

NOVEL APPROACH FOR COUNSELLING OF YOUNG CANCER PATIENTS

Seifart U^{1,2}, Langer T¹, Na I^{1,3}, Schulze J¹, Freund M¹

1 Deutsche Stiftung für junge Erwachsene mit Krebs, Berlin, Germany; 2 DGHO-Arbeitskreis Onkologische Rehabilitation, Berlin, Germany, 3

DGHO-Arbeitskreis Immundefekte und Immundysregulation, Berlin, Germany

Introduction

About 80% of cancer patients between the age of 18 to 39 survive their disease. Patients of this age group have to cope with a variety of problems that significantly differ from those of children or older adults. Young patients suffer enormously from the short- and long-term social burden (financial and social consequences) as well as from physical disorders associated with the disease or anti-cancer treatment, e. g. chemotherapy or radiation. The objective of this project is to consult patients on options for social support to avert financial problems and to provide medical help to reduce disease- or therapy-associated disorders. The consultation takes place in collaboration with the attending physicians.

Methods

The YOUNG CANCER PORTAL of the German Foundation for Young Adults with Cancer is a nationwide, open-access service for young patients. The advisory process is organized on the basis of a proprietary software. Patients are asked in a first step to register with their personal information and to raise their questions. A questionnaire captures their current situation regarding the disease status and daily life. Expert advice is given via protected mail, by phone, or in person by a regionally assigned oncologist with extra training in social medicine. Furthermore, a special access to the system offers the exchange of expertise for medical professionals. The protected database allows an anonymous collection and systematic analysis of the data by the foundation.

Results

The module for social law questions started on Nov 24, 2015, the module for endocrinological questions on Sep 22, 2016, and the module on immune defects in Aug 2017. Thus far, 495 people have registered and 345 patients have been advised. Female patients represent 72% of the pool, male patients 28%. Although more young women are affected by cancer (57% of diagnoses between 15 and 39 years), women are clearly overrepresented in our data. The median age is 30.5 years (range 18 to 52). The regional breakdown of the data shows a nationwide usage of the portal.

Conclusions

The YOUNG CANCER PORTAL is unique throughout Germany and offers a new way for expert-patient-communication with high acceptance by long-term survivors. The portals basic structure is appropriate for a modular addition of topics. Modules for long-term effects, fatigue and integrative oncology will be established.