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Psychooncology

Recommendations from the society for diagnosis and therapy of haematological and oncological diseases

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Psychooncology

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- Guideline
- Conflict of interests

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1 General information

Psycho-Oncology is particularly concerned with the psychological and social or family-related factors that patients and their relatives can relate to cancer. In addition to the individual and family issues involved with coping with the disease in cancer patients, it addresses psychological processes at different dimensions (e.g., psychosomatic, emotional, behavioral). Psycho-oncological care is of major importance in the context of prevention, early detection, diagnosis, treatment, rehabilitation, aftercare and palliative care [1].

2 Good to know

2.1 Why do I need a psycho-oncologist?

Psycho-Oncology is a part of oncology in order to be able to provide the holistic patient care required by current standards. Psycho-oncologists are qualified, for example, to use a scientifically tested short questionnaire ("screening") in a way that provides the treating oncologists and oncological nursing staff with conclusive information for cancer treatment within a very short time on the question "How stressed has the patient felt in the last week, including today? Based on these findings, the oncology care team derives together a kind of "strategy" of the next important priorities for the cancer treatment, for example with regard to doctor-patient communication or measures for adherence to the therapy discipline.

Nowadays, this screening is an integral part of cancer treatment. On the one hand, about one third of all cancer patients suffer from psychological distress within the first five years after the initial diagnosis of cancer, which can be successfully treated by psychotherapy. More than half of the cancer patients report high psychological distress with a need for professional psychosocial care in the course of cancer treatment. On the other hand, exactly these psychological burdens are quite human. They should be actively addressed or treated quite similarly to a physical reaction to cancer or cancer therapy. Compared to non-cancer patients, cancer patients are more likely to experience psychological distress and report reduced quality of life. In clinical practice, however, it is very difficult in individual cases to identify patients who belong to this burdened group and consequently require professional psychosocial support.

Therefore, a so-called distress screening of all cancer patients is recommended. This involves the use of a short psychological test to assess the extent of psychosocial distress. If a scientifically tested and defined threshold value (cut-off value) is exceeded, the need for professional, psycho-oncological support is indicated [2, 3, 4]. Professional psycho-oncological support is recommended from the beginning of cancer treatment because it [3, 4]:

- reduces psychological and somatic distress,
- prevents the further development of mental disorders,
- optimizes cancer treatment (patient role, cooperation / acceptance),

- stabilizes families (children, parents, partners),
- helps the patient to demand his or her rights,
- supports disease management and improves quality of life and
- can enable participation in normal life again.

2.2 What can psychotherapy do?

In contrast to older patients, young adults are still confronted with the far-reaching consequences of cancer diagnosis and treatment for decades. Psychotherapeutic methods can successfully treat a wide range of psychological stress and sustainably improve the physical and psychological areas of the quality of life of those affected.

2.3 Who is allowed to do psychotherapy?

A psychotherapist is someone who has successfully completed several years of state regulated training. Like a doctor, a psychotherapist has a so-called approbation to practice medicine, which is approved by the state. Psychotherapists therefore bill the public health insurance companies.

The following groups may call themselves "psychotherapists":

- Psychological psychotherapists,
- Child and adolescent psychotherapists,
- Specialists whose training includes psychotherapy and
- Physicians with additional training in psychotherapy.

If you are searching the Internet for a psychotherapist who is trained in psychotherapeutic healing, the following distinctions are important for you:

- Psychologist ≠ Psychotherapist,
- Naturopath for Psychotherapy ≠ Psychotherapist,
- Psychological counseling ≠ Psychotherapy,
- Coaching ≠ Psychotherapy,
- Marriage and partnership counseling ≠ Psychotherapy and
- Talk therapy ≠ Psychotherapy.

2.4 Who is allowed to do psycho-oncology?

Although the professional title of psycho-oncologist has not yet been a legally protected term, obligatory criteria have existed since 2014 for hiring psycho-oncologists in hospitals and when applying for licenses to practice as a psychotherapist or specialist. In accordance with the principle of interdisciplinarity, different professional groups can be active in psycho-oncology. First and foremost, psychologists, physicians, social workers/social pedagogues, and other social science professional groups should be mentioned here. Attention should be paid to the following graduation and naming of the following professional qualifications [3, 4]:

- As a basic qualification for a psycho-oncological activity, the completion of a university degree in the subjects of medicine, psychology or other subjects such as social work or education should be proven. In addition, specific psycho-oncological advanced and further training should be available, which must be evidenced by a recognized certificate (e.g. "DKG-certified") and indicated in the name (DKG, German Cancer Society).

- For specific psycho-oncological activities such as diagnostic or psychotherapeutic treatment, a so-called curative qualification (medical or psychological psychotherapists) is absolutely necessary. This means that if psycho-oncological diagnostic or treatment is planned, only psychotherapists or medical specialists with the above-mentioned specific DKG-certified training may perform this.

For artistic therapists working in psycho-oncology (music, dance, art therapists, etc.), a corresponding bachelor's or master's degree or in-service training that meets the quality standards of the respective professional associations of the "Bundesarbeitsgemeinschaft Künstlerischer Therapien BAG-KT" is a requirement.

2.5 What are possible psychotherapy goals for cancer patients?

In situations of psychological and social stress, there are numerous offers of help and therapies that have been proven effective in scientific studies.

Objectives of psycho-oncological interventions on the physical level include, among others, in terms of extended prevention:

- alleviating the consequences of illness and treatment, e.g. pain, learning to cope with the consequences of illness and disability, e.g. fatigue (see also AYApedia Fatigue),
- assist in improving physical functioning,
- promoting a healthy lifestyle with exercise and sports (see also AYApedia Exercise and Sports),
- promotion of healthy nutrition (see also AYApedia Nutrition), and
- promote healthy sleep.

The objectives of psycho-oncological interventions on the physical level include the alleviation of the consequences of the disease and treatment, e.g. pain, learning to cope with the consequences of the disease and disability, e.g. fatigue (see also AYApedia Fatigue), support in improving physical functioning and promoting a healthy lifestyle with exercise and sport (see also AYApedia Exercise and Sport), healthy nutrition (see also AYApedia Nutrition), and healthy sleep. Objectives at the psychological level include [1]:

- reduction of psychological symptoms and psychological distress,
- learn to deal with fears and other mental burden,
- strengthening the sense of self-worth and dignity despite physical changes and (increasing) dependence on others (e.g. doctors or parents),
- acceptance of one's physical weakness and reduced independence,
- showing new perspectives on life after cancer,
- promoting confidence and hope (including alternatives to hope for healing),
- integrating the experience of illness into subjectively coherent life contexts, which I experienced up until the cancer,
- mobilization of own, inner resources,
- appreciation of strengths and accomplishments in the individual's life,
- working on the acceptance of change and
- dealing with dying, death, mourning and saying goodbye.

2.6 What I should know about psychotherapy in statutory health insurance

See Appendix A, document PTV 10-1

2.7 What psychotherapeutic treatment options are available?

See Appendix B, document PTV 10-2

2.8 What else would be recommended in addition to classical psychotherapy?

The following are considered complementary, or supplementary, procedures to psycho-oncological support or psychotherapeutic treatment:

- Relaxation techniques (autogenic training, progressive muscle relaxation, fantasy journeys),
- Artistic therapies (music therapy, art therapy, dance therapy),
- Occupational therapy,
- Exercise Therapy and
- Sociotherapy.

Relaxation techniques should be continued on one's own after professional guidance and practice. With these methods, patients receive an instrument that enables them to reduce emotional tension (self-management) and strengthens their ability to regulate emotions (resource orientation). Compared with more intensive forms of psychotherapy, relaxation techniques are low-threshold and can therefore be used by almost anyone, regardless of where they are undergoing treatment (3,4). Autogenic training is a particularly effective method for relaxing and relieving tension, see Appendix C, Course Material AT.

2.9 In what areas of life might there be changes or challenges that I should face?

Due to the developmental dynamics of young adulthood, the following areas of life should be mentioned [5, 6]:

- Fertility and childbearing, see also AYApedia Fertility and fertility preservation
- Mental health and quality of life,
- Body image, body experience, body-self,
- Cognitive-emotional performance ("chemobrain"),
- Social relationships and family dynamics (peers, parents, partners),
- Health behavior regarding smoking, alcohol, drugs, nutrition, sports/fitness, see also AYApedia Exercise and Sports
- Sexuality,
- Confrontation with mortality,
- Delays or loss of education/job,
- Financial dependency, risk of financial hardship or loss of the legal system of protection,
- Confidence in one's own health and body "which has suddenly abandoned me" and

- Fear of the future, "because suddenly any decision can be one for my whole life."

2.10 What are particularly challenging medical situations from a psycho-oncological perspective for young adults with cancer?

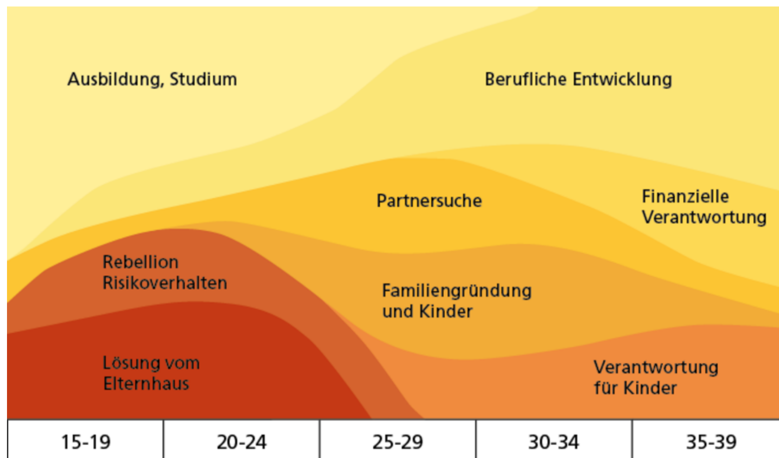
- particularly strong emotional distress, such as worries about the future, pessimism, strong mood swings/insecurity, decision-making problems/self-doubt, feelings of guilt,
- psychological/psychosomatic symptoms, such as sleep disturbances, vomiting, nausea, tension/irritability, reduced drive, suicidal thoughts, physical anxiety complaints (high blood pressure, headaches, back pain, loss of appetite), pain, etc., they may also be affected by the symptoms,
- If the continuation of a necessary cancer therapy is endangered, e.g. discontinuation of cancer treatment or rejection of curative procedures out of fear, reduced treatment adherence with regard to taking medication, dealing with side effects, organization of outpatient aftercare,
- having a biographical history of mental illness or other life situations that are perceived as critical and
- social or financial hardship, lack of social support from peers, re-experiencing and provoking family conflict situations with parents or treating physicians by proxy.

What is it that sometimes the treating physicians do not fully understand me or perhaps I even have the impression that I get into sometimes repeated conflicts with them? From a developmental psychological perspective, young adults already have a wide range of personal identity development even without a diagnosis of cancer, see Figure 1. Adolescence is considered one of the most important phases of life. Adolescents question themselves, at the same time seeking independence, autonomy and familiar closeness, try out identities and form their own social roles (e.g. hip hop, hipster, skater, emo, goth). The experience of this period is marked by biological, cognitive and mental maturation processes. These processes are associated with a variety of physical, psychological and social changes with corresponding developmental tasks. The developmental psychological concept, based on the work of Havighurst, assumes that the maturation step across the transition to the next stage of life, i.e. adulthood, can only occur after an age-specific set of tasks has been accomplished. The developmental tasks are considered a basic requirement of the human community, but must be understood and managed as individual and very personal demands [5, 6, 7, 8, 9].

Developmental tasks of adolescence and young adulthood are:

- building new and mature relationships with peers,
- assumption of the female/male gender role,
- acceptance of one's own physical appearance and effective use of the body (how do I appear to other people?),
- emotional independence from parents and other adults,
- preparation for partnership, marriage and family life,
- preparation for a professional career,
- obtain values and an ethical system,
- development of an ideology and ability to form one's own opinion and
- strive for and achieve socially responsible living.

Figure 1: Psychosocial domains within young adult developmental tasks [10].



Legend:
Source: Freund M, German Foundation for Young Adults with Cancer 2017).

In conclusion, there are two points to be made to answer the question [5, 6]:

- When young adults face cancer, they face two stresses:
  - the developmental psychological process between early adolescence and early adulthood (see above developmental tasks and figure) and
  - the disease management process between cancer diagnosis finding and various possible late effects of disease and tumor treatment.
- The physical and emotional experience and personal coping with the existential dependencies caused by the cancer and the cancer treatment are in absolute contrast to the character of the life situation of a healthy young adult growing up.

In short, especially as a teenager and young adult, one simply has "no time and no head" for cancer. Or as young adults sometimes say after a cancer diagnosis, "Cancer doesn't fit in with me at all!" In a time where it is primarily about separation, finding the self and a primarily own opinion and identity, I inevitably come into conflict "with the adult world" in the clinic as the following quotes from AYA cancer patients prove:

- "I'm not comfortable here with all the old people, I get goosebumps just thinking about having to be in the room with those."
- "I'm in here and the others are out there."

2.11 On the function of parents in young adults with and after cancer.

The treatment of cancer, in addition to its importance for the patient, always has an impact on the daily life and stress of family members [5]. For adolescents and young adults, parents, in addition to current partners, are often considered primary family contacts. In particular, at least an inner parental attitude of care and responsibility is often expected or even needed again by the children, the young adults. During the time of tumor therapy and aftercare, parents assume a real key position for their sick "children" in terms of emotional regulation and action-oriented, medically relevant support. They are needed again very close to everyday life, such as support in the management of side effects/late complications or the maintenance of independent everyday areas (e.g. finances, education, housing). They resume their old positions and roles almost regardless of the actual age of the AYA patient. AYA parents can also be involved in securing the long-term success of oncological treatment by providing a renewed existential framework. Meanwhile, we know from initial studies that parents are often psychologically burdened themselves. They are severely affected emotionally by the shock of the cancer news, feel helpless, powerless and physically ill. Psychological stress in parents is considered a recog-

nized risk factor for the success of cancer treatment. Scientific studies of family stress in everyday life showed a correlation between the psychological stress of young adults with cancer and perceived family conflict situations.

3 Tips and tricks

3.1 "I currently sometimes "just don't understand" and don't really dare to ask a few things in rounds in front of all the staff. What should I do?"

Even if "no stone is left unturned" after the diagnosis of cancer, we would like to encourage you to address any doubts, thoughts or perceived uncertainties. Of course, this is often more feasible in a one-on-one conversation than in the "grand rounds". It would only be fatal not to dare to address your own thoughts and doubts at all. Ask the attending physicians about the possibility of a discussion with a psycho-oncologist.

3.2 "I can't get any rest at night, even though I don't even think about it anymore. What's wrong with me?"

The diagnosis of a cancer disease or the decision for a certain cancer treatment means stress for a person. Even if we don't always notice it ourselves, the physical and mental systems for processing the new situation are all running at full speed. So it is unpleasant, but also quite human, to have difficulty getting to sleep or getting through the night at this time. Relaxation techniques such as progressive muscle relaxation, autogenic training (see Chapter 5.3 Appendix C) or even fantasy journeys can help to alleviate sleep disturbances.

For many patients, this stress also manifests itself in not engaging in activities they otherwise enjoyed (e.g. listening to music, reading a book). "At the moment, I don't like it. Everything is just too much for me." This multitude of new information, decisions and physical as well as mental impressions (e.g. by means of seeing, smelling, tasting, hearing) leads to being overwhelmed. Our brain goes into "crisis mode" during these times. Sleep disorders can be an indication of this.

3.3 "I have quite a few good friends, only they hardly get in touch at the moment. What does that mean?"

The cancer disease catapults not only oneself, but also one’s relatives and friends out of their usual way of life. These people, who are connected to me through family or friendship, suddenly find themselves in need of coping with the disease because of my cancer. On the one hand, they want to stand by me, support me and care about me. On the other hand, however, these same-aged friends, like me, are in young adulthood. As friends of someone affected by cancer, they are also face the typical stresses of cancer in young adulthood. Being young and living with cancer are two very different worlds. It takes a lot of inner strength, which some of my friends don't think they have. Suddenly I'm supposed to talk about "everyday things" with my friend who has cancer. But sometimes it's really hard, because my everyday life is no longer that of my friends. If they are really important to me, I would talk to them briefly about it, maybe even via chat. That it is difficult for ME as a cancer patient to talk to them even though I have this cancer. And maybe he or she feels the same way. That alone could bring us back into contact with each other.

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5 Appendix

5.1 Appendix A

PTV 10-1: Outpatient psychotherapy in the statutory health insurance system

5.2 Appendix B

PTV 10-2: What psychotherapeutic treatment options are available?

5.3 Appendix C

Autogenic training (AT course material)

6 Gender

Gender terms used in this text represent all gender forms.

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8 Disclosure of Potential Conflicts of Interest

according to the rules of the responsible Medical Societies.