that appropriate nutritional care of cancer patients can enhance their quality of life and life expectancy [3–14].

The present situation in Germany is really worrying. About one third of cancer inpatients in Germany suffer from a nutritional deficiency. 20–30% of all cancer patients in Germany die of the consequences of nutritional deficiencies rather than from the

disease itself [15–17]. However, clinicians hardly ever regularly screen cancer patients for nutritional deficiencies [18–22]. Little is known about the situation in outpatient care, although this is the setting for most cancer patients. The situation will probably be about the same as for inpatients.

Depending on where the tumour lies and how advanced it is, 10–85% of patients lose weight [23–27]. Most cancer patients are found to have lost significant weight when the diagnosis is made. Even in overweight patients, this weight loss has negative effects on their function and the success of their treatment [20, 27–32]. This is not inevitable: International studies on patients with various forms of cancer have shown that regular nutrition counselling and interventions can improve individualised and appropriate intake of energy and nutrients and lead to better treatment results. Although this benefit for cancer patients is recognised, about 25% of cancer patients still die from the consequences of nutritional deficiencies [12, 17, 20, 32–41].

A poor nutritional status

- triggers a vicious circle of weakness, tiredness, lack of mobility and additional weight loss [42, 43],
- significantly prolongs time in hospital, due to treatment side effects [44],
- leads to a sustained reduction in quality of life [43],
- increases morbidity and mortality [43].

On the one hand, ever more expensive drugs may increase survival by just a few weeks – sometimes with severe side effects. On the other hand, nutritional therapy is neglected throughout Germany, even though it is simple, ensures quality of life and improves survival.

Current nutritional care for cancer patients in Germany

Many cancer patients and their families are aware of the importance of nutrition. But their questions and needs are ignored, as there is no broad or general provision in Germany of scientifically based nutritional information, nutritional training, individual instruction on nutrition or specific nutritional therapies for cancer patients and their families [45].

The theme of nutrition in oncology is not adequately covered in the training, further education or advanced studies of physicians and nutrition scientists. Even though the theme “oncology and nutrition” is legally required for the training of dietitians, these resources are not currently used in Germany – neither in inpatient nor outpatient settings [45, 46].

Even though multi-professional care of cancer patients, by collaboration between experts and certification, has become a matter of course, the patient is mostly left to his own devices as regards nutrition [47].

The inadequate nutritional care for cancer patients and their families is essentially due to the framework of the German health system. Outpatient nutrition counselling is not a medicine in the sense of § 92 SGB V (*Sozialgesetzbuch* = social security code). At the moment, outpatient nutrition counselling is a service that the legal health insurance funds can provide, but which can be refused without giving reasons and which is not enforceable. Even if approved, the extent of the reimbursement can vary greatly. Thus, the possibility of using nutrition counselling also depends on the patient’s means.

On the other hand, nutrition counselling is related to DRGs (diagnosis related groups), although this is not enough to provide all the funds required by the nutrition team [48]. But nutritional deficiency is a significant cost factor in the health service. Two thirds of cancer patients stay significantly longer in hospital. Although well nourished patients can be discharged after a mean of 13.1 days, cancer patients stay in hospital for a mean of 19.5 days – more than 6 days longer [17, 27, 49].

The patients' view

Patients and their families feel that they are left alone in nutritional matters. As a consequence, they may have recourse to internet sources or base their decisions on unqualified information. The therapeutic potential of nutrition is then not exploited. So-called "cancer diets" may have an unfavourable effect on the course of the disease; they are propagated by unqualified and profit-orientated persons or institutions, but are being increasingly accepted. What is essential for the patient's quality of life is that he/she should be given balanced nutrition that is appropriate to the individual needs. However, the change in the situation after a cancer diagnosis mostly raises questions as to what makes up an appropriate diet. This is why patients with cancer and their families demand qualified nutrition counselling and therapy for all cancer patients.

What are our chances of good nutritional care in Germany?

Adequate and individually adjusted nutritional care can significantly improve cancer patients' quality

of life and life expectancy [10, 50, 51]. The current deficiencies in the provision of appropriate nutritional therapy have major and demonstrable unfavourable consequences for patients, as well as important social and economic implications (both for business management and for political economy) [10, 50–52].

These deficiencies in the provision of care can only be made good if it is accepted that this is an important problem. Nutritional care must be a component of the efficient care of cancer patients, which is a demand and an objective of the National Cancer Plan.

The additional costs to the health system for establishing appropriate and modern nutritional care are lower than the secondary costs of inadequate nutritional therapy. Improvement in nutritional medical therapy would therefore mean:

- a substantial improvement in the expected survival of cancer patients,
- an essential contribution towards improving their symptoms and enhancing their quality of life,
- an improvement in the chance of chronically ill patients to take part in life,
- a significant contribution towards reducing the costs of the health service.

For this reason, the Working Groups on Prevention and Integrative Oncology (PRIO), Social Work in Oncology (ASO), Palliative Medicine (APM) and the Conference of Oncology Nurses and Paediatric Oncology Nurses (KOK) in the German Cancer Society, the German Professional Association of Nutritional Science and Home Economics (VDOE), the German Society for Nutritional Medicine (BDEM), the Professional Association of Practising Gynaecological Oncologists in Germany (BNGO), the German Nutrition Society (DGE), the German Dietitian Association (VDD), the Association for Nutrition and Dietetics (VFED), as well as the self-help organisations the House of Cancer Self-Help – Federal Association (HKSH), the House of Life, the Head-Neck Tumour Foundation and the Self-Help Network Head-Neck-Mouth, demand the following:

- The right to adequate nutritional care for all cancer patients, both as inpatients and as outpatients. This means inclusion in the Medicines Directives of outpatient nutrition counselling of cancer patients and their families, as well as establishment and payment of nutritional teams for inpatients.
- Incorporation of the theme of "nutrition in oncology" in the training, further education or advanced studies of all professions involved in the care of cancer patients and the establishment of advanced training concepts
- Obligation to perform screening for nutritional deficiencies
- Qualified individualised nutrition counselling or therapy for all patients with impending or actual nutritional deficiency

- A low-threshold qualified service for all cancer patients and their families
- Development and agreement to scientifically based standards for the therapeutic nutritional support of tumour patients, as well as the consistent implementation of existing evidence-based guidelines and quality insurance instruments [1, 53–55]
- The inclusion of a therapeutic nutritional service in the certification criteria for oncological centres
- Support for research in nutrition in oncology. This should encompass both clinical research and health care research.

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Citation:

Arbeitsgemeinschaft Prävention und Integrative Onkologie (PRIO) (ed.) (2016) Improving nutritional care for cancer patients in Germany. Joint position paper from the German Cancer Society's (GCS) Working Group on Prevention and Integrative Oncology (PRIO), in collaboration with other associations. *Ernährungs Umschau* 63(02): 43–47

This article is available online:
DOI: 10.4455/eu.2016.011

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DOI: 10.4455/eu.2016.011