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# Psychosocial Care in Paediatric Oncology and Haematology

## 2019

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Appendix A:	Guideline report on the creation of the guideline and the updates of 2013 and 2019, incl. → evidence tables → declaration of interests of all participants
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**Note:** Literature sources in the following document are cited in accordance with American Psychological Association APA (6th ed.) guidelines.

## 0 DEVELOPMENT PROCESS OF THE GUIDELINE

The development of guidelines for psychosocial care has been commissioned by the Society for Paediatric Oncology and Haematology (GPOH) as part of quality assurance measures for the improvement and further development of the acute treatment and follow-up care of children, adolescents and young adults with cancer. Clinical practice guidelines, i.e. the scientifically based presentation of diagnostic-therapeutic procedures, are an important tool for state-funded quality assurance measures in the health system (§§ 137 e-g SGB V).

The professional society PSAPOH (Psychosoziale Arbeitsgemeinschaft in der Pädiatrischen Onkologie und Hämatologie - Psychosocial Association in Paediatric Oncology and Haematology) has been working on the development of a uniform, nationwide structured procedure for psychosocial treatment in the case of malignant diseases in childhood and adolescence since 1997. The integration of comprehensive clinical experience and the scientific findings available is of central importance for the development of guidelines and standards of psychosocial care.

The guideline describes the structural and framework conditions as well as important aspects of psychosocial diagnostics, indication, intervention and documentation. It is intended as an instruction manual, based on the best possible evidence currently available, for the practical work of the multiprofessional psychosocial team. Additionally, it aims to make psychosocial care transparent for professionals cooperating in the fields of medicine, nursing, physiotherapy and speech therapy, as well as external teams providing support and also for patients and relatives.

Questions dealt with by the guideline include the following:

- Which emotional and social stressors are described among children with cancer and their relatives during specific treatment phases?
- Which factors promote or hinder the adaptation to disease by patients and relatives?
- How and at which points in time are stressors, resources and adaptation to disease recorded?
- For which stress factors are supportive measures offered? When and to what extent are they offered?
- Which interventions are offered to support the coping process, to strengthen resources and promote quality of life?
- Which groups of patients and treatment modalities require intensified psychosocial interventions and at which points in time?
- Which specialist, professional qualifications are required for the implementation of psychosocial care?

The S3 guideline is a further development of the S1 guideline “Psychosocial Care in Childhood and Adolescent Oncology” (*H.M. Schröder, Lilienthal, Schreiber-Gollwitzer, & Griessmeier, 2006*). This guideline has been revised, expanded and evidence-based. It has been passed in a consensus process by a representative panel of experts drawn from the relevant professional organisations, advocacy groups and specialist associations.

With regard to the central questions and core statements, consolidating literature research was carried out as the basis for the coordination of chapters 2 – 6.4. In addition, a comparison with international guidelines and recommendations was conducted (see the guideline synopsis in the guideline report).

In 2007, the Institut für Medizinische Psychologie, Universitätsklinikum Hamburg-Eppendorf was commissioned to provide scientific support for the implementation of the consensus process and the systematic literature research. The methodical procedure followed the AWMF recommendations for drawing up guidelines for diagnostics and therapy (AWMF 2004). The process of reaching a consensus was conducted with the advice and cooperation of AWMF.

The evidence-basing was carried out on 3 levels:

- Systematic literature research for selected issues
- Adaptation of statements and recommendations from international guidelines
- Consensus recommendations of the representative panel of experts

The guideline was updated in 2013 and 2019. In addition to research of comparable international guidelines, a systematic research of the literature was again conducted to enable the inclusion of new knowledge in the guideline. The results of the updates were agreed on by members of the expert group and the participating scientific associations.

Additionally, an audit was carried out in 2018 in order to gather information on the degree of implementation of the guideline in practice and its usefulness, and also to find out about barriers to its practical realisation. Scientific support for the updates was given by the Univ. Klinik für Kinder- und Jugendheilkunde der Medizinischen Universität Wien.

The guideline report for the “Psychosocial Care in Paediatric Oncology and Haematology” guideline gives detailed information on the development process of the S3 guideline, the methods used and aspects regarding implementation, updating and financing.

# 1 INTRODUCTION / BACKGROUND

## 1.1 Development of psychosocial care

Today, psychosocial care is a standard part of treatment in paediatric oncology and haematology, and in Germany, has a more than 30-year background of experience from which concepts and structures for everyday practice have been developed (*Creutzig, Jürgens, Herold, Göbel, & Henze, 2004*). Today, medical advances in the treatment of malignant diseases in childhood and adolescence make recurrence-free survival possible for 80% of all patients (*Berthold, Bode, Böcker, Christaras, & Creutzig, 2006; Creutzig et al., 2002; Gatta, 2014*). The basis for the high rates of cure for children and adolescents is extremely intensive treatment, usually associated with serious physical side effects. In addition, the consolidation of treatment centres into national or international treatment networks, as within the GPOH, has also proved to be a factor in this success (*Rossig et al., 2013*).

The disease- and treatment-related stressors are associated with a high degree of suffering for young patients and their relatives. They can lead to traumatisation, psychological illness and considerable loss of quality of life. The patients' physical, social, emotional and cognitive development is endangered. For the whole family, the diagnosis of cancer in childhood and adolescence means a prolonged and extreme emotional situation focused on the life-threatening nature of the disease. It gives rise to profound changes in family life and is accompanied by a considerable degree of psychosocial stress for the whole family.

The family represents the most important source of support for the patient in coping with the disease and its treatment, and the whole family system therefore requires professional psychosocial support (*Vance & Eiser, 2004; Wittmeyer, Kaufmann, & Lampert, 1990*), with social and psychological aspects being of equal importance. The individual emotional and social burdens of patients and relatives are reflected in a variety of publications and reports of experiences by those affected (*Barkmann, Blohm, & Wallner, 2006; Bartig et al., 1998; Bruns, 1992; P. K. H. Kelly, 1986; Steiner, Eulerich-Gyamerah, & Kochendörfer, 2003; Stember, N.2015*).

The experiences of former patients and their relatives played an important role in the process of developing psychosocial concepts. From the outset, the complexity of the psychological, social and economic pressures on the family made the provision of integrated therapeutic and social care necessary. Early on, parents' self-help groups and support associations were founded and today still provide aid for families by setting up parents' houses, funding jobs, and other activities. In 1977, on the initiative of parents' groups and paediatric oncologists, the process of integrating psychosocial personnel from professions that included psychologists, educators, social workers, art and music therapists and pastors into the medical treatment setting was begun (*H. Häberle, 2001*). In a continuing process, and in consultation with doctors and nursing staff, practice-related, needs-oriented care provision was developed in individual treatment centres (*Janssen, 1989*).

Based on the findings of a model project initiated in 1986 and backed by the Federal Ministry of Employment (*Koch, Siegrist, Schmid, & Wedell-Niemann, 1989*), multiprofessional psychosocial provision was able to be adopted nationwide as part of regular care from 1990 onwards. Here, a staffing ratio of 1 member of staff per 15-18 new admissions per year was recommended (*Göbel, Kornhuber, Schellong, & Winkler, 1991*). Paediatric oncology and haematology thus took on a pioneering role in the psychosocial care of chronically sick children and adolescents and their families.

Since 2017, the certification of child oncology centres by OnkoZert (<https://www.onkozert.de/>) requires that the psychosocial service of a centre must consist of one representative from the psychology and social work professions and one education specialist; for the fields of psychology and social work, a ratio of 2 full-time positions for every 44 cases per year is required. This staff-patient ratio was developed and confirmed nationwide in several member surveys by the PSAPOH (2009, 2013, 2014).



In German-speaking countries, a wide range of experience-based treatment concepts for various areas of care have been developed, (Di Gallo, 2004; Griefßmeier & Bossinger, 1994; Häberle & Niethammer, 1995; Kokoschka, 1984; Labouvie, Hasan, & Bode, 2003; Lilienthal, Schröder, Schreiber, & Griefßmeier, 1998; Schreiber-Gollwitzer, Schröder, & Niethammer, 2002; J. Schröder, Hiller-Ketterer, Häcker, Klemm, & Böppele, 1996; Thiel, 1990; Topf, Trimmel, Vaschalek, Felsberger, & Gadner, 1994); a model for standardised care was evaluated (Kusch, Labouvie, Jager, & Bode, 1997; Labouvie, 2005), and national guidelines drawn up (H.M. Schröder et al., 2006). The central elements of psychosocial care such as counselling and therapeutic services were described as part of a multi-centre study in Germany (Mechels, 2008; Schreiber-Gollwitzer, Schröder, Griefßmeier, Labouvie, & Lilienthal, 2003), and the structural quality was examined in a nationwide survey (Griefßmeier, Venker-Treu, & Kusch, 2003).

Care concepts for dying children and their families were developed in close cooperation with the medical treatment teams, taking the special requirements of the palliative situation into account (Führer, Duroux, & Borasio, 2006; Führer & Zernikow, 2005; Köchendorfer, 2002; Mundle, 2002; Niethammer, 1999, 2008; Ritter, 2003). In the light of medical progress, ethical questions pose a particular challenge for the organisation of the patient's dying and final phase of life (von Engelhardt, 2006).

Studies on the quality of life of patients and relatives show the need for continuing psychosocial support in the context of multidisciplinary follow-up care and the need also for evaluation of risk factors in the adaptation process after the end of treatment (Eiser, 2007; Stam, Grootenhuis, Brons, Caron, & Last, 2006).

Internationally, guidelines and recommendations on a wide range of psychosocial topics have been continuously developed from 1993 onwards by a committee of the SIOP (Société Internationale d'Oncologie Pédiatrique) (Jankovic et al., 2004; Jankovic et al., 2008; Masera et al., 1997; Masera et al., 1995; Masera et al., 1993; Masera et al., 1998; Masera et al., 1999; Spinetta et al., 2000; Spinetta et al., 1999; Spinetta et al., 2002; Spinetta et al., 2003) and by other organisations such as AAP, ACT, A(P)OSW, CAPO und ICCCP (Association for Children with Life-Threatening or Terminal conditions and their Families (ACT), 1998; Association of Oncology Social Work (AOSW), 2012; Association of Pediatric Oncology Social Work (APOSW) & Association of Oncology Social Work (AOSW); Berkow et al., 2004; Canadian Association of Psychosocial Oncology, 2010; SIOP – Working Committee on Psychosocial Issues in Pediatric Oncology. (Guidelines 1993-2004)/and ICCCP, 2002), for example. Various care concepts for child cancer patients and their families also emerged in Anglo-American countries (Bearison & Mulhern, 1994; Chesler et al., 1993; M.M. Lauria, Clark, Hermann, & Stearns, 2001; M. M. Lauria, Hockenberry-Eaton, Pawletko, & Mauer, 1996).

A 2015 systematic review (Wiener, Viola, Koretske, Perper, & Paenaude, 2015) gives an overview of 27 different standards, guidelines and consensus statements that were published in relevant literature databases (MEDLINE and PubMed) between 1980 and 2013.

Subsequently, a group of psychosocial experts from the USA set out to define updated, consensus- and evidence-based standards for psychosocial care. As a result, interdisciplinary specialists from the field of paediatric oncology together with representatives of parents' organisations, published 15 evidence-based standards within the framework of the *Psychosocial Standards of Care Project* relating to various topics in psychosocial care (Wiener, Katak, Noll, Patenaude, & Kupst, 2015 as well as following articles in *Pediatric Blood Cancer* 2015, Volume 62).

**The common basis of all the concepts is family orientation, the strengthening of resources and resistance, and a multiprofessional supportive therapy that is oriented towards the disease process (J. C. Holland & Rowland, 1990; Noeker & Petermann, 2002). The consensus among experts in the field of psychosocial oncology, that a resource-oriented approach is preferable to a psychopathological view, is of central importance (Schwarz et al., 2002).**

The necessity of including psychosocial care in the medical treatment concept is founded on the evidence of the contribution that psychosocial support makes towards improving well-being and adaptation to disease of the patients and their relatives, and in reducing stress factors (*Askins & Moore, 2008; Kazak, 2005; P. P. Patel et al., 2011*).

## 1.2 Goals and areas of responsibility in psychosocial care

Important goals and areas of responsibility of psychosocial care in everyday clinical practice are:

### **Support in coping with the disease**

- Counselling and support for patients and families in a persistent stress situation
- Encouragement of a functional, age- and development-appropriate adaptation to the disease
- Strengthening the resources, competence and autonomy of the patient and the family
- Treatment and support in acute crises and in the palliative situation
- Promotion of the greatest possible health-related quality of life and psychological health

### **Ensuring therapy and cooperation**

- Promoting compliance with the implementation of medical treatment
- Strengthening familial competence in the emotional and social care of the patient
- Organisational help for the care of the patient at home

### **Treatment of specific symptoms**

- Symptom-oriented interventions in case of emotional, behavioural and other problems

### **Social counselling and support/ organisation of follow-up care**

- Information and counselling aimed at securing the family's socioeconomic basis
- Help in applying for benefits/entitlements
- Initiation and coordination of supportive measures, help with finding financial aid
- Application for and initiation of in-patient rehabilitation
- Counselling aimed at the reintegration of the patient in kindergarten, school and vocational training
- Arranging continuing outpatient supportive measures and therapies

### **Prevention**

- Avoidance of secondary and concomitant mental illness in the patient and relatives
- Avoidance of social isolation and difficulties and also excessive familial strain
- Avoidance of social, emotional and cognitive late effects/developmental disorders

## 2 STRUCTURE AND FRAMEWORK

### 2.1 Definition of psychosocial care

- (1) Psychosocial care in paediatric oncology and haematology<sup>2</sup> encompasses all the clinical and scientific research activities concerning the evaluation and treatment of individual, psychological, familial, social and social welfare/entitlement issues relevant to the disease and their influence on coping. It also includes the development of concepts aimed at the ongoing improvement of treatment.
- (2) Psychosocial care in paediatric oncology and haematology is conducted in cooperation with the medical and nursing treatment team. The emphasis is on promoting the resources of the patient and family during the course of the disease, during therapy, follow-up care and, if the need arises, during dying, death and (anticipatory) mourning. The basis for this is a supportive and informative relationship with the children, families and the social environment. It is oriented towards the physical, emotional, social and developmental potential of sick children and adolescents and their social environment, taking individual styles and ability to cope and adjust into account.

### 2.2 Basic principles of psychosocial care

The basic principles of psychosocial care in paediatric oncology and haematology are described in the following chapter. They are supported by various national and international guidelines, standards or consensus statements for psychosocial care in (paediatric) oncology and the care of children in hospital. An overview of these is given in table 1, column 2. In addition, column 3 lists studies that provide evidence for the basic principles concerned. The aspects listed are explained in more detail in the text that follows.

#### 2.2.1 Holistic approach to treatment

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- (3) The basis for psychosocial care is the recognition of the psychosocial implications of a life-threatening disease and its treatment, which can lead to acute and chronic psychological stress reactions and disorders.
- (4) Psychoreactive and psychosocial problems are at the forefront of psychosocial care, and require specific psychosocial interventions, taking the course of the disease into account. Previous psychological illnesses, stressors and psychosocial risk factors should not be ignored.
- (5) The patients' and relatives' efforts to cope should be regarded as the expression of existing competencies, and should be examined to see how far they are suited to supporting the long-term adaptation process.

#### 2.2.2 Prevention

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- (6) Early psychosocial support should be aimed at the prevention of psychological sequelae and comorbidities in patients and relatives. It should also serve to prevent social, emotional and cognitive late effects/developmental disorders.
- (7) Psychosocial care should make the prevention of social isolation, social difficulties and excessive familial stress possible.

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<sup>2</sup> Further on in the text, this field is often referred to by the abbreviated term "paediatric oncology".

Table 1: Basic principles of psychosocial care and related publications

	Psychosocial care in paediatric oncology takes the following basic principles into account:	Used in similar form in the following guidelines/standards/consensus statements <sup>3</sup>	Evidence for the basic principle listed <sup>4</sup>
1	<b>Holistic treatment</b>	7, 27, 28, 35	
2	<b>Prevention</b>	5, 14, 16, 20, 24, 26, 34, 35, 41	
3	<b>Family orientation</b>	1, 3, 6, 7, 8, 16, 19, 20, 25, 28, 32, 34, 35, 38, 39, 41, 42	<i>Crespo, Santos, Tavares, and Salvador (2016) (4)</i>
4	<b>Centred on the individual</b>	1, 3, 6, 5, 8, 14, 24, 28, 32, 35, 37, 38	<i>Pergert, Ekblad, Bjork, Enskar, and Andrews (2016) (5)</i>
5	<b>Resource-oriented</b>	7, 8, 11, 30, 35, 38	
6	<b>Supportive therapy</b>	7, 8, 28, 30, 35, 38	
7	<b>Orientation towards the course of the disease</b>	6, 8, 20, 25, 28, 30, 35, 38, 42	<i>Levine et al. (2017) (4), Weaver et al. (2016) (1)</i>
8	<b>Interdisciplinary cooperation</b>	3, 5, 6, 7, 8, 28, 32, 35, 37, 38	<i>Davis, Burrows, Ben Khallouq, and Rosen (2017)(4)</i>
9	<b>Treatment and the observation of basic ethical attitudes</b>	2, 8, 13, 32	<i>Barlevy, Wangmo, Elger, and Ravitsky (2016) (5), Kars, Grypdonck, de Bock, and van Delden (2015)(6), S. Kelly et al. (2016) (6), Lovgren, Bylund-Grenklo, Jalmsell, Wallin, and Kreicbergs (2016) (6), Robertson et al. (2018) (5), Siembida and Bellizzi (2015) (5), Sisk, Kang, and Mack (2017) (5), Weaver, Baker, et al. (2015) (6)</i>

### 2.2.3 Family orientation

- (8) Children and adolescents need emotional support, security and protection. For the patient, the family is the essential source of support in coping with the disease and its treatment.
- (9) Psychosocial interventions are aimed at strengthening and maintaining parental and familial competence in the social and emotional support of the patient.
- (10) Cancer and its treatment in childhood and adolescence mean persistent psychosocial stress for the parents and siblings. Psychosocial care provision encompasses information, advice, and interventions aimed at relieving stress in the family.
- (11) Relatives should be encouraged to adapt their circumstances to the situation created by the illness and to cope with the stressors associated with it actively and on their own responsibility.

<sup>3</sup> The literature sources in column 2 refer to the articles cited in appendix A.

<sup>4</sup> Column 3 lists publications from the systematic literature review undertaken as part of the 2015-2018 update of this guideline. Citations are followed by a number in brackets that notes the quality of the evidence (1=systematic review or meta-analysis-controlled studies, 4= observational study [cohort- case-control-, cross-sectional study], 5= systematic review of descriptive and qualitative studies, 6= qualitative study). For the 2013-2014 period the standards of the *Psychosocial Standards of Care Project for Childhood Cancer* (given here in column 2) and the studies included there (*Wiener, Kazak, Noll, Patenaude, & Kupst, 2015*) are referred to.

#### 2.2.4 Centred on the individual

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- (12) Psychosocial care fundamentally requires an individual approach; in particular, the age and development stage of the children and adolescents, the heterogeneity of oncological diseases and their treatment and also individual familial resources and previous stress factors should be taken into account.
- (13) Information on the disease and treatment - complementing the information and advice given by the physician - is offered to the patient after and during the course of the diagnosis. This information should be given repeatedly in an age-appropriate, easily understandable and sensitive way, after consultation with the parents and with their cooperation.
- (14) Psychosocial care aims to provide age-/child-appropriate individual support and guidance during the carrying out of medical procedures as well as help in coping with the consequences of the disease and its treatment.
- (15) Psychosocial care should show respect towards different ethno-religious values regarding ways of dealing with inner-family responsibilities, gender roles and emotions in the treatment process. Attitudes towards disease should be explored and respected. In the case of language difficulties, an interpreter should be engaged when important topics need to be clarified.

#### 2.2.5 Resource orientation

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- (16) Psychosocial care aims to promote functional coping mechanisms in the patient and family, taking into account the age-appropriate development of the sick child or adolescent, and thus strengthening resistance to disease- and treatment-related stress factors.
- (17) Psychosocial care uses individual interests, abilities and skills to promote the personal resources of the patients and their family members, for example, self-esteem, self-efficacy, an optimistic attitude, hope, and staying power.
- (18) Psychosocial care promotes social resources such as stable family relationships, family cohesion, a positive, structured parenting climate and open communication.
- (19) Psychosocial care should be committed to enabling patients to take part appropriately in their social environment (peer group, school, clubs etc.) and maintain social relationships within the framework of their illness and treatment situation.

#### 2.2.6 Supportive therapy

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- (20) The long-term familial crisis situation caused by cancer in childhood and adolescence requires supportive therapy measures.
- (21) Psychosocial care includes supportive care and advice on admission, treatment, discharge, rehabilitation/follow-up care and palliative care.
- (22) Oncological facilities should aim for continuity in the provision of psychosocial care in order to enable the establishment of stable, supportive relationships with patients and their relatives.
- (23) Psychosocial care should allow adequate time for building and maintaining trust in the treatment and promote the compliance of patients and their relatives.
- (24) Psychosocial care should be primarily supportive rather than uncovering during the intensive phase of medical treatment.

- (25) In order to ensure optimum care, psychosocial care should adopt a supportive and, if necessary, mediating function between the patient, relatives and medical and nursing personnel if conflicts arise.

### 2.2.7 Orientation towards the course of the disease

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- (26) Patients and their families should have access to psychosocial support during the whole course of the disease.
- (27) Psychosocial care is oriented towards the process of the disease and treatment, and monitors the need for psychosocial care in consultation with medical and nursing personnel, the patient and relatives.
- (28) The form and extent of psychosocial interventions should be oriented towards the psychological and physical state of those affected and take their subjective problems and needs during the course of the disease into account.
- (29) Psychosocial diagnosis to determine the indication for process-oriented interventions should be carried out early on and during the course of the disease in order to make anticipatory care possible.
- (30) Palliative care concepts should be presented to patients and their families at an early date in order to reduce fears and stressors (especially fear of pain and other disease-specific symptoms) independently of their disease status. When necessary, child and adolescent patients and their families should receive long-term psychosocial care in the palliative situation. This care should be adapted to the development of the patient and oriented towards standards, but at the same time it should be flexible and geared to individual needs.
- (31) After the death of a child, the family should be contacted in order to assess their needs and risk factors for a problematic psychosocial development and, where necessary, to get them appropriate support.

### 2.2.8 Interdisciplinary cooperation

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- (32) Psychosocial care in an acute hospital is based on close interdisciplinary cooperation with the medical and nursing team. Regular consultation in the form of case, ward and departmental meetings should take place in order to coordinate patient care and work organisation.
- (33) Psychosocial personnel should exchange information – on treatment planning, the interventions that have been carried out and their results - within the multidisciplinary psychosocial team on a regular basis.
- (34) Psychosocial care is committed to networking inpatient and outpatient as well as acute and rehabilitative therapy measures, e.g. on transfer to follow-up care or later to long-term follow-up care, or on transition to adult medical care.
- (35) Psychosocial care coordinates and links support from non-professional helpers, for example, parents' associations, survivor groups, voluntary workers and donors, taking into account the well-being of the sick children/adolescents and their families.

### 2.2.9 Basic ethical attitudes

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- (36) Psychosocial personnel respect the integrity and dignity of patients and their relatives and support their right to self-determination.
- (37) Patients' and relatives' individual needs for protection are to be guaranteed in the context of psychosocial care in paediatric oncology. This includes the duty to maintain confidentiality, care in dealing with confidential information and the primacy of treatment over research.
- (38) Psychosocial care respects the right of patients and their relatives to adequate treatment independently of their cultural and ethnic background and religion.
- (39) Psychosocial care is based on a benevolent and supportive attitude which shows respect for adaptive and psychologically essential defence mechanisms.
- (40) Psychosocial care should inform honestly and in a way that is appropriate to the situation. Playing down, giving promises that cannot be kept, and being too quick to offer comfort should be avoided.
- (41) Psychosocial care should be committed to the patient's health-related quality of life in the planning and implementation of treatment measures.
- (42) Patients should receive information on their disease and treatment that is appropriate for their age and development and fulfils their individual need for information.
- (43) Adolescent patients should be involved in information and in the decision-making process concerning their treatment.
- (44) Adolescents and their parents should be informed of possible late effects (for example in relation to fertility) and of possible interventions or possibilities for support.
- (45) Psychosocial care should support open communication between parents, patient and siblings and encourage truthfulness in dealing with the disease and treatment.
- (46) Psychosocial care supports the family in finding an individual and dignified approach to the last phase of life and death.
- (47) Psychosocial interventions for children and adolescents should be implemented in consultation with and with the agreement of the parents.
- (48) Psychosocial care accepts the right of the child, adolescent or relatives to refuse the psychosocial interventions offered.

## 2.3 Organisation and structure

Guiding principles of the structure and organisation of psychosocial care in paediatric oncology and haematology are described in the following chapter. They are supported by various national and international guidelines, standards and consensus statements dealing with psychosocial care in (paediatric) oncology and children in hospital. Column 2 of table 2 gives an overview of these. In addition, studies that provide evidence of the relevant principle are given in column 3. The points listed are explained in detail in the text which follows.

Table 2: Structure and organisation of psychosocial care in paediatric oncology and related publications

	Content relating to structure and organisation	Used in similar form in the following guidelines/standards/consensus statements <sup>5</sup>	Evidence for principle cited <sup>6</sup>
1	Psychosocial care as a standard in paediatric oncology	6, 7, 8, 15, 17, 27, 35, 39	<i>Tenniglo et al. (2017) (6)</i>
2	Conditions regarding personnel, time, premises and administration	5, 8, 15, 17, 24, 27, 35	

### 2.3.1 Psychosocial care as a standard in paediatric oncology and haematology

(49) Psychosocial care is an integral part of medical treatment and follow-up care. It is structurally and organisationally integrated into paediatric oncology. Psychosocial personnel are part of the treatment team and work in the corresponding ward and/or outpatients department.

(50) For all patients, psychosocial care involves basic care and, when necessary, intensified care.

(51) Psychosocial care is low-threshold and generally accessible. It should meet the needs of the children and adolescents and their relatives.

### 2.3.2 Conditions regarding personnel, time, premises and administration

(52) Psychosocial care requires a multidisciplinary team with the adequate quality and quantity of expertise in psychology, social work, education, creative arts therapy, and psychotherapy.

(53) Areas of responsibility and competence of individual members of psychosocial staff should be defined in writing in a job description and brought into line with current professional standards and guidelines.

(54) The psychosocial service should be headed by a psychologist or clinical psychologist, an educator with an additional psychotherapy qualification, a social worker with an additional psychotherapy qualification, a child and adolescent psychotherapist, a child and adolescent psychiatrist, or a paediatrician with a suitable psychological qualification (for psychotherapeutic medicine, psychotherapy or psychiatry).

(55) In order to ensure adequate psychosocial care of both patients and relatives, staffing levels should be oriented towards the demand for care.

<sup>5</sup> The literature sources in column 2 refer to the articles cited in appendix D.

<sup>6</sup> Column 3 lists publications from the systematic literature review undertaken as part of the 2015-2018 update of this guideline. Citations are followed by a number in brackets that notes the quality of the evidence (6= qualitative study). For the 2013-2014 period the standards of the "Psychosocial Standards of Care Project for Childhood Cancer" (given here in column 2) and the studies included there (*Wiener, Kazak, Noll, Patenaude, & Kupst, 2015*) are referred to.



- (56) Psychosocial personnel should have rooms at their disposal that guarantee the necessary privacy for diagnostics, counselling and therapy. They should be easy to reach for relatives and patients using wheelchairs and infusomats, for example. Furthermore, rooms should guarantee an atmosphere of confidentiality, and give personnel the resources necessary for the best possible care.
- (57) Adequate funds should be available to psychosocial workers for testing procedures, questionnaires (see chapter 4), patient information, play and therapeutic materials, and literature, for example.
- (58) The ward should have a well-equipped play room and age-appropriate activities and rooms for children and especially for adolescents.
- (59) Psychosocial care should advocate a child-, youth- and family-friendly hospital environment which promotes the resources of patients and relatives.

## 2.4. Quality assurance and documentation

Guiding principles of quality assurance and documentation in psychosocial care in paediatric oncology and haematology are described in the following chapter. They are supported by a range of national and international guidelines, standards and consensus statements regarding psychosocial care in (paediatric) oncology and children in hospital; column 2 of table 3 gives an overview of these. Furthermore, studies that supply evidence on the relevant topics are listed in column 3. The points listed are later explained in detail in the text.

Table 3: Structure and organisation of psychosocial care in paediatric oncology and related publications

	Principles of quality assurance and documentation	Used in similar form in the following guidelines/standards/consensus statements <sup>7</sup>	Evidence for principle cited <sup>8</sup>
1	<b>Qualification of psychosocial personnel</b>	6, 8, 32, 35	
2	<b>Further and advanced training</b>	5, 24, 27, 35	<i>Robertson et al. (2018) (5), Schiessl, Gottschling, and Gronwald (2016) (5), Bradford et al. (2018) (4)</i>
3	<b>Documentation</b>	6, 5, 8, 24, 27, 32, 35	
4	<b>Evaluation and research</b>	8, 27	

### 2.4.1 Qualification of psychosocial personnel

- (60) In acute hospitals, psychosocial care in paediatric oncology should be provided by professionally trained staff from the fields of psychology, social work, education, social education, art and music therapy. Additional qualifications in the fields of psychotherapy, (paediatric) psychooncology or neuropsychology are desirable.

<sup>7</sup> The literature sources in column 2 refer to the articles cited in appendix D.

<sup>8</sup> Column 3 lists publications from the systematic literature review undertaken as part of the 2015-2018 update of this guideline. Citations are followed by a number in brackets that notes the quality of the evidence (4= observational study [cohort- case-control-, cross-sectional study], 5= systematic review of descriptive and qualitative studies). For the 2013-2014 period the standards of the *Psychosocial Standards of Care Project for Childhood Cancer* (given here in column 2) and the studies included there (*Wiener, Kazak, Noll, Patenaude, & Kupst, 2015*) are referred to.

(61) In addition to professional qualifications, psychosocial staff should have the following interdisciplinary skills:

- Knowledge of oncological and haematological diseases in childhood and adolescence, their treatment and late effects
- Knowledge of age- and culture-specific concepts of disease, loss, death and grief, and confidence in dealing with these topics
- Knowledge of chronic diseases and the specific stress reactions associated with them
- In-depth knowledge of the relevant psychological disorders in children and adolescents
- Ability to deal with crisis situations, anxiety and uncertainty
- Ability to establish a stable working relationship based on trust and an empathetic, respectful attitude
- Tolerance towards the range of emotions and coping styles of patients and their relatives
- Ability to maintain the balance between sympathy and detachment
- Good ability to cooperate and communicative competence
- Ability to handle psychological stress, and knowledge of measures for mental hygiene

#### 2.4.2 Mental hygiene of members of the psychosocial team

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(62) Frequent confrontation with suffering, pain and powerlessness and with the existential issues of life and death can be a severe emotional burden, especially for psychosocial staff, too. Appropriate measures for mental hygiene and for strengthening individuals and the team should be provided during working hours.

(63) Psychosocial workers should receive regular supervision by an external supervisor in order to reflect on their work on a professional basis and to find their own ways to relieve strain.

(64) Useful organisational/institutional strategies for the prevention of work-related stress could include team debriefings after critical disease and treatment processes or the death of a patient and other integrated multidisciplinary approaches.

#### 2.4.3 Further and advanced training

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(65) Psychosocial personnel should take part regularly in specialist further and advanced training courses. The focus should be on specific aspects of paediatrics. Further training courses relating to the skills listed under (60) are offered by the PSAPOH, among others.

(66) The PSAPOH/GPOH “Paediatric Psychooncology” certificate allows psychosocial staff to acquire a specific additional qualification by taking part in relevant PSAPOH conferences and/or seminars, in supervision, quality circles (specialist and regional groups within PSAPOH) and by completing several years of professional experience (as detailed appendix C).

(67) Psychosocial personnel should offer information and further training, for example, for medical and nursing staff at the clinic, for therapists outside the clinic, and also for teachers and voluntary helpers.

#### 2.4.4 Documentation

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(68) As part of status and process documentation, psychosocial care in paediatric oncology should include the systematic and continuous recording and documentation of stressors and resources of patients and families and the documentation of psychosocial interventions.

(69) Psychosocial personnel have a duty to keep documentation and care standards up to date and should orient themselves towards the recommendations and standards of professional organisations and associations.

(70) The documentation must meet the current data protection requirements for personal data.

#### 2.4.5 Evaluation and research

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(71) Psychosocial research is necessary in paediatric oncology for the further development of care concepts and provisions. The transfer of scientific findings to clinical practice should be supported.

(72) Psychosocial research issues should be integrated into interdisciplinary research and therapy optimisation studies.

### 3 STRESS FACTORS AND RESOURCES

Oncological diseases have psychological and social implications. In the patient and also in the family, these are determined by the type and character of the individual disease-specific physical and emotional stressors. The typical stressors and impairments have been shown in numerous scientific studies (e.g. *Dahlquist, Czyzewski, & Jones, 1996; Eiser, 1998; Fuemmeler, Elkin, & Mullins, 2002; Kazak et al., 1995; Kröger, 2005; Mulhern, Carpentieri, Shema, Stone, & Fairclough, 1993; Noeker & Petermann, 2002; Peterson et al., 2018; Sulkers et al., 2015; Tsimicalis, Stinson, & Stevens, 2005; Van Dongen-Melman, 1995; Wittmeyer & Kaufmann, 1989; R.L. Woodgate, 2000.*) These studies often examine the stress experienced by the children and adolescents themselves, their parents and their siblings. *Wakefield et al. (2017)* also refer in their study to the marked stress of the grandparents involved. In addition, non-disease-related secondary stressors of one or more family members, such as unfavourable sociocultural or psychosocial conditions, can make coping with disease and treatment more difficult (e.g. *Caplin et al., 2017; Hürter, 1990; Kazak, 1992; Kusch, Labouvie, Fleischhack, & Bode, 1996*).

#### 3.1 Stressors related to disease

Stress factors related to disease comprise all the conditions and demands that arise from the disease and the therapy. The diagnosis and prognosis of the disease itself, medical-diagnostic and therapeutic measures, the treatment regime, short-term side effects and the persistent consequences of the disease and treatment lead to varying psychosocial stressors. Table 4 gives an overview of the stressors that in clinical experience play a major role for child and adolescent patients, their siblings, parents and other relatives. There are publications dealing in detail with many but not all of the stressors encountered in clinical practice. Recent publications are also listed in table 4.

More details on possible disease-dependent stressors can be found in chapter 6 of this guideline and in the modules relating to basic psychosocial care in paediatric oncology and haematology (*Leiss et al., 2012*).

Tabelle 4: Stressors related to disease

Stressors	Concretisation	Publications <sup>9</sup>
<b>Psychosocial stressors resulting from the shock of the diagnosis and (acute) crises (during the whole course of the disease)</b>		
<ul style="list-style-type: none"> <li>• Confrontation/dealing with the diagnosis and prognosis, life-threatening/incurable nature of the disease and an uncertain disease process</li> </ul>		
<ul style="list-style-type: none"> <li>• Fear of late effects resulting from the disease and therapy</li> </ul>		<i>Arabiya, Collyer, Hamdan-Mansour, Khalil, and Darawad (2018) (4); Cerqueira, Pereira, and Barbieri Figueiredo Mdo (2016) (5); Mandrell et al. (2016) (4); van der Geest et al. (2015) (4); Weaver, Heinze, et al. (2015) (Standard 13)</i>
<ul style="list-style-type: none"> <li>• Sudden change in the circumstances of the family</li> </ul>		
<ul style="list-style-type: none"> <li>• Critical situation in the patient, parents or siblings</li> </ul>		
<ul style="list-style-type: none"> <li>• Where appropriate, dealing with recurrence or progression</li> </ul>		
<ul style="list-style-type: none"> <li>• Where appropriate, dealing with the palliative treatment situation</li> </ul>		
<b>Psychosocial stressors due to medical-diagnostic measures</b>		
<ul style="list-style-type: none"> <li>• Experience of stressful, frightening and painful medical examinations</li> </ul>	<ul style="list-style-type: none"> <li>- punctures</li> <li>- diagnostic imaging</li> <li>- taking of blood samples inter alia</li> </ul>	<i>Flowers and Birnie (2015) (Standard 8)</i>
<ul style="list-style-type: none"> <li>• Ongoing check-ups during and after treatment</li> </ul>		
<b>Psychosocial stressors due to medical-therapeutic measures/treatment</b>		
<ul style="list-style-type: none"> <li>• Dealing with necessary treatment procedures</li> </ul>	<ul style="list-style-type: none"> <li>- operation, chemotherapy,</li> <li>- radiotherapy,</li> <li>- stem cell transplant</li> <li>- decisions on the course of therapy (e.g. change in assignment to risk group)</li> </ul>	<i>Loiselle et al. (2016) (4)</i>
<ul style="list-style-type: none"> <li>• Experiencing stressful, frightening and painful medical-therapeutic measures</li> </ul>	<ul style="list-style-type: none"> <li>- taking tablets</li> <li>- mouth care</li> <li>- preparation for surgery</li> <li>- invasive procedures inter alia</li> </ul>	<i>Dupuis et al. (2016) (4); Pai and McGrady (2015) (Standard 12)</i>
<ul style="list-style-type: none"> <li>• Restrictions to lifestyle (of the whole family) due to the treatment regime and the necessity for the long-term restructuring of everyday life</li> </ul>	<ul style="list-style-type: none"> <li>- reorganisation of everyday family life</li> <li>- strain on the parents' relationship</li> <li>- strain on siblings</li> <li>- interruption of education</li> <li>- increased financial expense</li> <li>- organisational problems</li> <li>- existential economic hardships</li> <li>- threat of job loss inter alia</li> </ul>	<i>C. A. Bona (2016); K. Bona et al. (2015); K. Bona, London, Guo, Frank, and Wolfe (2016) (4); Compas et al. (2015) (4); Erker et al. (2018) (4); Gerhardt, Lehmann, Long, and Alderfer (2015) (Standard 10); Hjelmstedt, Lindahl Norberg, Montgomery, Hed Myrberg, and Hoven (2017) (4); Hoven, Gronqvist, Poder, von Essen, and Lindahl Norberg (2017) (4); Marques (2017) (4); Orsey and Wakefield (2016) (4); Pelletier and Bona (2015) (Standard 5)); Santos et al. (2017) (4); Soejima et al. (2015) (4); Soliman, Dimaras, Souka, Ashry, and Gallie (2015) (4);</i>

<sup>9</sup> Publications from the systematic literature research undertaken as part of the 2015-2018 updating of this guideline are listed. Studies from a total of 191 publications, are matched with the stress factor that is rated as being of major clinical importance (see also guideline report). For the 2013 to 2014 period, the standards of the "Psychosocial Standards of Care Project for Childhood Cancer" and the studies included in it are referred to (Wiener, Kazak, et al., 2015 (see also appendix D)).

Table 4 continued: stressors related to disease

		<i>Wiener et al. (2017) (4); Yang, Mu, Sheng, Chen, and Hung (2016) (5)</i>
<ul style="list-style-type: none"> <li>Parents' ongoing concern and multiple stressors</li> </ul>	<ul style="list-style-type: none"> <li>emotional overload</li> <li>chronic exhaustion etc,</li> </ul>	<i>Nam et al. (2016) (4); Vander Haegen and Luminet (2015) (4); Kearney, Salley, and Muriel (2015 (Standard 6)); Steele, Mullins, Mullins, and Muriel (2015 (Standard 4)); Wiener et al. (2016) (4)</i>
<ul style="list-style-type: none"> <li>Impairment of age-appropriate development due to the changed life situation</li> </ul>	<ul style="list-style-type: none"> <li>loss of autonomy and self-esteem</li> <li>feelings of guilt</li> <li>social isolation</li> </ul>	<i>Okado, Rowley, Schepers, Long, and Phipps (2018) (4); Tillery, Cohen, Berlin, Long, and Phipps (2017); Tillery, Howard Sharp, Okado, Long, and Phipps (2016) (4); Perez-Campdepados et al. (2015) (4) Standard 9</i>
<b>Psychosocial stressors due to side effects and consequences of the disease and medical therapy</b>		
<ul style="list-style-type: none"> <li>Physical impairment or changes due to the side effects of the medical therapy</li> </ul>	<ul style="list-style-type: none"> <li>infections</li> <li>nausea</li> <li>hair loss</li> <li>Cushing</li> <li>cachexia</li> <li>pain</li> <li>fatigue</li> <li>disturbed sleep</li> <li>need for intensive care</li> <li>taking tablets for the therapy of persistent side effects inter alia</li> </ul>	<i>Dupuis et al. (2016) (4); Lee, Narendran, Tomfohr-Madsen, and Schulte (2017) (5); Linder, Al-Qaaydeh, and Donaldson (2018) (4); Spathis et al. (2015) (5); Tomlinson et al. (2016) (5); Warris et al. (2016) (4)</i>
<ul style="list-style-type: none"> <li>Radical surgical procedures associated with loss of function</li> </ul>	<ul style="list-style-type: none"> <li>amputations inter alia</li> </ul>	
<ul style="list-style-type: none"> <li>Emotional or cognitive problems due to the disease or medical therapy</li> </ul>	<ul style="list-style-type: none"> <li>change in experience and behaviour</li> <li>emotional instability</li> <li>limitation of physical performance</li> <li>dealing with loss of skills and abilities</li> <li>loss of physical integrity</li> <li>coping with a changed body image inter alia</li> </ul>	<i>Annett, Hile, et al. (2015); Annett, Patel, and Phipps (2015) (Standard 2); Margelisch et al. (2015); K. E. Robinson et al. (2015)</i>
<ul style="list-style-type: none"> <li>Persistent physical, emotional or cognitive (late-) effects of the disease; fear of lasting impairments relevant to personality</li> </ul>	<ul style="list-style-type: none"> <li>growth disturbances</li> <li>fatigue</li> <li>limitation of cognitive performance</li> <li>limitation of fertility inter alia</li> </ul>	<i>Annett, Patel, et al. (2015) (Standard 2); S. Darling et al. (2018); S. J. Darling et al. (2018) (4); Fournier-Goodnight et al. (2017) (4); Klosky, Flynn, et al. (2017); Klosky et al. (2015); Klosky, Wang, et al. (2017) (4); N. Li, Jayasinghe, Kemertzis, Moore, and Peate (2017) (4); Lown, Phillips, Schwartz, Rosenberg, and Jones (2015) (Standard 3); Roddy et al. (2016) (4); Wyns et al. (2015) (4)</i>
<ul style="list-style-type: none"> <li>Insecurity in the reintegration/re-orientation phase</li> </ul>		<i>Thompson and Young-Saleme (2015) (Standard 11)</i>
<ul style="list-style-type: none"> <li>Fear of recurrence/progression</li> </ul>		<i>Clever, Schepper, Kupper, Christiansen, and Martini (2018) (4)</i>

### 3.2 Non-disease-related stressors

Non-disease-related stressors (Table 5) are factors that are not explained by the disease or the necessity of the treatment or did not originally arise in the context of the disease. They result – mostly before the onset of the disease – from the familial, personal or socioeconomic conditions of the patient and their family. They can constitute a significant risk factor with regard to the demands of dealing with the illness.

Table 5: Non-disease-related stressors

Stressors	Concretisation	Publications <sup>10</sup>
<ul style="list-style-type: none"> <li>Socioeconomic stress factors</li> </ul>	<ul style="list-style-type: none"> <li>unemployment</li> <li>financial difficulties</li> <li>single-parent family</li> <li>housing problems</li> </ul>	<i>Acharya et al. (2016); Bemis et al. (2015) (4); Hiyoshi, Montgomery, Bottai, and Hoven (2018) (4); Pelletier and Bona (2015 (Standard 5)</i>
<ul style="list-style-type: none"> <li>Language and cultural problems, legal uncertainties</li> </ul>	<ul style="list-style-type: none"> <li>unclear residency status</li> <li>unclear housing situation</li> <li>social dislocation</li> <li>lack of language skills</li> </ul>	
<ul style="list-style-type: none"> <li>Lack of social support and family cohesion</li> </ul>		<i>Harper et al. (2016) (4)</i>
<ul style="list-style-type: none"> <li>Dysfunctional coping strategies and unfavourable health behaviour</li> <li>Problematic parenting style</li> </ul>		<i>J. Chen et al. (2015) (4)</i>
<ul style="list-style-type: none"> <li>Pre-existing development disturbances or deficits</li> </ul>		
<ul style="list-style-type: none"> <li>Pre-existing somatic or mental illness of the patient or relatives</li> </ul>		
<ul style="list-style-type: none"> <li>See further Z-diagnoses in ICD-10</li> </ul>		

<sup>10</sup> Publications from the systematic literature research undertaken as part of the 2015-2018 update of this guideline are listed. From the total of 191 publications, observational studies (cohort, cross-sectional and case/control studies) (4) are matched with the stress factor that is judged as being of major clinical importance (see also guideline report and evidence tables, appendix A). For the 2013 to 2014 period, the standards of the “*Psychosocial Standards of Care Project for Childhood Cancer*” and the studies included in it are referred to (*Wiener, Kazak, et al., 2015*).

### 3.3 Personal and social resources

Resources are the positive potential the patient and family bring to the process of coming to terms with the life-threatening disease and its treatment. They are of major importance to patients in helping them to deal with this extraordinary situation. Coping with disease is an active process which includes the utilisation of existing resources and also the development of new behaviours and additional resources (McCubbin & McCubbin, 1991). The task of the diagnostic-therapeutic process consists of focusing on the one hand on the stress factors, problems and disorders, while on the other hand also focusing on the resources of patients and relatives (Grawe, Donati, & Bernauer, 1994; Klemenz, 2003; Schreiber-Gollwitzer, Schröder, & Niethammer, 2002). In the context of preventive aspects of psychosocial care, the strengths and competencies of the children and adolescents affected and their relatives are supported, taking their previous individual problem-solving strategies into account.

Since the 1980s, research has concentrated increasingly on questions of resilience, and individual and social resources that contribute towards the ability to remain emotionally healthy despite stressful circumstances. Based on a variety of theoretical concepts such as *coping*, *stress resistance*, *protective factors*, *invulnerability* and *resilience*, numerous studies have described factors that promote child development and coping with critical life events (Eilertsen, Hjemdal, Le, Diseth, & Reinjfell, 2016; Eiser, 1990; Lawford & Eiser, 2001; Luthar, Cicchetti, & Becker, 2000; Murphy et al., 2017; Petermann, Noeker, & Bode, 1987; Stam, Grootenhuis, & Last, 2001; M. Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015; Warschburger & Petermann, 2002). These are on the one hand personal resources and on the other hand social resources of the child/adolescent and their family. Social support within and outside the family, positive self-perception, sense of coherence, optimism, hope and a beneficial parenting climate are among the resources identified as having a protective effect on coping successfully with disease (Bettge & Ravens-Sieberer, 2003; Germann et al., 2015; Howard Sharp et al., 2017; Howard Sharp et al., 2015).

Stable coping factors, both short and long-term, have been found in the majority of families of young cancer patients (Kazak et al., 2003; Kupst, 1992). The following factors are among those that have been identified as promoting coping: familial integration and adaptability, reliable emotional bonds, trust, openness, optimistic attitude, favourable disease concepts, active problem-solving behaviour, fighting spirit, search for information, distraction strategies, self-encouragement, determination, religiosity and the search for a deeper meaning (Goldbeck, 1998; Grootenhuis & Last, 1997; Hockenberry-Eaton, Kemp, & Dilorio, 1994; Horwitz & Kazak, 1990; Kazak et al., 1997; Patenaude & Kupst, 2005; M.; Van Schoors et al., 2017; R.L. Woodgate, 1999a).

The results of current research also show that very anxious parents can benefit from coping strategies such as self-distancing in dealing with their feelings (Penner et al., 2016). Furthermore, the use of metacognitive strategies such as positive convictions, trust in cognitive abilities, among others (Toffalini, Veltri, & Cornoldi, 2015) and benefit-finding are seen as protective coping strategies (Willard, Hostetter, Hutchinson, Bonner, & Hardy, 2016). A systematic review of the phenomenon of post-traumatic growth showed a positive connection between post-traumatic growth and optimism. (Turner, Hutchinson, & Wilson, 2018).

Table 6 summarises the protective factors described in the literature and also those gathered from clinical experience.

Table 6: Protective factors: personal and social resources

Personal resources	Social resources
<ul style="list-style-type: none"> <li>● Optimistic attitude, hope</li> <li>● Positive experience of working through disease and death</li> <li>● Favourable disease concepts</li> <li>● Favourable coping strategies                             <ul style="list-style-type: none"> <li>○ active problem-solving</li> <li>○ fighting spirit</li> <li>○ search for information</li> <li>○ distraction strategies</li> <li>○ self-encouragement</li> <li>○ openness towards contacts</li> <li>○ creativity</li> </ul> </li> <li>● Positive self-perception</li> <li>● Feeling of self-efficacy (i.e. confident of ability to cope with situations/challenges etc. using own competencies)</li> <li>● Psychological stability</li> <li>● Religiosity and sense of a greater meaning</li> </ul>	<ul style="list-style-type: none"> <li>● Cohesion of family members</li> <li>● Reliable emotional connections</li> <li>● Socially well integrated family</li> <li>● Open communication within the family</li> <li>● Emotionally positive und secure parent-child relationship</li> <li>● Competent parenting style</li> <li>● Family adaptability</li> <li>● Secure economic and legal status</li> <li>● Ability to seek and accept social support</li> </ul>

In addition, the following **protective factors** are of central importance for the **siblings** of children and adolescents with an oncological/haematological disease:

- open and honest communication about the disease (*Eiser & Havermans, 1994*),
- adequate information about the disease and treatment (*Houtzager, Grootenhuis, & Last, 1999; Zegaczewski, Chang, Coddington, & Berg, 2016; Zeltzer et al., 1996*) and
- involving siblings in the process of the disease and patient care.

The complex interaction of demands, stress factors and resources is the basis for the individual and familial process of adapting to the disease and its consequences, and for subsequent psychosocial development. It is fundamental for the psychosocial treatment plan.



## 4 DIAGNOSTICS

### 4.1 Psychosocial diagnostics in clinical care

Psychosocial diagnostics serve to evaluate individual stressors and to identify coping and adjustment strategies available to the sick child, adolescent or young adult and their social environment. Psychosocial diagnostics can include the taking of a thorough history and exploration and/or the use of standardised tests/questionnaires and/or behaviour observation. Particularly in contact with a vulnerable population comprising children, adolescents and young adults with cancer, great stress should be placed on the consideration of both methodical and ethical standards, such as transparency and orientation towards daily life and the patients' resources. This should be reflected in the choice of tests in order to record not only possible weaknesses but also everyday strengths (*see for example. Leiss, 2011*), thus enhancing young patients' abilities to deal with stressors and deficits.

#### 4.1.1. Psychosocial diagnostics as routine basic diagnostics

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Psychosocial diagnostics form the basis for the further planning of psychosocial treatment and can at the same time promote team communication concerning the psychosocial treatment needs of individual families. In particular, instruments such as the resource and stress profile (*Schreiber-Gollwitzer & Schröder, 2012*), or in the English-speaking world, the Psychosocial Assessment Tool PAT (*Kazak et al., 2018; McCarthy et al., 2016*) and the Psychosocial Care Checklist PCCL (*Barrera et al., 2016*) have been shown to promote interdisciplinary communication.

The aim is to record psychosocial stressors and resources for all children, adolescents or young adults and their social field, and to assess disease adaptation and therapy motivation. These basic diagnostics, which are described in detail in table 7, should be conducted routinely as early as possible at the beginning of therapy (*cf.e.g. A. S. Kunin-Batson et al., 2016*), during the course of treatment (in the case of long-term therapy in particular), at the conclusion of intensive therapy and in follow-up care.

This is also formulated as a strong recommendation with a high level of evidence (from 149 studies) in *Pediatric psychosocial standards of care (Wiener, Kazak, et al., 2015)*: “Youth with cancer and their family members should routinely receive systematic assessment of their psychosocial health care needs” (*Kazak, Abrams, et al., 2015*).

##### 4.1.1.1 Importance of taking both self- and clinical assessment into account

Many scientific studies have shown that the inclusion in the diagnostic process of the perceptions of all those concerned (e.g. through self-assessment by the children/adolescents and external assessment by parents and teachers) is of great importance for a meaningful intervention plan (*Hermont, Scarpelli, Paiva, Auad, & Pordeus, 2015; Jones et al., 2018*). The development of digital means of self- assessment of symptoms during oncological therapy for children and adolescents (*e.g. O'Sullivan et al., 2018*) is useful here, as is a critical analysis of which test methods and questionnaires give a valid picture of the needs of adolescents and young adults (AYAs) with cancer. The inclusion of patients in the conception of test methods has proved very successful in this respect (*Taylor et al., 2015*).

##### 4.1.1.2 Screening versus comprehensive psychosocial diagnostics

Due to limited resources, there is a desire for time- and personnel-saving psychosocial diagnostic methods in order to give adequate support to higher-risk patients. However, several studies have shown that the use of screening methods can lead to patients with greater psychosocial needs being overlooked. *Recklitis, Blackmon, and Chang (2016)* showed in their study, for example, that 31.8% of survivors who were given a psychological/psychiatric diagnosis after a standardised clinical interview

(SCID), and 32.81% of survivors who were identified as having significant symptoms by a SCID were not identified by the Distress Thermometer.

Selected screening methods can therefore be justified under certain circumstances and at certain times, but they should be used with caution and must be combined with more extensive psychosocial examination methods. At the beginning of therapy especially, but also at other critical points in time during the course of treatment (e.g. on transition to follow-up care), treatment needs should not be assessed exclusively by screening.

In the great majority of clinics in German-speaking countries, the demand for differentiated psychosocial diagnostics instead of screening procedures at certain points in the course of treatment can be met, thanks to the establishment of integrated psychosocial care concepts.

#### 4.1.2. Psychosocial diagnostics as in-depth diagnostics

In addition to basic diagnostics, **specific, in-depth diagnostics** can be necessary, using appropriate standardised methods for the differentiated assessment of the relevant problem areas associated with the disease. The use of questionnaires and tests is oriented towards the results of the psychosocial anamnesis and exploration.

##### 4.1.2.1 Examination dimensions of in-depth diagnostics

In recent years, various research groups have developed methods concerning a range of specific issues. Parental stress (*Tanco et al., 2017*), sibling stress (*Long et al., 2018*), fatigue (*Friedrich et al., 2018*), pain (*Mahon et al., 2015; Thorsell Cederberg, Weineland Strandskov, Dahl, & Ljungman, 2017*), sleep disturbance (*Setoyama, Ikeda, & Kamibeppu, 2016*), eating behaviour (*Swartz et al., 2016*), and also dealing with suicidality (*Lucas et al., 2015*) are among the topics of current research.

With regard to follow-up care, methods have been (further) developed, in particular those concerning the transition process (*Klassen et al., 2015; Schwartz et al., 2017*) or the desire to have children (*Geue et al., 2015*). In addition, there have been attempts to develop and evaluate screening methods within the framework of follow-up care facilities, with the aim of identifying survivors in need of psychosocial support (*de Laage et al., 2016*). Methods such as the *Beck Depression Inventory-FS* (BDI - Fast Screen) or a *Mini-Symptom-Checklist* (Mini-SCL) have been used as screening methods in view of minimal resources, although based on results, these were not recommended to be used exclusively, but in combination with diagnostic interviews (e.g. SCID) (*Recklitis, Blackmon, & Chang, 2017*). Corresponding methods in use in German-speaking countries are listed in table 8, although some of the methods are still at the development stage or only available in English.

##### 4.1.2.2 Neuropsychological diagnostics before, during and after treatment

In principle, neuropsychological diagnostics are also in-depth diagnostics. In the case of certain risk factors such as brain tumours, ALL/AML or following certain forms of medical treatment or surgery (e.g. neurosurgery, radiotherapy of the central nervous system, intrathecal therapy, stem cell transplants), neuropsychological diagnostics are recommended as a central element of psychosocial care (e.g. *Boulet-Craig et al., 2018; Van Der Plas et al., 2018*).

Accordingly, *Annett, Patel, et al. (2015)* formulate a Standard from *Pediatric psychosocial standards of care (Wiener, Kazak, et al., 2015)* as follows:

*Children with brain tumours and other high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment.*

This standard was developed on the basis of 129 publications analysed, based on GRADE quality criteria (*see, for example. G. Langer et al., 2012*); the quality of the evidence of these studies was rated *high*, the recommendation as *strong*.

*Baum et al. (2017)* suggest six different levels of neuropsychological care, beginning with clinical observation, through questionnaires or interview, neuropsychological screening, extensive neuropsychological examination up to neuropsychological monitoring in follow-up care.

The findings of some research groups (*Chieffo et al., 2016; Irestorm, Perrin, & Olsson, 2018; Ris, Grosch, Fletcher, Metah, & Kahalley, 2017; Sands et al., 2017*) also stress the importance, acceptance and feasibility of an initial neuropsychological examination at the start of treatment in order to better classify cognitive late effects and give timely support to patients.

#### **4.1.2.3 Factors influencing the findings of neuropsychological diagnostics**

The findings of neuropsychological testing are subject to many influencing factors and sources of error. It is essential to know these because test findings, in clinical care and also in research, often have far-reaching consequences both for the person examined (e.g. decisions on schooling and school forms) and for a group that is examined (e.g. statements on what effects a certain therapy, such as radiotherapy has on the cognitive performance of children and adolescents with a certain kind of brain tumour).

Methodical quality criteria of a test or questionnaire should thus be taken into consideration when appropriate test methods for a particular issue are selected (*see for example Kubinger, 2009*). This makes it possible to judge the accuracy (*reliability*) of a test and whether it measures the feature it claims to measure (*validity*) (e.g. numeracy skills) and not some other feature (e.g. memory, if a child has to remember numbers before actual calculation; or motivation or schooling).

*Objectivity* in conducting, evaluating and interpreting tests is also of central importance in order to guarantee the comparability of test results. The way in which test tasks are set, which assessment errors they are subject to (e.g. the well-known halo effect, in which judgements on a person's unknown characteristics are made on the basis of the characteristics that are known), how the test situation is designed, and lastly, how the findings are evaluated and interpreted all have a great influence on the findings of a neuropsychological examination.

At all stages of the diagnostic process, a procedure that is as standardised as possible is recommended in order to arrive at conclusions that support and strengthen the children and adolescents examined.

By way of example, three studies that deal with factors influencing the findings of neuropsychological examinations are mentioned here:

*A. A. Holland et al. (2016)* show in their scientific study that children and adolescents with a medulloblastoma who were given a randomly allocated external motivation (in the form of a reward) were able to increase their literacy and numeracy performance compared to a control group that had no external motivation. Their performance was, however, still poorer than for healthy peers.

Furthermore, hearing impairments, which negatively affect the whole neuropsychological performance profile, should not be ignored (*Orgel et al., 2016*).

Moreover, *Wegenschimmel et al. (2017)* were able to show that in a group of children and adolescents with medulloblastoma, slower processing speed and visual-motor coordination led to poorer findings or lower IQ rates. This can lead to a disadvantage for these patients with regard to reintegration in school or workplace. Instead of interpreting global values such as IQ, it is therefore recommended to interpret only individual subtests, taking processing speed into consideration.

## 4.2 Psychosocial diagnostics in oncological treatment studies

Psychosocial diagnostics are now an integral element in many international oncological treatment protocols and studies. According to the problems faced by patients and relatives, parameters on quality of life, for example, on participation or neurocognitive function are assessed and the findings included in the further development of medical treatment protocols.

For patients with brain tumours, there is a consensus on which regions and which examination methods should be used if children and adolescents are being treated within the framework of SIOP-E studies (*Limond et al., 2015 for children and adolescents over the age of 5*). A ‘core plus’ approach is recommended, defining the core, which can be evaluated directly (e.g. using neuropsychological test methods) and indirectly (e.g. by external assessment of quality of life). The ‘plus’ permits the use of complementary methods that are country-specific and also specific to the kind of tumour, its localisation, the patient’s age, etc.

Accordingly, within the PSAPOH framework, a battery of tests *for neuropsychological diagnostics in paediatric oncology and haematology (ND-POH)* was designed. This is recommended within the framework of the HIT treatment network and used in some GPOH therapy optimisation studies as accompanying study. Obligatory core tests and optional (sub-) tests were defined and described in detail in a manual (PSAPOH, in preparation). It is thus possible to optimally respond to the needs of children and adolescents; neuropsychological diagnostics within the framework of oncological treatment studies are therefore at the same time an important element of psychosocial care.

The following tables 7 and 8 give an overview of the **examination dimensions** and the **examination methods** available in **German-speaking countries** for the points dealt with above (psychosocial diagnostics as basic diagnostics and in-depth diagnostics).

*Comment on tables 7 and 8: The examination methods are listed in alphabetical order per examination dimension. In principle, the norming of examination methods listed is not older than 10 years. In some exceptions, examination procedures with older norm dates or non-German norms are also listed if their use is of major clinical importance and no alternatives are currently available. Sources for the test procedures as well as additional information on the availability of the test procedure/questionnaire are given in appendix B of the guideline. The so-called ‘core Tests’ of the ND-POH are identified as such. **The methods listed merely represent a selection and a recommendation.***

Table 7: Psychosocial diagnostics as basic diagnostics

BASIC DIAGNOSTICS	
INITIAL DIAGNOSTICS	
<ul style="list-style-type: none"> <li>Initial contact on diagnosis</li> <li>Presentation of psychosocial care provision</li> <li>Start of diagnostic process</li> </ul>	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Psychosocial anamnesis               <ul style="list-style-type: none"> <li>sociodemographic data</li> <li>history of disease</li> <li>patient's and family's anamnesis</li> <li>evaluation of resources</li> <li>disease-dependent and -independent stressors</li> <li>coping with the disease</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>anamnesis and exploration</li> <li>resource - and stress profile (<i>Schreiber-Gollwitzer &amp; Schröder, 2012</i>)</li> <li>parental stress inventory (<i>Tröster, 2010</i>)</li> <li>family genogram</li> </ul>
→ Complementary diagnostics (patient) on suspicion of developmental/psychological abnormalities or disturbances	- in-depth diagnostics; if necessary, consultation of specialist psychologist/psychiatrist and taking the assessment of other therapeutic specialists into account
→ Complementary diagnostics (family) on suspicion of social conflict situation	- in-depth exploration of socioeconomic situation; consultation with social work specialists
ONGOING DIAGNOSTICS	
<ul style="list-style-type: none"> <li>Phase-specific and disease-oriented (in particular during long-term therapy)</li> <li>In critical situations (e.g. medical complications)</li> <li>In transition situations (e.g. preparing for a transplant)</li> </ul>	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Coping with disease, compliance</li> <li>Motivation for therapy</li> <li>Phase-specific issues</li> <li>Overall family stress</li> <li>Psychological findings of the child/ adolescent/ young adult</li> </ul>	<ul style="list-style-type: none"> <li>repetition of elements of the initial diagnostics or in-depth diagnostics</li> <li>if necessary, in-depth diagnostics</li> </ul>
<ul style="list-style-type: none"> <li>Diagnostics for the initiation of in- or out-patient rehabilitation measures</li> </ul>	- detailed psychosocial exploration of patient and care givers, psychosocial referral report/opinion (e.g. on neuropsychological diagnostics; special referral reports from rehabilitation clinics)
DIAGNOSTICS AT THE CONCLUSION OF INTENSIVE THERAPY and in the course of FOLLOW-UP CARE	
Examination dimension	Examination methods
<ul style="list-style-type: none"> <li>Status survey of:               <ul style="list-style-type: none"> <li>psychosocial situation</li> <li>adjustment to disease (patient and family)</li> <li>home care situation</li> <li>child's/adolescent's/ young adult's psychological findings</li> </ul> </li> </ul>	- repetition of elements of initial diagnostics
<ul style="list-style-type: none"> <li>Assessment of support needs for reintegration in everyday life/kindergarten/school/workplace</li> </ul>	<ul style="list-style-type: none"> <li>in-depth exploration of individual conditions and environmental factors relating to participation in everyday life</li> <li>in-depth diagnostics, where necessary consultation with psychology/education specialists</li> </ul>
→ Complementary diagnostics (patient) on suspicion of inadequate adaptation to the disease, behavioural- or emotional abnormalities or disturbances, fatigue, pain, sleep disturbances, abnormal eating behaviour	- in-depth diagnostics, where necessary, consultation with psychological/psychiatric specialists
→ Complementary diagnostics (patient) in case of neuropsychological impairments	- in-depth diagnostics, where necessary, consultation with psychological/psychiatric specialists

Table 8: Psychosocial diagnostics as in-depth diagnostics

IN-DEPTH DIAGNOSTICS		
Examination dimension <sup>11</sup>	Possible examination methods (current versions)	Age range (Y – years, M – months, SY – school year)
Development, intellectual skills (verbal & non-verbal)	Adaptive intelligence diagnostics 3 (AID 3)/ AID 3 – tailored testing (AID_3_tailored)	6;0 – 15;11 Y
	Advanced Progressive Matrices (APM)	from 12 Y
	Basic diagnostics of defined development disorders in pre-school age - (BUEVA-III)	4;0 – 6;5 Y
	Bayley Scales of Infant and Toddler Development – 3 <sup>rd</sup> Edition (BAYLEY-III)	1 – 42 M
	Coloured Progressive Matrices (CPM) <b>(ND-POH)</b>	3;9 – 11;8 Y
	Development test 6 months - 6 years - Revision (ET 6-6-R)	6 M – 6 Y
	Intelligence- and development scales for children and adolescents (IDS-2)	5 – 20 Y
	Kaufman Assessment Battery for Children – 2 <sup>nd</sup> Edition (KABC-II) <b>(ND-POH<sup>12</sup>)</b>	3 – 18 Y
	Non-verbal intelligence test (SON-R 2-8)	2;0 – 8;0 Y
	Non-verbal intelligence test (SON-R 6-40)	6;0 – 40;11 Y
	Standard Progressive Matrices (SPM) <b>(ND-POH)</b>	9 – 25 Y
	Wechsler Adult Intelligence Scale (WAIS-IV) <b>(ND-POH<sup>12</sup>)</b>	16;0 – 89;11 Y
	Wechsler Intelligence Scale for Children – 5 <sup>th</sup> Edition (WISC-V) <b>(ND-POH<sup>12</sup>)</b>	6;0 – 16;11 Y
	Wechsler Nonverbal Scale of Ability (WNV)	4 – 21 Y
Wechsler Preschool and Primary Scale of Intelligence – 4 <sup>th</sup> Edition (WPPSI-IV) <b>(ND-POH<sup>12</sup>)</b>	2;6 – 7;7 Y	
Attention, concentration, processing speed	Cognitive basic performance (COGBAT)	14 – 88 Y <sup>2)</sup>
	D-KEFS Trail Making Test (D-KEFS TMT)	8;0 – 89;0 Y
	Frankfurter attention inventory 2 (FAIR-2)	9 – 85 Y
	Test battery of attentional performance for children (KITAP)	6 – 10 Y
	Test battery of attentional performance for children (TAP 2.3.1) <b>(ND-POH<sup>12</sup>)</b>	6 – 90 Y <sup>13</sup>
	Test of Everyday Attention for Children - German adaption (TEA-Ch)	6 – 16 Y
	Test for evaluating concentration and attention at the elementary level (TEA-Ch-K)	4;0 – 6;6 Y
	Perception and attention functions battery (WAF)	from 7 Y
Learning ability, memory retention	Working memory test battery for children aged 5 to 12 Y (AGTB 5-12)	5 – 12 Y
	Battery for Assessment in Children – memory and learning ability test for ages 6 to 16 years (BASIC-MLT)	6;0 – 16;11 Y
	Developmental Scoring System for the Rey-Osterrieth Complex Figure (DSS ROCF)	5 – 14 Y
	Diagnostics for cerebral damage – II (DCS-II)	from 5 Y
	Rey-Osterrieth Complex Figure Test (ROCF)	6 – 89 Y
	Visual and verbal memory retention test (VVM)	15 – 79 Y
	Verbal learning ability and memory retention test (VLMT) <b>(ND-POH)</b>	from 6 Y
	Wechsler Memory Scale – Fourth Edition (WMS-IV)	16 - 90 Y
Planning and problem-solving ability / flexible thinking	Standardised Link'sche Probe (SLP)	14 – 60 Y
	Tower of London – German version (TL-D)	6 – 15 Y
	Tower of London – Freiburg version (TOL-F)	from 13 Y
	Wisconsin-Card-Sorting-Test (WCST)	6;6 – 89 Y
	Zoo-game	6 - 9 Y

<sup>11</sup> Test procedures are allocated to one examination dimension, even if they apply to several neurological dimensions (e.g. language skills and executive functions)

<sup>12</sup> individual subtests

<sup>13</sup> age varies according to subtest

Table 8 continued: in-depth psychosocial diagnostics

Examination dimension <sup>11</sup>	Possible examination methods (current version)	Age range (Y – years, M – months, SY – school year)
Visual-spatial perception/ eye-hand coordination, fine motor skills, graphomotor skills	Beery-Buktenica Developmental Test of Visual-Motor Integration (BEERY VMI) (ND-POH)	2;0 – 99;11 Y
	Frostigs development test of visual perception – 2 (FEW-2)	4 – 9 Y
	Frostigs development test of visual perception – youth and adults (FEW-JE)	9 – 90 Y
	Screening and differential diagnostics of graphomotor skills in the school context (GRAFOS)	4;8-8;6 years
	Motor skills series (MLS)	ab 14 Y
	Purdue Pegboard (Minnesota Dexterity Test) (ND-POH)	5 – 89 Y
	Developmental Scoring System for the Rey-Osterrieth Complex Figure (DSS ROCF); Rey-Osterrieth Complex Figure Test (ROCF)	5 – 14 Y 6 – 89 Y
Language/ word fluency	Regensburg word fluency test (RWT)	8 – 15 Y, 18 Y+
	Language development test for two-year-olds (SETK-2)	2;0 – 2;11 Y
	Language development test for three- to five-year-olds (SETK 3-5)	3;0 – 5; 11 Y
	Language level evaluation test for children aged 3-5 (SET 3-5)	3 – 5 Y
	Language level evaluation test for children aged 5-10 (SET 5-10)	5 – 10 Y
Academic skills	<b>Written language and mathematical precursor skills</b>	
	Mathematics- and arithmetic concepts at preschool age – diagnosis (MARKO-D)	4-6;6 Y
	Test of basic mathematical skills at kindergarten age (MBK 0)	3;6-7 Y
	Würzburg pre-school test (WVT): written language (precursor-) skills, language skills, mathematical (precursor) skills	10-11 or 4-5 months before starting school
	<b>Reading/writing</b>	
	Basic competencies for reading and writing performance (BAKO 1-4)	end of 1 <sup>st</sup> – 4 <sup>th</sup> SY
	Reading comprehension test for pupils in year 1 to year 7 – version II (ELFE II)	1. – beginning of 7 <sup>th</sup> SY
	Hamburg writing test 1-10 (HSP 1-10)	1. – end of 10. SY
	Reading and writing tests II (SLRT-II)	reading: 1. – 6. SY, writing: 1 <sup>st</sup> – beginning of 5 <sup>th</sup> SY
	Salzburg reading screening for school years 2-9 (SLS 2-9)	2 <sup>nd</sup> – 9 <sup>th</sup> SY
	<b>Mathematics</b>	
	Basic mathematics diagnostics for years 4–8 (BASIS-MATH 4-8)	4 <sup>th</sup> – 8 <sup>th</sup> SY
	Eggenberger maths test (ERT 0+ – 4+)	end of kindergarten – middle of 5 <sup>th</sup> SY
	Diagnostics of mathematical - und number processing abilities for years 2 to 6 RZD 2-6)	End of 2nd – mid 6 <sup>th</sup> SY
	Test for assessing number and arithmetic skills from kindergarten to year 3 (TEDI-MATH)	4 – 8 Y
	Test method for dyscalculia (ZAREKI-R)	1 <sup>st</sup> – 4 <sup>th</sup> SY
Neuropsychological test battery for assessing number processing and arithmetic in children - kindergarten version (ZAREKI-K)	during last year before starting school	

Table 8 continued: in-depth psychosocial diagnostics

Examination dimension <sup>11</sup>	Possible examination methods (current version)	Age range (Y– years, M – months, SY -school year)
Health-related quality of life	Child Health Questionnaire – Parent Form (CHQ-PF28)	4- 13 Y
	Gießen Beschwerdebogen (Giessen complaint questionnaire): for children and adolescents (GBB-KJ), for adults (GBB -24)	4 – 18 Y from 16 Y
	Health Utility Index (HUI)	children/adults
	Questionnaire on quality of life for children and adolescents – self-assessment and assessment by parents (KINDL-R): Kiddy KINDL (4-6 Y), Kid KINDL (7-13 Y), KiddoKINDL (14-17 Y)	4 – 17 Y
	Late adolescence and young adulthood survivorship-related quality of life measure (LAYA-SRQL, deutsche Version)	16 – 39 Y
	Pediatric Quality of Life Questionnaire (PEDQOL)	8 – 17 Y
	Pediatric Quality of Life Inventory™ (PedsQL™) – Self-assessment and assessment by parents; various modules available in German, including brain tumour, cancer, neurofibromatosis, multidimensional fatigue scale, paediatric pain coping scale	2 – 25 Y
	Fatigue questionnaire (EORTC QLQ- FA12)	from 14 Y
	Questionnaire on health status (SF-36)	from 14 Y
Behaviour/emotional health/ psychosocial functionality	<b>Self-assessment by children, adolescents and young adults</b>	
	Behaviour rating inventory of executive function (BRIEF)	11 – 16 Y
	Beck depression inventory – Fast Screen for medical patients (BDI-FS)	from 13 Y
	Depression inventory for children and adolescents (DIKJ)	8 – 16 Y
	Depression test for children of elementary school age (DTGA)	7 - 11 Y
	Depression test for children - II (DTK-II)	9 – 14 Y
	Diagnostic system for mental disorders according to ICD-10 and DSM-5 for children and adolescents – III (DISYPS-III)	11 – 18 Y
	Questionnaire on emotional regulation in children and adolescents (FEEL-KJ)	10;0 – 19;11 Y
	Health competency scales	6 – 16 Y
	Interviews on stress disorders in children and adolescents (IBS-KJ)	7 – 16 Y
	Child anxiety test III (KAT-III)	6 – 18 Y
	Brief symptom checklist (BSCL) or short form: Mini symptom checklist (Mini-SCL)	from 16 Y
	Participation scales – 24 hours per day / 7 days per week (PS 24/7)	6;0 – 18;11 Y
	Structured clinical interview for DSM-5®-disorders – clinical version (SCID-5-CV)	ab 18 J
	Strengths and Difficulties Questionnaire (SDQ-Deu)	11 – 17 Y
	Questionnaire on stress and coping with stress in childhood and adolescence - Revision (SSKJ 3-8 R)	7 – 16 Y
	Stress processing questionnaire by Janke and Erdmann, adapted for children and adolescents (SVF-KJ)	8 – 16 Y
	Questionnaire for adolescents (YSR/11-18R)	11 – 18 Y
	Questionnaire on desire for having children (LKM)	from 18 Y
	<b>Assessment by parents / teaching staff</b>	
	Behaviour rating inventory for evaluating executive functions in kindergarten-age children (BRIEF-P)	2 – 6 Y
	Behaviour rating inventory of executive function (BRIEF)	6 – 16 Y
	Questionnaire for parents on the behaviour of children and adolescents (CBCL/6-18R); questionnaire for teachers on the behaviour of children and adolescents (TRF/6-18R)	6 – 18 Y
	Diagnostics system for mental disorders according to ICD-10 and DSM-5 for children and adolescents – III (DISYPS-III)	4 – 18 Y
	Health competence scales – parents' version (German-language adaptation of scale after Grootenhuis, M.A. und Last, B.F.)	6 – 16 Y
	Questionnaire for the evaluation of cognitive processes in 4 to 6-year-olds (KOPKI 4-6)	4 – 6 Y



Table 8 continued: in-depth psychosocial diagnostics

Untersuchungsdimension <sup>11</sup>	Possible examination methods (current version)	Age range (Y – years, M – months, SY – school year)
Behaviour/ emotional health/ psychosocial functionality	Participation scales – 24 hours per day / 7 days per week (PS 24/7; version for parents and teachers)	6;0 – 18;11 Y
	Strengths and Difficulties Questionnaire (SDQ-Deu) - parents (2-17 Y), teachers (4-17 Y)	2 – 17 Y
	Behaviour rating sheet for pre-school children (VBV 3-6)	3 – 6 Y
	Vineland Adaptive Behaviour Scales (VABS) – Interview and questionnaires <sup>14</sup>	birth to adulthood
Parental stress	Parental stress questionnaire (ESF)	parents of children: Kindergarten up to 6 <sup>th</sup> SY
	Questionnaire on fear of progression for parents of child cancer patients (PA-F-KF/E)	parents
Methods supporting exploration	Children’s Self-Report and Projective Inventory (CSRPI)	5 – 12 Y
	Family relationship test (FBT)	
	Family in animals (FIT)	
	Plämo-Kasten (Playmobil material for use in diagnostics and therapy) or similar	

<sup>14</sup> currently only available in English/Spanish language and norms

## 5 LEADING SYMPTOMS and INDICATION

### 5.1 Reactions to a severe stressor: differential diagnostics

The indication for psychosocial interventions is based on significant psychological and social burdens on the patient and their family. These burdens can lead to a range of reactions of varying degrees. The trauma of a life-threatening disease presents itself as an intense experience of discrepancy between the threatening situation and individual coping capacities, associated with feelings of helplessness and defenceless abandonment (G. Fischer & Riedesser, 1999).

The reaction of a child, their parents, siblings and other relatives to a severe, life-threatening illness should not principally be interpreted as a psychological disturbance, but depending on the intensity of the symptoms, it can turn into one.

In paediatric oncology we therefore usually refer to adequate stress reactions, i.e. those that are appropriate to the event or occurrence that caused them with regard to expression and intensity- as distinct from the pathological stress reactions and adjustment disorders in terms of ICD 10 (Dilling, 2004). Persistent stress reaction (B. Schreiber-Gollwitzer & Gollwitzer, 2007) is defined as follows:

*Subjective suffering and emotional disturbance as a reaction to extraordinary mental or physical stress. With regard to the severity of the stress, the reaction is adequate in expression and intensity. The reaction includes symptoms of depressive mood, anxiety, despair, withdrawal or also aggressive or expansive behaviours, social behaviour problems and psychosomatic problems, which do not fulfil the criteria for a disorder in accordance with ICD 10, but nevertheless present a considerable need for psychosocial intervention. A temporary relief from or revival of symptoms, possibly in a different form, and usually due to the course of the disease, can occur, but is always linked to the event that caused it or the stressor.*

In the Anglo-American world these forms of reaction are also referred to as “emotional distress” (Bultz & Carlson, 2006; NCCN - National Comprehensive Cancer Network, 2007). Other models refer to the concept of “chronic sorrow” (see for example Ahlström, 2007).

Studies have repeatedly shown that a significant majority of sick children and adolescents and also their relatives are affected by these stress reactions (compare for example Kunin-Batson et al., 2016; Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2015). Even if this *persistent stress reaction* does not constitute a pathological event in the narrow sense, there is often a considerable need to take action and give support due to the severity and intensity of the subjective pain and decreased level of functioning. The assessment of the appropriateness of the reaction, taking into account the severity of the burden on the one hand, and on the other hand, and the subjective perception of stress and knowledge of the personal characteristics of the patient, is fundamental. (A. D. Cox, 1994; Resch, 1999).

Depending on the temporal connection, if the reaction to a severe stressor significantly exceeds the expected level in its symptoms, manifestation and degree, it is referred to as an *acute stress reaction*, *post-traumatic stress disorder (PTSD)*, *adjustment disorder* or other *emotional, affective or social behaviour disorder* (ICD 10) to distinguish it from a *persistent stress reaction*. The proportion of patients affected is estimated both in literature and practice to be much smaller than those exhibiting a *persistent stress reaction*. Thus, in a multi-centre study conducted in six German paediatric oncology centres, Dietrich et al. (2016) found that 17.4% of 213 parents had PTSD symptoms, in line with similar studies.

Similarly, in a study by Tillery et al. (2016) 83% of the 253 8-17-year-old respondents were allocated to a resilient group after they themselves and a parent had assessed a PTSD. The proportion of anxiety disorders and depression in the children, adolescents and young adults affected is estimated

as slightly higher in scientific literature, although the broad spectrum of different definitions, measurement methods, study designs and also cultural backgrounds and systems of care do not make it possible to generalise this data.

Figure 1 makes the diagnostic distinction between persistent stress reactions and the acute stress reaction and adjustment disorders of ICD 10.

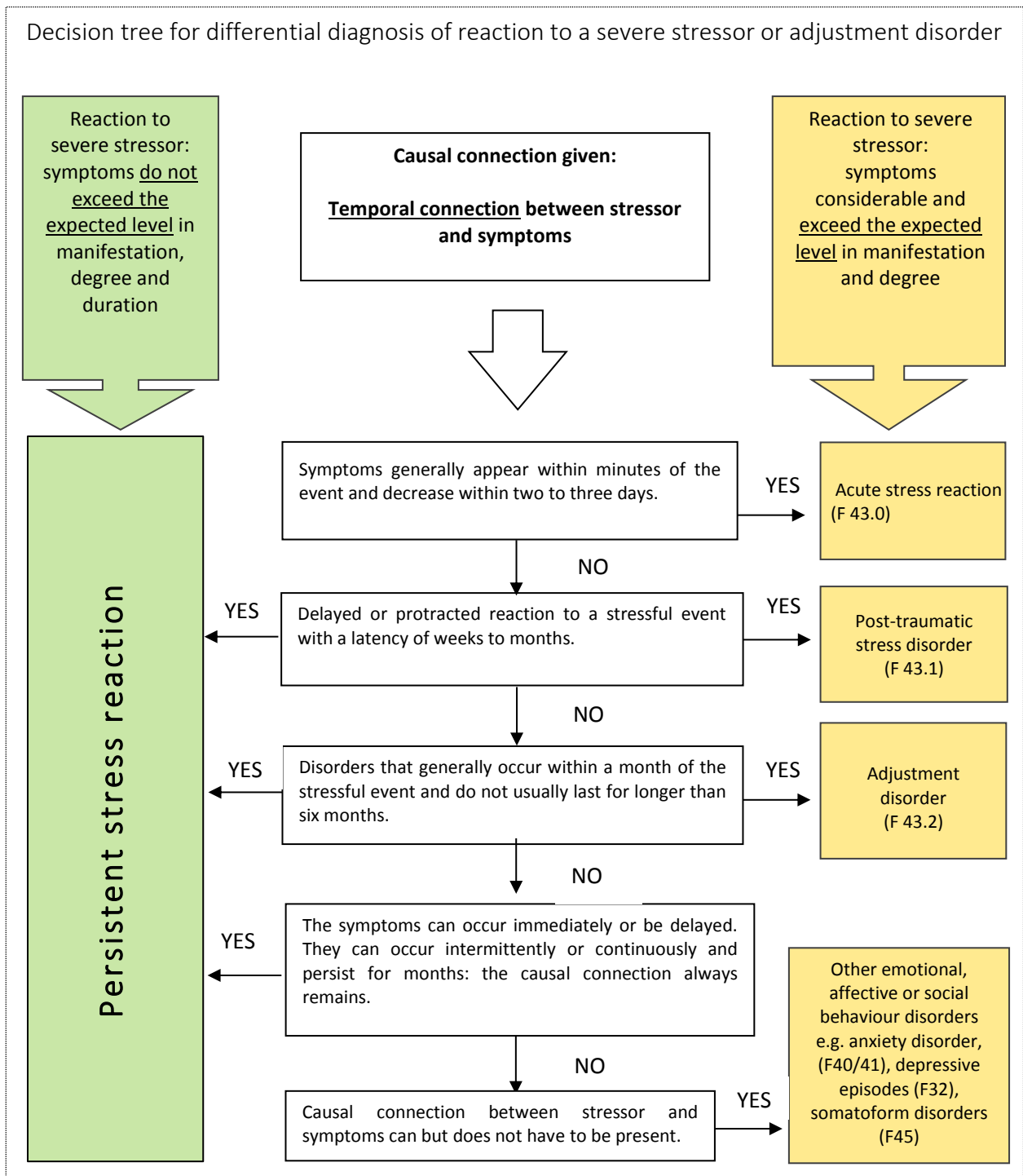


Figure 1: Diagnostic decision tree (B. Schreiber-Gollwitzer & Gollwitzer, 2007)

## 5.2 Reactions to a severe stressor: Leading symptoms and indication

The leading symptoms for psychosocial interventions are signs of dysfunctional disorders and problems, and those which affect emotional, cognitive, behavioural or familial functioning. They can be seen as a concomitant, comorbidity or as a consequence of the disease.

There is not always a clear distinction between adequate reactions to severe stressors by sick children and adolescents and their relatives, and reactions that are stronger than expected.

### 5.2.1 Indication for psychosocial care of child and adolescent patients

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Figure 2 gives an overview of the leading symptoms of a *persistent stress reaction*. The algorithm clarifies the diagnostic and differential diagnostic considerations leading to the indication for the provision of either **basic or intensified psychosocial care** of the sick children, adolescents or young adults.

In addition, the guidelines for young children and pre-school children (*Gontard, Möhler, & Bindt, 2015*) contain treatment paths for a variety of disorders which could also be taken into consideration in the planning of psychosocial treatment.

### 5.2.2 Indication for psychosocial care of the family/relatives

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Alongside the indication for psychosocial treatment of sick children, adolescents and young adults, social pedagogic and/or psychological support for the family is indicated if relatives experience a *persistent stress reaction*. The treatment is necessary because of the crucial importance of parental support for the implementation of treatment and the patient's adaptation to the disease (*Vance & Eiser, 2004*). Moreover, scientific literature describes the far-reaching interaction between the emotional stress of the parents with the emotional stress of the child or of the other parent (*compare Nakajima-Yamaguchi et al., 2016; Okado, Tillery, Sharp, Long, & Phipps, 2016; Wikman et al., 2017*). Furthermore, in their study of 100 mother-child dyads, *Rodriguez et al. (2016)* have shown that greater emotional stress in the mother has a negative effect on communication with her child.

The indication for *social pedagogic care of the family* is primarily given in social conflict situations caused by the treatment. These conflicts occur in the context of the parents' function of protecting and providing for the patient and their siblings, and in maintaining the family's socio-economic basis. The family's socio-economic situation is a high risk factor in the process of adaptation to the disease (*Kazak, 1992; Pelletier & Bona, 2015; see also chapter 3*).

The indication for the *psychological supportive care of relatives* is given in the case of emotional problems in coping with the disease and treatment and a high level of suffering due to the latent threat of death and fear of progression. It is also given in the case of unfavourable coping mechanisms and interaction disorders which can cause the patient significant stress.

The Z diagnoses in ICD-10 are especially important with regard to potential dysfunctions or problems and disorders that impair family functioning. They indicate potential familial stressors and disorders which make the support of psychosocial workers necessary for ensuring the implementation of treatment.

Examples include:

- problems related to housing and economic circumstances (Z59)
- problems related to social environment (Z60)
- problems related to parenting (Z62)

- other problems relating to the close family circle (Z63)
  - family breakdown due to separation or divorce (Z63.5)
- problems relating to lifestyle (Z72)
- problems with coping with life (Z73)
  - state of total exhaustion (Z73.3)
- family history of malignant tumours (Z80)
- family history of mental and behavioural disorders (Z81)

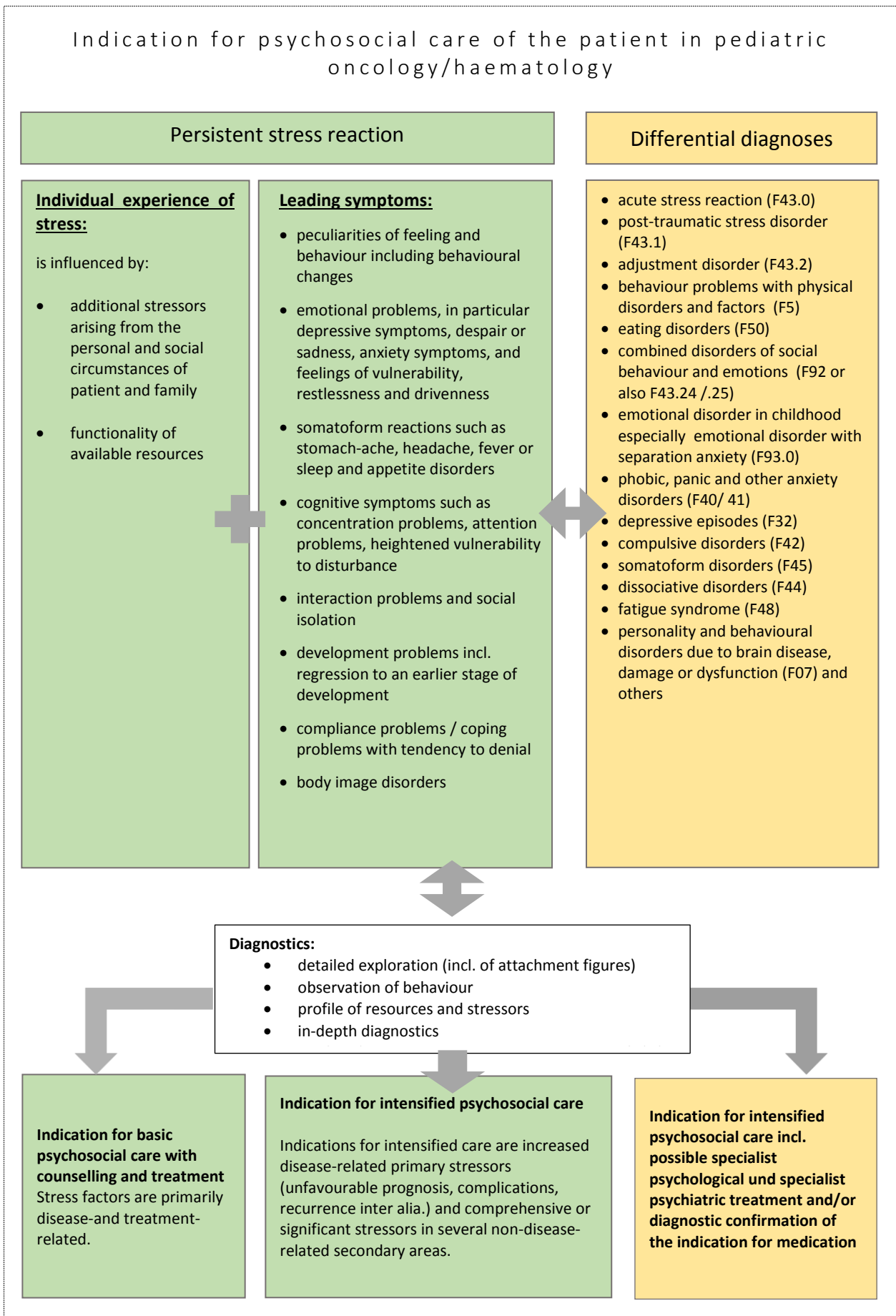


Figure 2: Indication for psychosocial care of the patient in paediatric oncology/haematology (B. Schreiber-Gollwitzer & Gollwitzer, 2007)

Explanation of the diagnoses and leading symptoms used in the algorithm in figure 2:

#### Behavioural problems and changes

A range of different behavioural problems from the areas of drive, impulse control, perception and thinking, and social interaction are subsumed under this heading.

It also refers to behaviours that are not problematic in the real sense, but unusual and untypical for the child concerned, as they can indicate a significant adjustment problem.

#### Emotional problems (anxiety, contact refusal, among others.)

These are emotional impairments of varying degrees of intensity. Children can appear sad, anxious, wary, reserved, shy or very unsettled. Symptoms of irritability and aggressivity can also occur. Examples of this are in particular:

##### depressive symptoms

States with depressed mood, loss of drive and interest, reduced concentration, sleep disturbance, loss of self-confidence or self-esteem, social withdrawal, symptoms such as loss of appetite or increased tiredness. In childhood, depressive symptoms often tend to be shown in connection with regressive behaviours or somatoform disorders.

##### anxiety symptoms

Basic mental state is characterised by episodic or permanent anxiety and worry associated with complaints such as restlessness, nervousness, excitement, exhaustion, difficulties in concentrating, and physical symptoms of tension.

#### Development problems or disorders

Development disorders relating to cognitive, emotional, social and identity development, and the development of self-concept. Development that is typical for the age of the child can be delayed, restricted or hindered. Regression to an earlier development stage (bed-wetting etc.) is also possible.

#### Compliance problems (e.g. in dealing with medical requirements)

These occur in the form of partial or complete withdrawal from cooperation with treatment and can extend to therapy refusal and range from rejection to resistance, from “can’t” to “won’t”. Exploration and knowledge of the mechanisms behind this behaviour are crucial.

#### Body image disorders due to visible and non-visible body changes

Patients experience their own appearance and the physical changes as stressful and focus their attention intensely on them. This rejection of the physical changes in association with an altered self-experience and altered body perception leads in some cases to significant crises in self-esteem, interactional inhibition and withdrawal from social contexts, possibly for fear of rejection and stigmatisation.

#### Somatoform reactions

Development of physical symptoms such as stomach-ache, headache, fever etc. as a disorder in areas of specific organs or organ systems (respiratory, cardiovascular, gastrointestinal, urogenital), in the absence of an organic cause for the symptoms. Sometimes, additional, distinct health-related fears which are difficult to allay occur. Frequently, a massive overstrain lies behind the development of these physical symptoms. In clarifying these symptoms, it is important to exclude the possibility that they are side-effects of the oncological therapy that the patient experiences as particularly invasive and stressful, for example pain. Similarly, rarely occurring complications of treatment should be excluded.

#### Social isolation due to prolonged stays in hospital

Frequent and sometimes prolonged stays in hospital (e.g. due to weakened immune defence following chemotherapy or a stem cell transplant) and the resulting absence from school and the necessary withdrawal from social contacts due to immunosuppressive therapy limit the child’s relationships with friends, schoolfriends and playmates. The fear of having lost touch, of being rejected (also because of possible changes in appearance, for example) keeps children in a state of social isolation.

#### Social conflict situation, problematic life circumstances

The spectrum of potential social, economic and cultural problems and problem constellations ranges from economic difficulties to unresolved residency status, from divorce to a family member needing constant care etc. These can exist prior to the disease and have negative effects on the treatment situation or have been caused by the disease, for example interruption of employment due to the child's illness, leading to a deterioration of the economic situation.

#### Interaction problems (communication problems between family members, among others)

The family relationship structure is reshaped due to the disease, often involving the separation of the sick child and a parent from the other family members. Sibling problems, partnership conflicts and a range of further problems can be caused or exacerbated by this.

#### Unfavourable individual and familial mechanisms for coping with the disease, and locus of control

The process of coping with the disease can be negatively affected and complicated by an unfavourable emotional and intellectual approach to it. This includes, for example, a pessimistic or mistrusting attitude, passivity, avoidance of information, low confidence in self-efficacy, guilt-based explanations for the cause of the disease etc.

#### Other marked changes in behaviours and reactions (e.g. medication-induced changes in behaviour)

### **The most important disorders in ICD-10 to be taken into account in psychosocial care are:**

#### Acute stress reaction (threatened decompensation, crisis reaction inter alia)

A temporary disorder of considerable severity which occurs due to an extraordinary physical or mental stressor and generally subsides within hours or days. Withdrawal from anticipated social interactions, limitation of attention, disorientation, anger, despair, hopelessness, hyperactivity, extraordinary grief are exhibited (compare ICD 10:F43.0).

#### Adjustment disorders (regressive, aggressive or depressive reaction inter alia)

States of subjective suffering and emotional disturbance which hinder social functions and performance and occur during the adjustment process after a major life change, a stressful life event or after serious illness; associated with depressive reaction, mixed anxiety and depressive reaction, disturbance of other feelings, disordered social conduct or a mixed disturbance of feelings and social conduct (compare ICD 10 F43.2).

#### Post-traumatic stress disorder (chronic traumatisation inter alia)

Delayed or protracted reaction to a stressful event or situation of an exceptionally threatening nature. The disturbance follows the trauma with a latency period which may range from weeks to months. Typical symptoms include episodes of repeated reliving of the trauma in memories, occurring against the persisting background of a sense of "numbness" and emotional blunting, indifference towards other people, unresponsiveness to surroundings, and avoidance of situations that prompt memories. There is usually a state of autonomic hyperarousal with hypervigilance, an enhanced startle reaction, and insomnia (compare ICD 10:F43.1).

#### Emotional disorders with separation anxiety

These are centred on the persistent concern that something could happen to the attachment figure. Separation problems occur particularly in the evening, with fear of sleeping, frequent waking during the night. Symptoms are unhappiness and withdrawal, extreme anxiety, tantrums, crying etc. (compare ICD 10: F93.0).

In individual cases, other disorders should be considered where necessary.



### 5.3 Indication for basic or intensified psychosocial care

The findings obtained in the diagnostic process lead to an assessment of the intensity of psychosocial care needed.

Various studies in the USA, Australia and Europe (*e.g. Sint Nicolaas et al., 2016*) showed *standard stress* in around two-thirds of the families affected, making basic care (*universal*) necessary. In the *Pediatric Psychosocial Preventative Health Model (PPPHM)*, Kazak, Schneider, Didonato, & Pai (2015) contrast this group (1) with families suffering a higher degree of stress (2) who need intensified, targeted interventions (*targeted*) and families with a very high degree of stress (3) who accordingly need the highest intensity of care (*clinical*). *Sint Nicolaas et al. (2017)* found a similarly high proportion of families with medium-high (30%) or very high/clinical stress (5%) in a group of 83 families from 4 child oncology centres in the Netherlands.

In German-speaking countries the resource and stress profile *Ressourcen- und Belastungsprofil (Schreiber-Gollwitzer & Schröder, 2012)*, an external assessment method for the therapist, allows the allocation of families to intervention-relevant risk groups for stress. The method was revised in 2012, and test quality criteria are currently being evaluated. If a family is found to have standard stress, they thus require *basic care* with the aim of preventing or reducing psychosocial consequences of the disease or treatment. The content and aims of this basic care have been formulated in *Allgemeinen und Ergänzungsmodulen der psychosozialen Basisversorgung in der pädiatrischen Onkologie und Hämatologie 2012 (Leiss et al., 2012)* (English: General and complementary modules of basic psychosocial care in paediatric oncology and haematology.) By contrast, families with multidimensional or a high degree of stress require *intensified psychosocial care*.

#### 5.3.1 Indication for basic psychosocial care

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The indications for basic psychosocial care are primarily disease- and treatment-related stressors, referred to as disease-related stressors. Stressors that are not related to the disease, rated as less serious in degree, can constitute a further indication (see 5.3.2, and also 3.1 und 3.2).

A need for intensified psychosocial care can also arise within the framework of basic care at critical points during the course of the disease and treatment.

#### 5.3.2 Indication for intensified psychosocial care

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Indications for intensified care are increased disease-related primary stressors (unfavourable prognosis, complications, recurrence, among others.) and comprehensive or considerable stressors in several non-disease-related secondary areas. The adjustment capability of the patient and family can for example be affected due to limited psychosocial resources, unfavourable sociocultural conditions etc., or there may be substantial secondary psychological stressors in the sense of emotional disturbances of the sick child, adolescent or young adult or one or more members of the family.

The following is a list of risk groups that require intensified care in clinical practice due to extreme stress factors (before and during therapy).

Studies that specifically deal with various stress reactions (e.g. anxiety disorder, post-traumatic stress disorder – see also figure 1) are given in brackets.

- patients with a poor or unclear prognosis (*Tackett et al., 2016*)
- patients with recurrence
- patients in critical situations (e.g. in intensive care)
- patients in palliative care
- patients with brain tumours (*C. Fischer, Petriccione, Donzelli, & Pottenger, 2016; Zyrianova, Alexander, & Faruqi, 2016*)
- patients who need radical surgery (e.g. amputation)
- patients who receive a stem cell transplant (SCT)
- patients undergoing long-term therapies and/or whose disease takes a chronic course
- patients with cancer predisposition syndrome
- patients with psychological problems or additional illnesses
- adolescent and young adult patients (AYAs) (*Lang, David, & Giese-Davis, 2015*)
- parents of children who receive a cancer diagnosis in early childhood (*Vernon, Eyles, Hulbert, Bretherton, & McCarthy, 2017*)
- single parents
- low-income families/families with an unemployed parent (*Masa'deh & Jarrah, 2017*)
- families in which a member is mentally or physically ill
- families who have travelled from outside the country for medical treatment
- families with language difficulties

## 6 THERAPY / INTERVENTIONS

Psychosocial interventions should follow the basic principles of family orientation, focus on the individual and strengthening of resources. They should offer an informative, continuous and supportive relationship which is geared to the individual needs of the sick children, adolescents, young adults, and their relatives (see also chapter 2).

Psychosocial interventions should be oriented towards the current state of health of the patient and their relatives. They are aimed at achieving direct relief and practical help for the patient and relatives, and securing a long-term stabilising and preventive effect.

The following procedures and methods are used to implement the goals of psychosocial care:

- **Information, orientation aid** / 9-401.1 Familien- Paar- und Erziehungsberatung<sup>15</sup>
- **Psychosocial diagnostics** / 1-901 (Neuro-) psychologische u. psychosoziale Diagnostik
- **Supportive therapy**<sup>16</sup> / 9-401.3 Supportive Therapie
- **Crisis intervention** / 9-401.5 Integrierte Psychosoziale Komplexbehandlung
- **Social welfare counselling and support** / 9-401.0 Sozialrechtliche Beratung
- **Family and couples counselling, parental guidance** / 9-104.1 Familien- Paar- und Erziehungsberatung
- **Preparation, follow-up and support for medical measures** / 9-500 Patientenschulung
- **Educating patients and relatives / psychoeducation** / 9-500 Patientenschulung
- **Clinical-psychological treatment** (e.g. training of social and emotional competence) / 9-401.3 supportive therapy
- **Neuropsychological therapy** / 9-404 neuropsychological therapy
- **Relaxation techniques** (e.g. breathing techniques, autogenic training, progressive muscle relaxation, imagination) / 9-401.3 Supportive Therapie
- **Psychotherapy** (e.g. conversational therapy, behavioural therapy, systemic therapy, hypnotherapy, depth psychology) / 9-41 Psychotherapie
- **Play and creative pedagogy** / 9-401.3 Supportive Therapie
- **Creative arts therapy** (e.g. music- and art therapy) / 9-401.4 Künstlerische Therapie
- **Palliative support** / 8-982 Palliativmedizinische Komplexbehandlung
- **Planning and initiation of outpatient and inpatient follow-up care and rehabilitation** / 9-401.2 Nachsorgeorganisation
- **Organisation of reintegration into school and workplace** / 9-401.2 Nachsorgeorganisation
- **Coordination of inpatient and outpatient psychosocial care** / 9-401.2 Nachsorgeorganisation

Two approaches are outlined below, describing the timing, intensity and target groups of psychosocial interventions: (1) the difference between *basic* and *intensified care* and (2) the *phase-specific model of psychosocial interventions*

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<sup>15</sup> The OPS codes in the DRG system relevant for billing in Germany, with which the respective interventions are recorded, are given in italics. In Austria, the LKF system (Austrian DRG system) is used.

<sup>16</sup> "Supportive therapy" is understood to mean a therapeutic procedure focused on the current health problems of patients and their families. It is of varying duration and focusses on the psychological processing of the diagnosis and the course of the disease, on coming to terms with the disease, its side effects and the necessary treatment as well as the familial, individual, academic, social and job-related problems that result.

## 6.1. Basic versus intensified care

All paediatric oncology patients should receive basic psychosocial care (see also chapter 5, Indication). In cases of great psychosocial stress and multiple risk factors coupled with limited psychosocial resources, intensified care according to the indication should be provided (see chapter 5.3.2). An individual treatment plan is drawn up. Interventions in this area are higher-frequency and continuous. They can concentrate on varying aspects of care (*Schreiber-Gollwitzer, B.M., Schröder, H.M. et al., 2003*). The degree of stress is subject to considerable fluctuation and is recorded continuously during the course of treatment. Outreach psychosocial care is given throughout all phases of treatment, particularly at the beginning of treatment and in crisis situations. An offer of care is made within a short timeframe.

Interventions of basic versus intensified care are outlined in tables 9 and 10. Furthermore, in order to more closely specify basic psychosocial care, the quality assurance panel of the PSAPOH has developed general and disease-specific modules for six points in time during the course of treatment. Oriented towards this guideline, they define concrete stress situations, demands made on patients and families, stress reactions, interventions and goals (*Leiss et al., 2012*).

A specialised professional qualification is necessary for carrying out certain interventions (e.g. psychological diagnostics or art therapy). However in many cases, activities span different professional groups (e.g. supportive therapy). Interdisciplinary cooperation of different professional groups and the varying perspectives and methods involved are essential.

## 6.2 Phase-specific psychosocial interventions

Psychosocial interventions should be oriented towards individual needs, which can change according to different phases in the disease and treatment. Acute changes require flexible and immediate response by the psychosocial worker.

In all phases, it can become necessary to adapt the care strategy to meet current needs in the sense of *crisis intervention*<sup>17</sup>.

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<sup>17</sup> Crisis intervention is defined here as the acute, temporary care of people in case of drastic events or states that are experienced as traumatic or threatening and that can cause a massive change in life. According to *Sonneck, Kapusta, Tomandl, & Voracek (2016)* crisis intervention is to be distinguished from measures of acute psychiatry and comprises all the actions that can help the person involved to cope with their current difficulties. "Negative social, mental and medical consequences which are immanent as maladjustment or psychological breakdown in every crisis can thus be prevented." As general principles of crisis intervention the authors include a rapid beginning of treatment, the activity of the helper, flexible methods, focus on the current situation, involving the social environment, the adequate relief of emotional pressure and interprofessional cooperation.

Table 9: Interventions of basic psychosocial care


Basic care should comprise...	
<p><b>Diagnosis</b></p>  <p><b>End of therapy</b></p>	<ul style="list-style-type: none"> <li>• Initial contact immediately after diagnosis/admission</li> <li>• Crisis intervention</li> <li>• Psychosocial anamnesis (during the first 4 weeks)</li> <li>• Psychosocial (differential) diagnostics and planning of treatment</li> <li>• Social and psychological counselling</li> <li>• Family and couples counselling, parental guidance</li> <li>• Practical orientation aids; organisational support in daily life</li> <li>• Psychoeducative measures</li> <li>• Supportive therapy: promotion of ability to cope with treatment situations, functio laesa or disablement; measures for coping with pain; promotion of social contacts; mobilisation of individual resources</li> <li>• Ongoing diagnostics oriented towards the specific disease</li> <li>• Individual and group art- and music therapy</li> <li>• Play and creative pedagogy</li> <li>• Measures aimed at distraction, relaxation and pleasure</li> <li>• Physical- and exercise therapy</li> <li>• Rehabilitation counselling and organisation</li> <li>• Final interview at the end of intensive therapy, transition to follow-up care</li> <li>• Counselling relating to reintegration into daily life, kindergarten, school and workplace</li> <li>• Initiation/coordination of psychosocial follow-up care</li> </ul>

Table 10: Interventions in intensified care

Intensified care should comprise...	
<ul style="list-style-type: none"> <li>• higher-frequency basic-care interventions</li> <li>• individualised, more complex setting</li> </ul>	<ul style="list-style-type: none"> <li>• further interventions:             <ul style="list-style-type: none"> <li>- clinical-psychological treatment</li> <li>- neuropsychological therapy</li> <li>- psychotherapy</li> <li>- palliative support</li> </ul> </li> </ul>

Tables 11 to 15 summarise possible disease-related stressors, demands made on patients, parents and siblings and their stress reactions, and also focus on psychosocial interventions in individual phases. The tables are oriented towards observations in everyday clinical practice. The systematic recording of psychosocial factors, for example in the context of oncological registers/(therapy optimisation) studies, would be desirable.

**Table 11: Diagnosis phase / Beginning of therapy** (see also modules 1 and 2 of basic psychosocial care)

Stressors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• strange, frightening surroundings</li> <li>• unfamiliar, painful and frightening examinations</li> <li>• very extensive diagnostic programme</li> <li>• confrontation with the life-threatening nature of the diagnosis</li> <li>• loss of parental security</li> <li>• sudden change in entire circumstances due to admission to hospital e.g. separation from social and school environment</li> <li>• abrupt, sometimes emergency beginning of treatment</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• unclear preliminary diagnoses, long diagnostic latency</li> <li>• uncertainty, waiting for results</li> <li>• confrontation with the life-threatening diagnosis and the imminent therapy</li> <li>• uncertain treatment outcome</li> <li>• existential collapse of the family's world</li> <li>• lack of prerequisites for understanding disease and treatment</li> <li>• discrepancy in coping styles within the family</li> <li>• insufficient language skills</li> <li>• destabilisation of existing systems of meaning and belief</li> <li>• alien cultural environment</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• unclear, threatening situation</li> <li>• sudden change in daily life</li> <li>• sudden separation from family members</li> <li>• confrontation with the sibling's life-threatening disease</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• understanding the meaning of the life-threatening nature of the disease</li> <li>• enduring anxiety and uncertainty</li> <li>• taking in and understanding information on the disease and treatment</li> <li>• enduring the (unexpressed) worries and tensions of the parents</li> <li>• cooperation with diagnostic and therapeutic procedures</li> <li>• dealing with changes in daily life (strange surroundings, people, procedures)</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• development of hope, confidence and trust in the medical treatment</li> <li>• giving the sick child support, security and reliable closeness</li> <li>• making decisions about the treatment</li> <li>• gaining orientation in the processes of the treatment system</li> <li>• acquiring knowledge of the disease and treatment</li> <li>• working through diagnosis, therapy and prognosis</li> <li>• parents' double role of giving and needing support</li> <li>• controlling and coping with own emotions</li> <li>• honest discussion of the diagnosis within the family, age-appropriate information for siblings</li> <li>• restructuring of family's everyday life</li> <li>• involving grandparents</li> <li>• giving information to relatives, school, employer</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• coping with the threatening situation</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• disease symptoms, pain</li> <li>• irritation and destabilisation due to hospital and treatment</li> <li>• fear of separation from the parents</li> <li>• age-specific reactions to the diagnosis e.g. fear of dying, helplessness, anger, grief, despair</li> <li>• inability to understand what is happening</li> <li>• resistance to threatening feelings</li> <li>• feelings of guilt about pathogenesis</li> <li>• Psychological disorders see ICD-10</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• premonitions and worries</li> <li>• diagnosis shock and fear of the future</li> <li>• overwhelmed by feelings (fear of the child's death, impotence, helplessness, anger, grief, feelings of guilt, despair,)</li> <li>• resistance to threatening feelings, numbness, denial; excessive, pointless activity</li> <li>• limited ability to absorb information, confusion</li> <li>• fears that their whole world will collapse, fear of losing control</li> <li>• concern for siblings</li> <li>• overtaxed by complicated medical issues</li> <li>• need for information/avoidance of information</li> <li>• effort at maintaining appearance of naturalness and strength towards the children</li> <li>• Psychological disorders see ICD-10</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• fear for the sick sibling</li> <li>• profound feelings of uncertainty due to changes in the family</li> <li>• separation anxiety</li> <li>• feelings of guilt about pathogenesis</li> <li>• Psychological disorders see ICD-10</li> </ul>	<p><b>Psychosocial diagnostics</b></p> <ul style="list-style-type: none"> <li>• obtaining history</li> <li>• recording understanding of the disease by the patient and his parents, clarifying unanswered questions</li> <li>• evaluating stress factors and resources</li> <li>• clarifying individual need for care</li> <li>• neuropsychological diagnostics in case of threatened CNS impairment</li> <li>• identification of language and cultural barriers</li> </ul> <p><b>Information and orientation aids</b></p> <ul style="list-style-type: none"> <li>• additional information on disease, treatment and possible consequences of treatment</li> <li>• handing out (age-specific) written and audiovisual information for patients, siblings and parents that meets the basic requirements for patient information material (see also DISCERN, Appendix C)</li> <li>• support in processing complex information</li> <li>• information for teachers and fellow students of the patient and siblings</li> <li>• encouraging patient and relatives to actively seek information</li> </ul> <p><b>Supportive therapy</b></p> <ul style="list-style-type: none"> <li>• strengthening parents' confidence in their ability to learn and cope</li> <li>• explaining that strong emotional reactions (fear, impotence, helplessness, anger, feelings of guilt) are normal</li> <li>• help in taking the focus from fear of death to the struggle for life</li> <li>• promoting cooperation during medical procedures (role-play, relaxation, distraction)</li> </ul> <p><b>Family and couples counselling; parental guidance</b></p> <ul style="list-style-type: none"> <li>• supporting family members in dealing with emotional reactions to the medical diagnosis</li> <li>• counselling family members so they can support the sick child/adolescent in frightening and painful medical and nursing procedures</li> <li>• encouraging open communication and self-efficacy</li> </ul> <p><b>Play and creative pedagogy/ creative arty therapies</b></p> <ul style="list-style-type: none"> <li>• creation of an atmosphere that promotes trust</li> <li>• building up a continuing relationship</li> <li>• occupying children during consultations and treatment planning, lightening parents' load</li> <li>• giving orientation in connection with rooms, procedures, staff etc.</li> </ul> <p><b>Social welfare counselling and support</b></p> <ul style="list-style-type: none"> <li>• counselling and help in reorganising daily life and in claiming social benefits (employment situation, home-helps, care allowance, travelling expenses etc.)</li> <li>• help in arranging for an attachment figure to accompany the patient</li> <li>• arranging for schooling at home and in the clinic</li> </ul>

**Table 12: Treatment phase** (see also modules 3 and 4 of basic psychosocial care)

Stressors	Demands on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>prolonged and frequent stays in hospital</li> <li>long waiting times in hospital</li> <li>separation from other family members</li> <li>loss of personal privacy while in hospital</li> <li>diagnostic procedures, e.g. LP, MRT, BT</li> <li>numerous therapeutic procedures, e.g. taking tablets, infusions, mouth care</li> <li>changes in appearance, e.g. hair loss, Cushing, cachexia</li> <li>side effects, e.g. mucositis, fever, nausea, pain, physical weakness</li> <li>high danger of infection</li> <li>unclear symptoms</li> <li>serious physical impairments/complication e.g. necessity for intensive care</li> <li>witnessing recurrence, dying and death of fellow patients</li> <li>isolation in hospital, e.g. in case of infections or multiresistant pathogens</li> <li>mood swings due to medication, e.g. corticosteroid therapy</li> <li>loss of physical integrity</li> <li>temporary or permanent mental impairment or personality changes, e.g. organic psychosyndrome</li> <li>significant limitation of independence and autonomy</li> <li>lack of contact to friends, isolation</li> <li>exclusion from educational-vocational development</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>high care demands</li> <li>frequent changes in treatment modalities</li> <li>lack of possibilities to plan daily life</li> <li>insufficient sleep, rest and recreation</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>learning to understand the need for medical and nursing procedures</li> <li>development of a hopeful attitude</li> <li>getting used to everyday life in hospital</li> <li>active cooperation with medical and nursing procedures</li> <li>coping with repeated painful or frightening procedures</li> <li>putting up with diverse side effects</li> <li>coping emotionally with physical changes, making contacts in spite of visible stigmas</li> <li>expressing feelings and mental state when undergoing medical and nursing procedures</li> <li>dealing with the loss of prior social contacts and age-appropriate leisure activities, e.g. sport, going out</li> <li>in adolescents, dealing with the loss of independence and autonomy</li> <li>developing new interests, hobbies and activities</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>patient is accompanied by one of the parents in hospital</li> <li>willingness to learn nursing procedures and take on responsibility</li> <li>flexible adjustment of the family routine to the course of treatment, e.g. organising care for siblings</li> <li>change in interfamilial tasks and roles</li> <li>motivating the child/adolescent to cooperate actively, e.g. with regard to eating, drinking, taking tablets</li> <li>carrying out nursing procedures on their own at home</li> <li>constant supervision of the patient, observation of their state of health</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>fear of medical procedures</li> <li>anger and rebellion against medical procedures</li> <li>lack of cooperation / refusal e.g. taking tablets, blood samples, physical examination</li> <li>fear that the disease is incurable, fear of late effects/fear of the future</li> <li>aversion to foods and smells</li> <li>feelings of shame and loss of self-esteem with regards to physical changes, e.g. changes to hair and skin, Cushing, cachexia</li> <li>desire for lasting physical contact with parents, fear of separation and loss</li> <li>grief at lack of contact with siblings, friends and schoolmates, homesickness</li> <li>disappointment at having to give up sport and hobbies</li> <li>grief at possible necessary separation from or loss of pets</li> <li>emotional exhaustion, depressive mood</li> <li>feelings of dependence and impotence, helplessness, excessive adjustment</li> <li>aggression, anger, despair</li> <li>regressive behaviour</li> <li>social withdrawal</li> <li>disturbed sleep, nightmares</li> <li>denial, non-acceptance of the life-threatening nature of the disease</li> <li>in adolescents: termination of therapy</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>fears that the disease is incurable, fear of late effects and progression</li> <li>exhaustion, chronic stress, overtaxing due to multiple demands</li> <li>social withdrawal, isolation</li> <li>feelings of guilt, worries, search for a meaning</li> <li>aggressive behaviour and reproaches towards personnel treating the patient</li> <li>anticipatory grief</li> <li>depressivity, pessimistic attitude, suicidal tendency</li> <li>disturbed sleep, heart and circulatory problems and other symptoms</li> </ul>	<p><b>Supportive therapy</b></p> <ul style="list-style-type: none"> <li>reducing fear and insecurity</li> <li>promoting trust and confidence</li> <li>giving encouragement, strengthening ability to see healthy aspects</li> <li>supporting and mobilising individual resources, e.g. inner strengths, patience and endurance</li> <li>strengthening inner-family cohesion</li> <li>motivation for active cooperation</li> <li>promoting the understanding of therapy, clearing up fantasies about disease</li> <li>arranging and encouraging contact with other parents and patients to provide encouragement and exchange experiences</li> </ul> <p><b>Information and orientation aids</b></p> <ul style="list-style-type: none"> <li>providing more detailed age-appropriate information, e.g. on operations, radiotherapy, SCT (brochures, books, videos, DVDs, CDs etc.)</li> <li>special counselling for adolescents, e.g. on questions of fertility,</li> <li>psychoeducative groups, e.g. parents' evenings, information events</li> <li>support in processing complex information</li> <li>where necessary, arranging other forms of care, e.g. school, pastoral care, ambulatory counselling centres</li> </ul> <p><b>Psychosocial diagnostics</b></p> <ul style="list-style-type: none"> <li>continuous evaluation of state, social situation and current need for care of patient and relatives</li> <li>clarifying presence of current stress and adjustment disorders</li> <li>if psychological disorders are suspected, consultation with psychological/psychiatric specialist for evaluation and if necessary, therapy</li> <li>neuropsychological diagnosis in case of threatened CNS impairment</li> </ul> <p><b>Social welfare support</b></p> <ul style="list-style-type: none"> <li>support for self-help, personal responsibility and autonomy of the family</li> <li>inclusion of external help to lighten the family's load</li> <li>arranging financial support</li> <li>support in claiming benefits from public agencies</li> <li>coordination of different provisions for support</li> <li>preparation and help for discharge to home and for reintegration in school/employment</li> <li>provision of aids and appliances and arranging support measures</li> <li>arranging contact to self-help groups, booster clubs etc.</li> <li>counselling and help in reorganising daily life</li> <li>advice on inpatient family-oriented rehabilitation measures, or rehabilitation measures specifically for adolescent/young adult patients, help with making applications</li> </ul> <p><b>Family and couples counselling, parental guidance</b></p> <ul style="list-style-type: none"> <li>promoting adaptation to the disease- and treatment-related changes in family life</li> <li>support in decision-making and in dealing with invasive treatments</li> <li>help in dealing with conflicting interests and different coping styles in the family system</li> </ul>

<ul style="list-style-type: none"> <li>• additional financial expense, economic hardship</li> <li>• threatened loss of job</li> <li>• parents have little time for siblings</li> <li>• strain on partnership</li> <li>• discrepant coping styles in the family</li> <li>• loss of social contacts to friends and colleagues, limits on professional development, leisure, holidays etc.</li> <li>• persistent emotional strain, fear of progression</li> <li>• loss of personal privacy during hospital stays</li> <li>• witnessing recurrence, dying and death of other patients</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• loss of regular regime, security and parental attention</li> <li>• changed role in the family</li> <li>• accommodation away from home</li> <li>• loss of carefree childhood</li> </ul>	<ul style="list-style-type: none"> <li>• ability to evaluate threatening physical symptoms</li> <li>• empathy with the patient's situation</li> <li>• clear and constant parenting style towards the sick child</li> <li>• standing up for the individual needs of the child in the clinic and social environment (advocacy)</li> <li>• balancing the needs of all family members</li> <li>• adequate emotional and social care of siblings</li> <li>• providing siblings with ongoing information about the course of the disease</li> <li>• adequate time for individual regeneration and time for the parental relationship</li> <li>• expressing and dealing with parents' own feelings</li> <li>• ability to accept support</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• taking on age-appropriate responsibility within the family</li> <li>• dealing with diminished parental time</li> <li>• adjustment to changing care-givers and accommodation</li> <li>• dealing with fears and loneliness</li> <li>• scaling back their own needs, wishes and interests</li> </ul>	<ul style="list-style-type: none"> <li>• conduct that is damaging to health, e.g. overeating, smoking, delaying their own medical treatment</li> <li>• communication problems in the family/lack of mutual support by parents; disappointment and lack of understanding towards partner</li> <li>• parents' refusal of social support</li> <li>• overprotection, spoiling of the patient</li> <li>• symbiotic behaviour, lack of detachment from sick child/adolescent</li> <li>• neglect of the patient, e.g. unreliable administering of medication, insufficient fluids, failure to meet hygiene requirements</li> <li>• excessive demands on or neglect of siblings</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• feeling unloved and insignificant</li> <li>• fear of separation and loss</li> <li>• helplessness, insecurity</li> <li>• ambivalent feelings, e.g. jealousy, feelings of guilt, anger, worry about the patient</li> <li>• excessive attention-seeking behaviour</li> <li>• excessive adjustment, protecting parents</li> <li>• forced independence</li> <li>• aggressive behaviour</li> <li>• withdrawal behaviour</li> <li>• poorer grades in school</li> <li>• child's fear of becoming ill himself</li> </ul> <p>Psychological disorders see ICD-10</p>	<ul style="list-style-type: none"> <li>• strengthening inner-family communication, promoting exchange between parents and siblings</li> <li>• encouragement to express and deal with feelings arising from the disease and treatment</li> <li>• support in maintaining family, neighbourhood and friend relationships/strengthening the support network</li> <li>• indicating the necessity of parents' regeneration with regard to sleep, rest, nutrition, exercise</li> <li>• counselling on siblings' stressors and a supportive way of dealing with them</li> <li>• strengthening confidence in parenting ability</li> <li>• encouraging parents and counselling for the social environment, enabling the patient to have contact with other children within the limitations of the treatment</li> <li>• help in maintaining the patient's social network</li> <li>• encouragement in taking up further psychiatric-psychotherapeutic treatment of the patient, parents and/or siblings where indicated. If necessary arranging treatment</li> </ul> <p><b>Clinical-psychological treatment/psychotherapy/psychooncology</b></p> <ul style="list-style-type: none"> <li>• measures accompanying treatment to help the patient and relatives cope with the disease</li> <li>• psychological preparation before and follow-up after medical and nursing procedures e.g. LP, operations, SCT, radiotherapy, MIBG</li> <li>• psychological measures for coping with pain</li> <li>• measures for strengthening the autonomy and self-esteem of the patient</li> <li>• measures for reducing anxiety and stress, e.g. relaxation techniques, cognitive techniques, hypnotherapy</li> <li>• help in dealing with family feelings of guilt and blaming</li> <li>• measures for strengthening parents' competence in dealing with the sick child/adolescent and siblings</li> <li>• support in dealing with issues concerning the meaning of life, spirituality, dying and death</li> </ul> <p><b>Creative arts therapies</b></p> <ul style="list-style-type: none"> <li>• providing opportunities to encourage emotional expression</li> <li>• measures for strengthening self-confidence and autonomy</li> <li>• working through conflict situations on the symbolic level (sounds, images)</li> <li>• creative work to ease fears, provide distraction and reduction of pain, support in developing coping strategies</li> <li>• providing opportunities for non-verbal communication and interaction</li> <li>• promotion of creative abilities to support "healthy" aspects and strengthen existing resources</li> </ul> <p><b>Play and creative pedagogy</b></p> <ul style="list-style-type: none"> <li>• creation of an atmosphere that promotes trust</li> <li>• playful processing of the treatment situation</li> <li>• measures aimed at distraction, relaxation and pleasure</li> <li>• activating the child's/adolescent's abilities and resources</li> <li>• providing sense of achievement and promoting quality of life</li> <li>• support of age-appropriate development</li> <li>• measures aimed at promoting contact with other children/adolescents</li> <li>• organising patients' birthdays, holidays, seasonal festivals</li> <li>• organisation of events</li> <li>• individual activities for bed-ridden or isolated patients</li> </ul>
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**Table 13: Remission phase/ follow-up care** (see also modules 5 and 6 of basic psychosocial care)

Stressors	Demands on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• maintenance therapy/ ambulatory therapy, e.g. for leukaemia</li> <li>• regular surveillance diagnostics</li> <li>• temporary and possibly permanent physical impairments e.g. wheelchair use</li> <li>• reduced general resilience and stamina, slowing down</li> <li>• late effects of the disease and treatment, e.g. organ damage, functional disturbances and disabilities</li> <li>• decline in cognitive performance, e.g. attention, memory, concentration</li> <li>• isolation due to loss of social contacts</li> <li>• altered appearance, physical and social stigmas</li> <li>• catching up on missed lessons, need to repeat a school year, changing schools</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• loss of “security” (given by the treatment framework) after the termination of therapy</li> <li>• loss of the protective hospital environment</li> <li>• lack of a guarantee of a cure/ fear of check-ups</li> <li>• unclear results, questionable signs of relapse, times of uncertainty</li> <li>• uncertainty about reversibility of patient’s emotional, mental and physical impairments</li> <li>• discrepant coping styles in the family</li> <li>• shock at recurrence and/or death of fellow patients</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• impossibility of restoring the family situation as it was prior to the illness</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• strengthening physical and psychological resistance</li> <li>• development of autonomy and self-confidence</li> <li>• resumption of social relationships</li> <li>• coping with personal maturity – discrepancy with peers</li> <li>• catching up on age-specific experiences/development processes</li> <li>• reintegration in daily life at school and work</li> <li>• coping with functional limitations and disabilities</li> <li>• processing traumatic experiences and integrating them in the life history</li> <li>• giving up the “special role” of sick child</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• development of confidence in the future</li> <li>• giving space to existential fears and learning to live with them</li> <li>• strengthening their own physical and psychological resistance/regeneration</li> <li>• regaining positive health behaviour</li> <li>• consolidating family cohesion and the partnership</li> <li>• regaining confidence in parenting competence</li> <li>• allowing the child to give up their “special role” as the sick child</li> <li>• normalising everyday life</li> <li>• coping with the patient’s impairments and late effects</li> <li>• organisation of aids and support measures</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• expression of their own interests and needs</li> <li>• normalisation of sibling relationships</li> <li>• dealing with personal maturity processes</li> <li>• regaining trust and confidence/family support</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>• coping strategies based on denial</li> <li>• fear of recurrence</li> <li>• problems with self-esteem in case of disease-related physical, emotional and mental impairments</li> <li>• difficulties with (re-)integration in kindergarten and school, social anxiety</li> <li>• Psychological disorders see ICD-10</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>• chronic fear of recurrence, “Damocles sword”</li> <li>• fear of stressful check-up results</li> <li>• lasting uncertainty about the planability of life</li> <li>• emergence of intense emotions that have previously been controlled or suppressed</li> <li>• massive physical and emotional exhaustion</li> <li>• chronic physical complaints, e.g. backache</li> <li>• long-term impairment of quality of life</li> <li>• Psychological disorders see ICD-10</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>• high expectations of a return to normality</li> <li>• desire for “compensation”</li> <li>• disappointment at the lasting changes in the family due to the illness</li> <li>• persistent jealousy, anxiety, feelings of guilt</li> <li>• problems at school</li> <li>• Psychological disorders see ICD-10</li> </ul>	<p><b>Supportive therapy</b></p> <ul style="list-style-type: none"> <li>• encouraging the processing and integration of the disease-related experiences into the personal life history</li> <li>• supporting the patient in casting off their “role as a sick person”</li> <li>• support in dealing with fear of relapse</li> <li>• promoting the autonomy and self-confidence of the patient</li> </ul> <p><b>Psychosocial diagnostics/ final diagnostics</b></p> <ul style="list-style-type: none"> <li>• clarifying how individual members of the family process the disease</li> <li>• clarifying care at home</li> <li>• diagnostics for preparation of in/outpatient rehabilitation measures</li> <li>• clarifying need for support for reintegration in school/employment</li> <li>• initiation of complementary diagnostics if inadequate processing of disease/psychological disorder is suspected in the patient ⇒referral to clinical psychology, child and adolescent psychiatrist or psychotherapist</li> <li>• initiation of complementary diagnostics if developmental impairments, intelligence impairments, or neuropsychological impairments are suspected ⇒referral to clinical neuropsychology</li> <li>• clarifying needs and supporting patient on transfer to short- and long-term follow-up care</li> <li>• meeting of all those involved to support transition</li> </ul> <p><b>Organisation of follow-up care / social welfare support</b></p> <ul style="list-style-type: none"> <li>• arranging family-oriented and/or neurological inpatient rehabilitation measures or arrangement of rehabilitation measures specifically for adolescent patients / help in claiming costs from insurance</li> <li>• initiation/coordination of outpatient psychosocial follow-up care</li> <li>• counselling patients, parents, kindergarten teachers and school teachers on the patient’s reintegration in kindergarten, school, training and employment</li> <li>• preparing for a return to school in cooperation with clinic tutors and home tutors and the child’s school</li> <li>• preparation and arrangement of targeted remedial measures in case of developmental delays and late effects in the patient</li> <li>• preparation and drafting of sociomedical and psychosocial reports</li> <li>• arranging seminars, events and camps for patients, parents and siblings</li> </ul> <p><b>Family and couples counselling, parental guidance</b></p> <ul style="list-style-type: none"> <li>• counselling on age-appropriate emotional processing of the trauma of disease</li> <li>• counselling on dealing with late effects, e.g. loss of extremities, infertility, growth disturbances, disability</li> <li>• counselling on measures to aid the emotional and physical regeneration of the parents</li> <li>• counselling on parenting issues regarding patient and siblings</li> <li>• encouraging parents to support the independence of adolescent patients</li> <li>• encouraging taking up of further clinical psychological/psychotherapeutic/psychiatric treatment of patient, parents and/or siblings if indicated; if necessary, arranging this</li> </ul> <p><b>Creative arts therapy</b> (see treatment phase)</p>

**Table 14: Recurrence/ progression (see also modules 1- 4 of basic psychosocial care, PSAPOH 2012)**

Stressors	Demands on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>renewed diagnostics and therapy procedures</li> <li>worsening of chances of cure and survival</li> <li>renewed limitation of physical, social and mental development due to the treatment</li> <li>witnessing parents' shock and despair</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>confrontation with the lack of success of treatment so far</li> <li>worsening of chances of cure and survival taking decisions on invasive or experimental treatments</li> <li>dealing with intensified therapy regimes, invasive operations inter alia</li> <li>where applicable, insecurity due to new treatment location (new treatment team, loss of relationship to old team)</li> <li>collapse of individual and family life plans</li> <li>discrepant coping styles in the family</li> <li>destabilisation of existing belief and meaning systems</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>renewal of threatening situation and profound feeling of insecurity</li> <li>threatened loss of the sibling</li> <li>witnessing parents' shock and despair</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>accepting the renewed treatment while knowing about the stressors associated with it</li> <li>dealing with prolonged difficult living conditions and limitations</li> <li>dealing with loss of control and fear of death</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>regaining hope</li> <li>dealing with worsened prognosis</li> <li>absorbing and processing complex information</li> <li>renewed adjustment of family life to the treatment situation</li> <li>open communication about prognosis and further treatment possibilities</li> <li>renewed building of trust in medical treatment and personnel</li> <li>building up an appropriate perspective on the future</li> <li>mobilising new resources</li> <li>motivating the patient for the new therapy and encouraging them</li> <li>open communication inside and outside the family, age-appropriate information for siblings</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>dealing again with the threatening situation and profound feeling of insecurity</li> <li>dealing with increased anxiety and grief</li> <li>increased scaling back of own needs regarding parents and the sibling</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>fear of death</li> <li>profound insecurity and emotional instability</li> <li>loss of faith in the treatment and hope of cure</li> <li>significant separation anxiety</li> <li>regressive behaviour</li> <li>demanding, dominant behaviour, low tolerance of frustration</li> <li>aggressive behaviour towards parents and siblings</li> <li>child protects parents from his own fears</li> <li>refusal of treatment measures</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>shock, existential anxiety</li> <li>doubts about choice of medical treatment so far, loss of trust</li> <li>feelings of guilt or blaming</li> <li>unstable emotions (fluctuating between anger, despair and hope)</li> <li>exaggerated optimism or pessimism regarding the course of the disease</li> <li>exhaustion, weakness, inability to act</li> <li>resignation, anticipatory grief</li> <li>psychosomatic complaints</li> <li>increased resort to alternative/adjunct treatments, e.g. healer</li> <li>spoiling of the patient, problems with setting boundaries</li> <li>withdrawal from the patient</li> <li>symbiotic relationship with child</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>fear of the sibling's death</li> <li>loss and separation anxiety</li> </ul> <p>Psychological disorders see ICD-10</p>	<p>The spectrum of psychosocial interventions is as for the diagnosis and treatment phase. The content of the interventions is adapted to the changes and requirements in the course of the disease and treatment. Maintaining the patient's quality of life when the prognosis changes is of central importance.</p> <p><b>Areas of intervention are:</b></p> <ul style="list-style-type: none"> <li>supportive therapy</li> <li>information, orientation aids</li> <li>family and couples counselling, parental guidance</li> <li>social welfare support</li> <li>clinical psychology</li> <li>psychotherapy</li> <li>creative arts therapies</li> <li>play and creative pedagogy</li> </ul>
further stressors: see initial treatment	further demands: see initial treatment	further reactions: see initial treatment	interventions see treatment phase

**Table 15: Palliative phase / dying and death** (see also module 1- 4 of basic psychosocial care)

Stressors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>confrontation with increasing deterioration of health</li> <li>symptoms of disease, e.g. pain, shortness of breath, bleeding</li> <li>loss of function in areas of everyday life</li> <li>physical decline, loss of strength</li> <li>experience of existential threat</li> <li>experience of separation, loneliness and isolation</li> <li>experiencing relatives' shock</li> <li>unanswered questions about dying and life after death</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>shock caused by the unavoidability of death</li> <li>incongruence between current state of health of child and prognosis</li> <li>insecurity due to the imminent dying process</li> <li>confrontation with the child's increasing suffering</li> <li>extreme, unforeseeable strain, day and night</li> <li>discrepant coping styles in the family</li> <li>uncertainty for a long period of time</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>heightened perception of the family's grief and despair</li> <li>experiencing the attention focused on the dying child</li> <li>experiencing the changes in the health of the sick sibling</li> <li>incomprehensible, frightening life situation</li> <li>threatening fantasies about dying and death</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>dealing with symptoms of disease</li> <li>recognising the increasing hopelessness</li> <li>dealing with emotional responses to the progression of the disease and the process of dying</li> <li>dealing with loss of control and fear of death</li> <li>hope of achievable goals ( sympathetic closeness, comfort and pain relief)</li> <li>taking leave of family and friends</li> <li>recognising and expressing wishes</li> <li>making unfinished things possible</li> <li>filling the remaining time with life</li> <li>dealing with questions concerning the meaning of life</li> <li>finding images of transition</li> </ul> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>recognising the increasing hopelessness</li> <li>making a dignified death possible</li> <li>conveying closeness, security and mutual trust</li> <li>maintaining calm and openness</li> <li>leave-taking, allowing the dying child to go their way</li> <li>coping emotionally with fear, loss, pain and grief</li> <li>allowing the dying child to participate in life as much as possible</li> <li>recognising the needs of the child, understanding messages and signals</li> <li>realising the value of the moment in life, conscious planning for the remaining time</li> <li>dealing with questions on the meaning of life</li> <li>building "bridges" for remembering the child</li> <li>maintaining or changing daily family life and functioning</li> <li>restructuring life circumstances</li> <li>recognising the siblings in their pain; recognising the siblings' need for normality in life</li> </ul> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>finding warmth and security</li> <li>allowing themselves to have conflicting feelings</li> <li>developing concepts on connection to the sibling after death</li> </ul>	<p><b>Patient</b></p> <ul style="list-style-type: none"> <li>fear of isolation, separation anxiety</li> <li>fear of dying, fears of death</li> <li>feelings of meaninglessness, impotence, despair</li> <li>switching between hope and fear</li> <li>emotional insecurity, irritation</li> <li>inner withdrawal, silence, excessive protection of relatives</li> <li>protracted mental-emotional maturity</li> <li>symbolic expression of inner processes</li> <li>expression of need for peace and concentration on essentials</li> <li>expression of desire not to be forgotten</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Parents</b></p> <ul style="list-style-type: none"> <li>intense emotional reactions e.g. anxiety, anger, yearning, feelings of guilt, despair</li> <li>helplessness, overtaxing</li> <li>physical and mental exhaustion</li> <li>fear of confrontation with questions concerning dying and death</li> <li>clinging to illusions, excessive denial</li> <li>couple and family conflicts, family disintegration</li> <li>Insecurity in dealing with grief in regard to social environment</li> <li>fear of psychological breakdown and self-abandonment</li> <li>doubts about previous beliefs, loss of meaning in life</li> <li>inability to restructure life/pathological grief</li> </ul> <p>Psychological disorders see ICD-10</p> <p><b>Siblings</b></p> <ul style="list-style-type: none"> <li>contradictory feelings towards the dying sibling, e.g. jealousy, anger, shame, yearning, feelings of guilt</li> <li>attempt to replace the dead child</li> <li>attention-seeking, e.g. through symptoms of illness</li> </ul> <p>Psychological disorders see ICD-10</p>	<p><b>Supportive therapy / palliative support</b></p> <ul style="list-style-type: none"> <li>continuous provision of supportive care for patient and relatives</li> <li>help in planning the last phase of life</li> <li>supporting parents in decision for palliative care at home</li> <li>initiation of palliative care at home by mobile team; handing over to mobile team</li> <li>strengthening the parents' protective function in the process of leave-taking</li> <li>making it possible for patients to take leave of people close to them</li> <li>emphasising the importance of physical contact, presence of the parents and non-verbal communication</li> <li>encouraging an open, honest and protective handling of patient's and siblings' questions concerning dying and death</li> <li>involving siblings in the dying and grieving process</li> <li>giving space for anticipatory grief, encouragement to allow the inexpressible</li> <li>giving space for the simultaneous experience of hope/confidence on the one hand, and on the other, despair in view of the unavoidability of death ("double awareness")</li> <li>support in coping with fear, loss, pain and grief</li> <li>taking individual cultural and religious concepts, and traditions in dealing with dying and death into account</li> <li>grief counselling for parents and siblings extending beyond the death of the child</li> <li>follow-up consultation with the relatives of the dead child in the clinic</li> <li>arranging contacts and follow-up care for grieving relatives</li> <li>arranging rehabilitation for grieving families</li> </ul> <p><b>Psychosocial diagnostics</b></p> <ul style="list-style-type: none"> <li>continuous assessment of the state of the whole family and their need for support</li> </ul> <p><b>Social welfare support</b></p> <ul style="list-style-type: none"> <li>finding out about resources for palliative care</li> <li>promoting a supportive network for care at home</li> <li>collaboration in an interdisciplinary, multidisciplinary helpers' conference/drawing up a plan for crises and emergencies</li> <li>arranging ambulatory care in the patient's home</li> <li>arranging psychosocial support for parents and attachment figures, e.g. services to lighten the family's load, ambulatory hospice services</li> <li>help in claiming financial aid and support in organising the last phase of life</li> </ul> <p><b>Information and orientation aids</b></p> <ul style="list-style-type: none"> <li>providing age-adequate information material on death and dying for the patient, parents, siblings, teachers and school classes etc.</li> <li>promoting understanding for the age-appropriate expression of "knowledge" of dying and childlike fantasies about life after death</li> <li>support in seeking rituals of leave-taking and remembrance</li> </ul> <p><b>Creative arts therapies / play and creative pedagogy</b></p> <ul style="list-style-type: none"> <li>finding age-specific forms of leave-taking</li> <li>expression and creation of inner world and images</li> </ul> <p><b>Complementary measures</b></p> <ul style="list-style-type: none"> <li>making school attendance, participation in class and contact with fellow students possible</li> <li>support in spiritual and religious questions</li> <li>pastoral care of patient and family, memorial services</li> </ul>

### 6.3 Evidence-basing of the effectiveness of selected psychosocial interventions

This section will look at which interventions have proved effective in the psychosocial care of children/adolescents with cancer and their relatives.

The following outline of the evidence for psychosocial interventions is oriented towards the various *goals* of the interventions. Accordingly, the following thematic priorities are dealt with in these subchapters:

- interventions regarding information, orientation aids and communication (chap. 6.3.1)
- interventions regarding emotional and social support (chap. 6.3.2)
- interventions aimed at reducing fatigue and improving fitness (chap. 6.3.3)
- interventions regarding support in practical and financial issues (chap. 6.3.4)
- interventions aimed at ensuring therapy and cooperation, and in case of specific symptoms within the framework of medical measures (chap. 6.3.5)
- interventions regarding prevention and rehabilitation (chap. 6.3.6)

For the purpose of scientific substantiation, studies arising from the literature research for the first draft of the guideline in 2008 and the update in 2013 are listed to begin with.

For the period from 2013 to 2014, standards of the “*Psychosocial Standards of Care Project for Childhood Cancer*” and the studies contained in them are included (Wiener, Kazak, et al., 2015).

In addition, publications from 2016-2018 that are the result of the systematic literature research for the new update of the guideline are listed. Studies with a *high* evidence level and clinical importance have been included (therefore: *systematic reviews or meta-analyses of controlled studies, randomised controlled studies, non-randomised controlled studies*). The GRADE system was used to rate the quality of the evidence and strength of the recommendation (see for example G. Langer et al., 2012). Details of the literature research and review can be found in the guideline report (appendix A). An overview in tabular form of the studies cited in this chapter can also be found there (evidence table appendix A)

Additionally, during the course of this literature research, numerous cross-sectional, observational, cohort and qualitative studies and also reviews of descriptive and/or qualitative studies of psychosocial intervention that have a low evidence level due to their design were found. However, the methodology of some is sound and they have a high clinical relevance. These are also shown in tabular form in appendix E, but they have not been used for the scientific substantiation of psychosocial interventions. This makes clear the importance of future, methodically sound studies of interventions.

#### Interventions for children, adolescents and their relatives aimed at enhancing knowledge, understanding and communication regarding the disease

*Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care (Thompson & Young-Saleme, 2015).*

Standard 7 of «Psychosocial Standards of Care Project for Childhood Cancer»

This standard was formulated on the basis of 23 publications analysed; the evidence of the studies as a whole, based on GRADE quality criteria, was rated *moderate* the recommendation *strong*. In principle, the majority of studies found that psychoeducation interventions were well accepted and regarded as helpful by patients and family members. In particular, interactive approaches adapted to individual needs were able to increase knowledge of the disease and the feeling of control, although the importance of anticipatory guidance was often pointed out.

Furthermore, in a systematic review by the *Children's Oncology Group (Rodgers et al., 2016)* which analysed 83 articles, 10 recommendations on methods of conveying information to sick children/adolescents, their parents and siblings were developed. Among other things, written records and audio recordings of diagnostic interviews were expressly recommended. However, the evidence level of the publications analysed in this overview was reated overall as *low*.

A review of studies on enhancing the communication of children and adolescents about their own cancer gives some evidence that computer-based learning, art therapy and social or school-reintegration programmes can lead to improvements in knowledge and understanding and also in psychological, social and behaviour variables (*Scott, Harmsen, Prictor, Sowden, & Watt, 2004*).

A review of studies on the enhancement of communication about cancer between children and adolescents and their relatives (*Scott, Entwistle, Sowden, & Watt, 2004*) provides evidence that structured group programmes, for example, can lead to improvements in knowledge, understanding and emotional state.

The use of IHCA (Interactive Health Communication Applications) in the care of chronically ill children/adolescents and adults (e.g. cancer, asthma, diabetes) results in positive effects on knowledge, acceptance of social support, health-related behaviour and clinical outcomes (e.g. disease parameters) (*Murray, Burns, See, Lai, & Nazareth, 2005*).<sup>18</sup>

*Peck, Tyc, Huang, and Zhang (2015)* also looked at a psychoeducation intervention in their study. However, the aspect they examined was the health behaviour of the parents. A randomised controlled study showed that the degree to which childhood cancer patients were exposed to passive smoking in their parents' car was more significantly reduced, at least initially, by a three-month targeted intervention for their parents compared to a group that had only been informed of the health risks.

However, there is expert-based consensus that psychosocial interventions aimed at giving support in processing complex issues have proved to be effective means of information and orientation.

To that effect, a guideline-oriented, standardised instrument for the work with children and adolescents (MEIN LOGBUCH – Ich kenne mich aus! English: My logbook – I know my way around!) is currently being developed by an interdisciplinary team working closely together with the quality assurance panel of the PSAPOH (*Weiler-Wichtl & Fohn-Erhold, under development*). The logbook offers a possibility for the practical implementation of interventions with concrete methods and materials dealing with information

<sup>18</sup> IHCA are computer-based applications which provide information and support for patients and relatives. In this context, support is understood to be social support (e.g. in forums), support in decision-making (e.g. decision trees) or support in changing behaviour.

and orientation, and also emotional and social support (6.3.2); it also aims to secure cooperation and reduce anxiety during medical procedures (6.3.5), and finally, deals with the rehabilitation aspect (6.3.6).

### **Interventions aimed at improving conversation techniques and participative decision-making**

Several studies included in the current systematic literature research (2015-2018) concern themselves with the question of how conversation techniques and participative decision-making with children, especially adolescents, and their relatives, can be improved, particularly in difficult, critical situations during the course of treating childhood cancer (*e.g.* Raz, Tabak, & Kreitler, 2016; Robertson *et al.*, 2018; Sisk *et al.*, 2017; Weaver, Baker, *et al.*, 2015). However, there are no intervention studies as yet and only a few studies include the child's perspective.

### **6.3.2 Effectiveness of psychosocial interventions for emotional and social support**

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#### **Psychosocial interventions aimed at reducing emotional distress / improving quality of life in child and adolescent cancer patients and their relatives**

*All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed (Steele *et al.*, 2015).*

Standard 4 of «Psychosocial Standards of Care Project for Childhood Cancer»

This standard was formulated on the basis of 173 analysed articles. Based on GRADE quality criteria, the quality of the evidence was rated overall as *high*; the recommendation was rated *strong*. Interventions from the field of cognitive behaviour therapy or training in problem-solving skills proved to be practicable and effective, and also approaches that, for example, integrated family-oriented methods (*e.g.* Kazak, 2005; Sahler *et al.*, 2013).

A meta-analysis of 12 randomised controlled studies of psychosocial interventions (a total of 1,393 participants) also showed the positive effect of a broad spectrum of psychosocial interventions not only on mental health, but also on physical health (approaches from the field of cognitive behaviour therapy; with or without physical training; family therapy; combined approaches, fulfilling wishes<sup>19</sup>) (Coughtrey *et al.*, 2018).

Similarly, two randomised controlled studies of wish fulfilment interventions found a positive effect on the emotional well-being of child and adolescent cancer patients (Chaves, Hervas, & Vazquez, 2016; Shoshani, Mifano, & Czamanski-Cohen, 2016).

In addition, a randomised study by Akard *et al.* (2015) established the effectiveness of a psychosocial intervention that consisted of the creation of “digital stories”, as a form of legacy. In the intervention group, interviews were conducted with children and adolescents. Together with music and suitable photo material chosen by the patient, these were used to create a film, a “digital story” about the child. The film was made available to the interviewees and their relatives. 79% of the parents of the children and adolescents reported that the films helped their children to express their feelings. Other positive effects included easier communication between children and their parents as well as a feeling of emotional comfort for the parents. Compared with a control group, the children and adolescents with a “digital story” had slightly better results for emotional and academic well-being.

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<sup>19</sup> by organisations that specialise in fulfilling heartfelt wishes of seriously ill children/adolescents

## **Specific psychosocial interventions for siblings**

*Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly (Gerhardt et al., 2015).*

Standard 10 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 125 analysed articles. Based on GRADE quality criteria, the quality of the evidence in the studies was rated overall as *moderate*, the recommendation was rated *strong*.

Furthermore, in a randomised controlled study of 75 siblings of child and adolescent cancer patients, *Barrera, Atenafu, Nathan, Schulte, and Hancock (2018)* were able to prove the effectivity of a group intervention in the sense of a reduction in anxiety in siblings and parents.

*Niemitz and Goldbeck (2018)* examined the effect of additional psychoeducative units for siblings in inpatient, family-oriented rehabilitation (FOR) in Germany. The psychoeducation units had a positive effect on the knowledge of the sibling's disease and on emotional well-being, although the same improvement was also found in the control group of children who had received standard care within the FOR framework.

The standard described above and the studies referred to therefore underpin the expert-based consensus that interventions for siblings play a central role in the psychosocial care of families of child cancer patients and should be initiated as early as possible in the course of the disease or treatment.

## **Specific psychosocial interventions for parents**

### **Individual interventions**

Several randomised controlled studies of approaches from the area of solution-focused brief therapy with parents were able to show positive effects on parents' emotional well-being. However, the studies have various methodological flaws (*Safarabadi-Farahani, Maarefvand, Biglarian, & Khubchandani, 2016; Zhang et al., 2018*).

A national, randomised controlled study in Denmark has proved the practicality and acceptance of the FAMOS family-oriented support programme (*Salem et al., 2017*). The programme starts shortly after the end of intensive medical therapy and is conducted at the family's place of residence.

### **Internet-based interventions**

In a randomised controlled study, a 10-week guided online self-help programme for parents of child cancer patients (during medical therapy) was able to achieve a reduction of symptoms of a post-traumatic stress disorder, depression, and anxiety among others (*Cernvall, Carlbring, Ljungman, Ljungman, & von Essen, 2015*). It was possible to establish the effects one year later (*Cernvall et al., 2017*).

The online CASCADE programme (*Wakefield et al., 2016*) enjoyed good acceptance and practicability among the parents of child and adolescent cancer survivors; it is not yet possible to reach a verdict on the effectivity.

### **Group interventions**

In their randomised controlled study, *Damreihani, Behzadipour, Haghpanh, and Bordbar (2018)* showed a positive effect of a group intervention (based on *positive psychology* theories) on the emotional well-being of mothers of leukaemia patients.

### 6.3.3 Effectiveness of psychosocial interventions for reducing fatigue and improving fitness

A systematic review of nine randomised controlled studies points to evidence that physical exercise can reduce the symptoms of fatigue and emotional stress (*Lopes-Junior et al., 2016*).

In randomised controlled studies, (N=222 or N=69 participants) *W. H. C. Li et al. (2018)* and *Chung, Li, Chiu, Ho, and Lopez (2015)* were able to show the positive effect of an adventure-based training programme: on the one hand, fatigue symptoms were reduced while on the other hand, physical activity, self-efficacy and quality of life were enhanced.

In a combined approach using physical and psychosocial interventions, *van Dijk-Lokkart et al. (2016)* found slightly more positive effects on the long-term quality of life in participants in the intervention group.

### 6.3.4 Effectiveness of psychosocial interventions providing support in practical and financial issues

*Paediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health.*

- *Assessment of risk for financial hardship should be incorporated at time of diagnosis for all paediatric oncology families. Domains of assessment should include risk factors for financial hardship during therapy including: pre-existing low-income or financial hardship, single parent status, distance from treating centre, anticipated long/intense treatment protocol, and parental employment status.*
- *Targeted referral for financial counselling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment.*
- *Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement (Pelletier & Bona, 2015).*

Standard 5 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 24 analysed articles. The quality of the evidence of the studies, based on GRADE criteria, was rated as *moderate* as a whole; the recommendation was rated *strong*.

A study by *Goodenough, Foreman, Suneson, and Cohn (2004)* on the predictors for claiming social worker support recommends very early social-work interventions due to serious financial losses at the onset of the disease.

In the view of the group of experts, counselling and support on social and economic issues and in claiming social benefits serves to ensure the implementation of medical treatment. Socioeconomic burdens play a critical role in the context of cancer in childhood or adolescence (see also chapter 3). Further research on interventions in this field therefore appear to be of great importance.

Detailed information can be found, for example, in the brochure „*Sozialrechtliche Informationen – für Familien mit einem krebskranken Kind*“ (English: *Social welfare information for families with a child cancer patient*) of the German childhood cancer foundation, DKKS (online availability - see appendix C).



### 6.3.5 Effectiveness of psychosocial interventions ensuring therapy and cooperation and for specific symptoms within the medical treatment framework

*All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures (Flowers & Birnie, 2015).*

Standard 8 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 65 analysed articles. The quality of the evidence of the studies (of interventions), based on GRADE criteria, was rated as *high* as a whole; the recommendation was rated *strong*. Interventions such as distraction, combined approaches (relaxation, breathing exercises, practice/simulation, parent training among others) or clinical hypnosis were proved to be effective.

#### **Psychosocial interventions for improving the ability of children to cooperate in radiotherapy**

A comparative study by *Klosky et al., (2004)* gives preliminary evidence of the effectiveness with regard to heart rate, but not sedation or distress, of an interactive programme aimed at improving children's ability to cooperate in radiotherapy and other longer-term medical procedures.

In addition, interventions can be helpful in preparation for radiotherapy (e.g. information material, joint visit to the radiotherapy room, role-play) and during treatment (e.g. relaxation, distraction).

The interventions given above can also be helpful for procedures in which the child is alone or has to lie still for a long time, e.g. imaging procedures.

#### **Psychosocial interventions for acute pain and anxiety**

The effectiveness of psychotherapeutic procedures with regard to pain reduction and anxiety in medical interventions such as bone marrow biopsy and lumbar puncture has been investigated in several comparative studies (*Broome, Rehwaldt, & Fogg, 1998; E. Chen, Zeltzer, Craske, & Katz, 1999; Dahlquist & Pendley, 2005; Dahlquist, Pendley, Landthrip, Jones, & Steuber, 2002; Hawkins, Liossi, Ewart, Hatira, & Kosmidis, 1998; S. Jay, Elliott, Fitzgibbons, Woody, & Siegel, 1995; S. M. Jay, Elliott, Katz, & Siegel, 1987; S. M. Jay, Elliott, Woody, & Siegel, 1991; Katz, Kellerman, & Ellenberg, 1987; Kuttner, Bowman, & Teasdale, 1988; Liossi & Hatira, 1999; S. L. Manne, Bakeman, Jacobsen, Gorfinkle, & Redd, 1994; S.L. Manne et al., 1990; Milling & Costantino, 2000; Sander Wint, Eshelman, Steele, & Guzzetta, 2002; Wall & Womack, 1989; Wild & Espie, 2004*). However, these studies have methodological flaws so that it is not possible to draw clear conclusions from them. The value of these procedures in these interventions has been relativised by more recent anaesthesiologic procedures.

Psychosocial interventions such as play therapy and relaxation techniques can be helpful for other painful procedures for which anaesthesiologic procedures are not normally used (e.g. port/vein puncture, changing dressings).

A systematic review of randomised-controlled studies of interventions aimed at reducing treatment-related anxiety and pain (*Nunns et al., 2018*) found two studies that underlined the positive effect of (clinical) hypnosis in reducing anxiety.

#### **Psychosocial interventions for chronic pain and severe acute pain**

The recommendations of "*Praktische Schmerztherapie in der pädiatrischen Onkologie*" (Practical Pain Therapy in Paediatric Oncology) by the *Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH)*, the *Deutsche Gesellschaft zu Studium des Schmerzes (DGSS)* and the *Deutsche Gesellschaft für Palliativmedizin, DGP* (*Zernikow et al., 2006*) – point to the usefulness of non-medicamental pain therapy (e.g. time, information, possibilities of control by the child). In particular, they point to the significance of interdisciplinary cooperation and the development of strategies in the whole treatment team.

In addition, in a Cochrane review, relaxation and cognitive behaviour therapy have proved effective in reducing the severity and frequency of pain in children and adolescents with chronic headache (Eccleston, Yorke, Morley, Williams, & Mastroyannopoulou, 2003).

The video, “Den Schmerz verstehen – und was zu tun ist in 10 Minuten” English: Understanding pain and what to do about it in 10 minutes) by the Deutsches Kinderschmerzszentrum (German child pain centre) presents clear and child-friendly strategies for pain reduction, underpinned with an accompanying booklet with scientific background information (Zernikow & Wagner, 2014).

### ***Psychosocial interventions for nausea and vomiting during chemotherapy***

Several comparative studies of psychotherapeutic (e.g. hypnotherapeutic) interventions (Hawkins et al., 1995; Jacknow, Tschann, Link, & Boyce, 1994; Redd et al., 1987; Zeltzer, Dolgin, LeBaron, & LeBaron, 1991) give weak evidence of a reduction of nausea and vomiting during chemotherapy. The value of these procedures has been changed by newer antiemetic medications. Interventions from the areas of hypnotherapy, behaviour therapy or art therapy are of value, particularly for nausea and vomiting with a strong psychogenic component. Here too, interdisciplinary cooperation and the development of joint treatment strategies is of major importance.

## **6.3.6 Effectiveness of psychosocial interventions for prevention and rehabilitation**

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### ***School reintegration programmes***

- *In collaboration with parents, school-aged youth diagnosed with cancer should receive school re-entry support that focuses on providing information to school personnel about the patient’s diagnosis, treatment, and implications for the school environment and provides recommendations to support the child’s school experience.*
- *Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team (Thompson et al., 2015).*

Standard 11 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 17 analysed articles. Based on the GRADE quality criteria, the quality of the evidence in the studies was rated *low* as a whole, the recommendation was rated *strong*. There are promising concepts for school integration programmes (e.g. Bruce, Newcombe, & Chapman, 2012; Northman, Ross, Morris, & Tarquini, 2015), but these require further evaluation.

By contrast, a meta-analysis found three school reintegration programmes that had a significant effect on the improvement of academic performance and a reduction in depressive symptoms. In addition, three programmes providing information for the child’s class at school had a positive effect in the form of increased knowledge of the disease and an increased interest in interaction with those affected (Helms et al., 2016).

### **Interventions for promoting social interaction and social skills**

- *Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patient's unique characteristics, including developmental level, preferences for social interaction, and health status.*
- *The patient, parent(s), and a psychosocial team member (e.g., designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment, and when the patient enters survivorship; it may be helpful to include school personnel or additional providers (Christiansen et al., 2015).*

Standard 9 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 64 analysed articles. Based on the GRADE quality criteria, the quality of the studies' evidence was *moderate* overall; the recommendation was rated *strong*. Support groups and camps, among others, are regarded as possibilities for promoting social interaction.

Furthermore, a group intervention for promoting social skills, in which 43 survivors with a brain tumour took part, showed a positive effect compared to a randomised control group (Barrera, Atenafu, Schulte, et al., 2018).

### **Interventions in case of neuropsychological deficits**

*Children with brain tumours and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment (Annett, Patel, et al., 2015).*

Standard 2 of «Psychosocial Standards of Care Project for Childhood Cancer»

The standard was formulated on the basis of 129 analysed articles. Based on GRADE quality criteria, the quality of the evidence in the studies overall was *high*, and the recommendation was rated *strong*.

Alongside this clear recommendation to regularly keep an eye on children and adolescents with a risk of neuropsychological deficits during and after medical treatment, in recent years it has also been possible to show the effectiveness of various therapeutic approaches.

Conklin et al. conducted computerised cognitive training (25 training units with COGMED, with weekly coaching by telephone) as a randomised controlled study. Survivors of brain tumours and leukaemia benefited from the intervention: attention, working memory and processing speed were increased and the parents of the participants also reported reduced inattention and fewer dysexecutive symptoms. The effect was maintained for a period of six months (Conklin et al., 2017; Conklin et al., 2015). Other approaches (Butler, Copeland, et al., 2008) were able to achieve an effect on academic performance and an improved assessment of performance by the parents, but not on the neuropsychological dimension (attention) that was examined. In a randomised controlled study with adolescents with medulloblastoma Zhu, Gong, and Gao (2015) were able to demonstrate the positive effect of a psychoeducative group programme. In addition, S. K. Patel et al. (2014) were able to prove the positive effect of a parent training programme on academic performance.

Appropriate neuropsychological testing of the affected functions is strongly recommended prior to these or comparable interventions (see also chapter 4). Knowledge of the course of concentration perception and memory performance among others is of great significance for the early recognition and treatment of possible deficits, especially for school reintegration. Interventions should be planned on an interdisciplinary basis, be oriented to individual needs and daily life, and begin as early as possible. Beside the therapeutic approaches mentioned above, approaches in speech therapy, ergotherapy and learning therapy as well as outpatient and inpatient rehabilitation should be considered.

## 6.4 Disorder-/ symptom-specific interventions

This chapter contains references to German-language guidelines on the diagnostics and therapy of psychological disorders according to ICD-10 which are particularly relevant for the psychosocial care of children and adolescents with cancer.

Table 16 lists the corresponding diagnosis groups together with sources in German-speaking countries. Guidelines for other diagnosis groups are available on the AWMF internet portal ([www.awmf-online.de](http://www.awmf-online.de)) and at [www.leitlinien.de](http://www.leitlinien.de).

Table 16: Relevant psychological disorders and treatment guidelines

Diagnosis (ICD-10)	Guideline (available online -> see appendix C)
Personality and behavioural disorders due to brain disease, damage or dysfunction (F07)	Guidelines of the <i>Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie</i>
Depressive episodes (F32)	
Phobic disorders (F40)	
Other anxiety disorders (F41)	
Obsessive-compulsive disorders (F42)	
Acute stress reaction (F43.0)	
Post-traumatic stress disorder (F43.1)	Guidelines of the <i>Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie</i>  Guidelines of the <i>Deutschsprachigen Gesellschaft für Psychotraumatologie (DeGPT)</i>
Adjustment disorder (F43.2)	Guidelines of the <i>Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie, Psychosomatik und Psychotherapie</i>
Dissociative disorders (F44)	
Somatoform disorders (F45)	
Combined disorders of social behaviour and the emotions (F92)	
Emotional disorders with separation anxiety (F93.0)	

## 7 FOLLOW-UP CARE AND REHABILITATION<sup>20</sup>

Alongside the main focus on acute care, the development of medical and psychosocial follow-up and transition concepts for former child and adolescent cancer patients has gained increasing importance. Table 17 lists guidelines of various expert associations that deal extensively with the subject of follow-up care.

Table 17: Guidelines for follow-up care after cancer in childhood and adolescence

Name of guidelines (online availability see appendix C and appendix D 10,36,37)	Latest update	Professional organisation responsible
Nachsorge von krebskranken Kindern, Jugendlichen und jungen Erwachsenen - Erkennen, Vermeiden und Behandeln von Spätfolgen  (English: Follow-up care of children, adolescents and young adults with cancer – recognising, avoiding and treating late effects )	2013 (currently under revision)	GPOH
Long-Term-Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers (COG LTFU Guidelines)	Version 5.0 –2018	Children’s Oncology group
Long term follow-up of survivors of childhood cancer – a national clinical guideline	2013	Scottish Intercollegiate Guidelines Network

Furthermore, there are follow-up care plans for study-related follow-up care of various oncological diseases or the relevant treatment studies (GPOH- or Europe-wide); (for online availability see appendix C).

Psychosocial content is increasingly taken into account in these interdisciplinary guidelines and follow-up care plans. However in view of the abundance of necessary topics in the follow-up care of children, adolescents and young adults with cancer, they are not dealt with in detail.

Two exclusively psychosocial standards on the subject of follow-up care (*Lown et al., 2015*) have been formulated in “*Psychosocial Standards of care Project for Childhood Cancer*” (*Wiener, Kazak, et al., 2015*).

1. *Long-term survivors of child and adolescent cancers should receive **yearly** psychosocial screening for:*
  - a. *adverse educational and/or vocational progress, social and relationship difficulties;*
  - b. *distress, anxiety, and depression; and*
  - c. *risky health behaviours*
2. *Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends and repeated at each follow-up visit.*

Both standards arise from the analysis of 93 studies on the topic of follow-up care. Based on the GRADE quality criteria, the quality of the evidence in the studies was rated *moderate* to *high* (for 1st standard) and *low* to *moderate* (for 2nd standard). The expert panel’s recommendation was rated *strong*.

An overview by Signorelli et al. (2017) also makes clear that child and adolescent cancer survivors who are included in a follow-up care setting have a better health and education status. The authors therefore conclude that there is a necessity for life-long follow-up care and continuous information about late effects.

<sup>20</sup> This chapter cites publications from the creation of the guideline and its revision (1) (until 2013); (2) for the 2013-2014 period, standards of the “*Psychosocial Standards of Care Project for Childhood Cancer*” (*Wiener, Kazak, et al., 2015*) and the studies included in it, and (3) from the current systematic literature research as part of the update of the guideline undertaken from 2015 to 2018 are referred to. 25 studies (above all systematic reviews) from a total of 427 publications on the subject of follow-up care are incorporated in this chapter. The studies included were judged as having a high relevance for the core statements of psychosocial care in follow-up care and accordingly were given a strong recommendation, and were included in the text in the steering group’s subsequent coordination process. A comprehensive work-up of the studies in the form of a separate publication which goes further than the core statements on psychosocial follow-up care is being carried out (explanation, see also guideline report, appendix A)

The following section deals with well-documented late effects experienced by children and adolescent cancer survivors, and also presents current care concepts.

## 7.1. WELL-DOCUMENTED LATE EFFECTS

Findings from studies of late effects and quality of life point to physical, emotional, cognitive and social consequences of the disease and treatment for a proportion of patients (*Calaminus, Weinspach, Teske, & Gobel, 2007; Friend, Feltbower, Hughes, Dye, & Glaser, 2018; T. Langer et al., 2002; Michel, Rebholz, von der Weid, Bergstraesser, & Kuehni, 2010; Moore, 2005; Moyer et al., 2012; Oeffinger & Hudson, 2004; L. L. Robinson et al., 2005; Vannatta, Gerhardt, Wells, & Noll, 2007; Zebrack & Chesler, 2002*).

A review by the Children’s Oncology Group (*Bitsko et al., 2016*) shows that while the majority of child and adolescent cancer survivors in long-term follow-up care report relatively few psychosocial problems, a significant subgroup experiences severe difficulties, extending to an increased incidence of suicidal thoughts. In their review, *Brinkman, Recklitis, Michel, Grootenhuis, and Klosky (2018)* arrive at similar findings and also make clear that fewer survivors live in a relationship and lead an independent life. They are also less likely to have a higher educational level or be in full-time employment and all in all, their socioeconomic situation is less favourable. Accordingly, *Mader, Michel, and Roser (2017)* also found in a meta-analysis of 27 controlled studies that child and adolescent cancer survivors have a 1.5 times higher risk of unemployment; for survivors of a brain tumour the risk was actually 4.62 times greater.

In their meta-analysis, *Marjerrison, Hendershot, Empringham, and Nathan (2016)* found that survivors exhibited a similar or lower rate of risk behaviour regarding smoking, alcohol or drugs than their siblings or a peer group; however, the feared intensifying effect of late sequelae has not been examined sufficiently.

There is an urgent need for specific psychosocial care provision, in particular for groups at risk of late effects (table 18).

Table 18: At-risk groups for late effects

Children, adolescents and young adults	Publications <sup>20)</sup>
<ul style="list-style-type: none"> <li>after tumours of the central nervous system (CNS tumours) <i>especially: posterior fossa syndrome</i></li> </ul>	<i>Fuemmeler et al. (2002); Freeman, O'Dell, and Meola (2004); Mulhern, Merchant, Gajjar, Reddick, and Kun (2004); Schulte et al. (2010); Ozyurt, Muller, and Thiel (2015); Shah et al. (2015); Schulte et al. (2017); R. L. Woodgate, Taylor, Yanofsky, and Vanan (2016)</i>  <i>Hanzlik, Woodrome, Abdel-Baki, Geller, and Elbabaa (2015); Lanier and Abrams (2017)</i>
<ul style="list-style-type: none"> <li>after acute lymphatic leukaemia (ALL)</li> </ul>	<i>Cheung and Krull (2015); Hearps et al. (2017); Vetsch et al. (2018)</i>
<ul style="list-style-type: none"> <li>after solid non-CNS tumours</li> </ul>	<i>Sleurs, Deprez, Emsell, Lemiere, and Uyttebroeck (2016)</i>
<ul style="list-style-type: none"> <li>after invasive operations</li> </ul>	<i>Eiser (1990); Felder-Puig, Häfele, and Topf (2006)</i>
<ul style="list-style-type: none"> <li>after stem cell transplants</li> </ul>	<i>Gunter, Karle, and Klingebiel (2001); Phipps, Dunavant, Lensing, and Rai (2004); Tsimicalis et al. (2005); Barrera, Atenafu, and Pinto (2009); Buchbinder et al. (2018); Chow et al. (2016)</i>
<ul style="list-style-type: none"> <li>with an elevated degree of non-disease-related stressors (individual and familial)</li> </ul>	<i>See chapter 3 of this guideline</i>

## 7.2. CONCEPTS AND STRUCTURES

### 7.2.1 Existing networks<sup>21</sup>

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*PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer)* is a European network consisting of different professions in paediatric oncology, survivors and their families. Its aim is to give children and adolescents access to long-term follow-up care following cancer treatment, and to improve their quality of life. A working group deals specifically with psychosocial topics.

Within the GPOH the *Late Effects Surveillance System (LESS)* working group focuses on follow-up care. In addition, the *PSAPOH follow-up care panel* deals with psychosocial topics in follow-up care, as do regional working groups in the PSAPOH (e.g. follow-up care in the Austrian regional group of the PSAPOH; working group for follow-up care in the Bavarian regional group).

National and international child cancer organisations (e.g. DLFH, Kinder-Krebs-Hilfe (e.g. *DLFH - Deutsche Leukämie-Forschungshilfe*, *ÖKKH - Österreichische Kinder-Krebs-Hilfe*, *CCI - Childhood Cancer International*, formerly *ICCCPO*), to which the survivor organisations also belong, are very active and some are leading groups within these networks.

### 7.2.2 Responsibilities of psychosocial follow-up care

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Psychosocial care is an established part of intersectoral, multidisciplinary follow-up care and accompanies children and adolescents with cancer and their families long after the end of therapy.

The beginning of follow-up care depends on the clinical picture and the treatment associated with it: sometimes follow-up care begins after surgery, sometimes at the end of a long course of intensive therapy, although the intensity of the treatment does not define the degree of follow-up care needed. Children and adolescents who have a short treatment phase can have a great need for follow-up care due to treatment-related late effects. In any case, follow-up care topics (e.g. possible late effects) should be included in the psychosocial treatment plan early on. Thus, final psychosocial diagnostics and counselling should be conducted in the acute clinic and support the transition to follow-up care.

The initiation, coordination and implementation of psychosocial follow-up care includes the following aspects (*see also basic care modules*):

- Psychosocial follow-up within the framework of multidisciplinary follow-up care
- Monitoring psychosocial development trajectory
- Early planning and coordination of outpatient and inpatient rehabilitation
- Networking with outpatient and inpatient aftercare institutions and (regional and national) providers
- Counselling on dealing with possible late effects
- Preparation and organisation of targeted support measures for cognitive and other late effects
- Support in coping with fear of recurrence and progression
- Measures to aid social, school and workplace integration
- Measures to prevent psychosomatic, emotional and social late effects
- Preparation for the transition to long-term follow-up care in adulthood
- Organisation of rehabilitation measures and other provisions for grieving relatives

Patients with neuropsychological late effects also have a special need for interventions that focus not only on learning difficulties, but also on aspects of emotional and social resource enhancement (*Barrera & Schulte, 2009; Bruce et al., 2012; Butler, Sahler, et al., 2008*).

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<sup>21</sup> The websites of the organisations and working and professional groups can be found in the index of online resources in appendix C.

Parents and siblings also have clear psychosocial problems (Kazak et al., 2004; Kusch et al., 1999; Meyler, Guerin, Kiernan, & Breatnach, 2010; Prchal & Landolt, 2009; Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003; Van Dongen-Melman, 1995) that require therapeutic measures dependent on their needs.

Specific aspects of stress and the associated needs of adolescents and young adults (AYAS) after cancer in childhood and adolescence give rise to special challenges in their follow-up care, too (Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG), 2006; Larsson, Mattsson, & von Essen, 2010; Quinn, Goncalves, Sehovic, Bowman, & Reed, 2015; Seitz, Besier, & Goldbeck, 2009). This also applies to the rising number of adolescents and young adults with significant physical and mental health risks after cancer in childhood or adolescence (Krull et al., 2010; Schultz et al., 2007; Zebrack, Mills, & Weitzman, 2007).<sup>22</sup>

### 7.2.3 Current provisions and structures in psychosocial follow-up care<sup>23</sup>

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#### **(1) Outpatient follow-up care/ outpatient rehabilitation**

Nationally and internationally, there are widely differing concepts for the implementation of psychosocial outpatient follow-up care. Alongside various, mostly multiprofessional and interdisciplinary models for follow-up care in the first 5-10 years after diagnosis (often referred to as acute or short-term follow-up care), which are primarily located in treating clinics, in recent years, clinical experience and numerous research findings have made it abundantly clear that there is an additional need for linked-up, multiprofessional concepts in long-term follow-up care. A successful transition to long-term care for adults plays a central role here.

An overview of follow-up care services or projects in Germany, Austria and Switzerland is available online and given in appendix C.

#### **(2) Inpatient follow-up care: family oriented rehabilitation, rehabilitation for adolescents and young adults, neurological rehabilitation**

The implementation of specific inpatient rehabilitation measures for families, adolescents and young adults is an integral part of the treatment concept in paediatric oncology and haematology. Psychosocial aspects are of great importance in these measures (H. Häberle, Schwarz, & Mathes, 1997; H. Häberle, Weiss, Fellhauer, & Schwarz, 1991; Inhestern et al., 2017; Leidig, Maier, Niethammer, Niemeyer, & Rau, 2001; Mathes, 1998). Patients with severe neurological and neuropsychological deficits receive treatment in inpatient neurological rehabilitation units.

#### **(3) Seminars, camps und mentoring projects**

Additional options for promoting the process of coping with the disease and psychosocial reintegration have been established with information events for patients with a range of symptoms, family seminars and seminars for young adults (Kröger, 2005; Kröger & Lilienthal, 2001). Moreover, free-time and vacation camps support the exchange of experiences between patients and siblings of all age groups.

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<sup>22</sup> This chapter cites publications from the creation of the guideline and its revision (1) (until 2013); (2) for the 2013-2014 period, standards of the "Psychosocial Standards of Care Project for Childhood Cancer" (Wiener, Kazak, et al., 2015) and the studies included in it, and (3) from the current systematic literature research as part of the update of the guideline undertaken from 2015 to 2018 are referred to. 25 studies (above all systematic reviews) from a total of 427 publications on the subject of follow-up care are incorporated in this chapter. The studies included were judged as having a high relevance for the core statements of psychosocial care in follow-up care and accordingly were given a strong recommendation, and were included in the text in the steering group's subsequent coordination process. A comprehensive work-up of the studies in the form of a separate publication is being carried out. Furthermore, in this guideline, only the core statements of the 269 publications that deal in detail with the needs of and interventions for adolescents and young adults after childhood cancer can be presented. Here too, a comprehensive work-up of the studies is to be included in a separate publication (explanation see guideline report, appendix A).

<sup>23</sup> A collection of current follow-up care provisions (for all subitems) including addresses for German-speaking countries can be found under [https://www.kinderkrebsinfo.de/services/nachsorge\\_angebote/index\\_aer.html](https://www.kinderkrebsinfo.de/services/nachsorge_angebote/index_aer.html) (see also appendix C).



Mentoring programmes and other services offered by 'survivors' organisations are aimed at strengthening the exchange of information and experiences among those affected.

Grief seminars are offered for parents and siblings of children who have died.

An overview of current services in Germany, Austria and Switzerland is available online and can be found in appendix C.

#### **(4) Information materials**

There is a wealth of age-specific information material covering different topics in follow-up care for children, adolescents and young adults with cancer and their relatives. Special follow-up care brochures have been created for some disease pictures. Other central topics are, for example, *school reintegration* and *driving ability* with and after a brain tumour. A collection of German-language materials and their availability on the internet is given in appendix C.

Some guides and brochures from English-speaking countries are also recommended (*Edwards, Marshall, & Haeems, 2015; Keenie, Hobbie, & Ruccione, 2012, see also appendix A; Larcombe, Eiser, Davies, & Gerrard, 2007, 2015, 2018*); however, there is no guarantee of completeness here or in appendix C.

**Summing up**, it must be noted that the needs of survivors must still be assessed as greater than the current provision, despite the numerous initiatives and concepts that have been implemented in many places.

In a survey of 1,189 randomly selected survivors in the USA, *C. L. Cox et al. (2016)* established a significantly higher need. 54% of survivors reported that they had a greater need in the psychological-emotional area, while 41% reported a higher need concerning coping with the disease; 35% said they had needed more for care and support. Similarly, there was an elevated need for information concerning the disease and treatment, the care system and follow-up observation. However, in "*A randomized controlled pilot trial of a Web-based resource to improve cancer knowledge in adolescent and young adult survivors of childhood cancer.*", *Kunin-Batson, Steele, Mertens, and Neglia (2016)* show that conveying information alone, whether in personal contact or via a website, cannot make up for the information deficit. Instead, additional interventions that address, for example, understanding of health and disease, or fears are recommended.

*Tallen et al. (2015)* also note in their review that more evidence-based knowledge and also competence and strategies are needed to cater for the individual physical and psychosocial needs of survivors and enable them to experience a high quality of life and participation in society. Accordingly, aspects of follow-up care should also be central elements in the training and further training of paediatric oncology personnel (*see for example Shapiro et al., 2016*).

## CONCLUDING REMARKS

In the context of the holistic treatment concept in paediatric oncology and haematology, psychosocial care supports humanitarian aspects in patient care (J.C. *Holland & Lewis 2001*) and thus contributes significantly to the improvement of the quality of life, patient satisfaction and promoting the health of individual family members.

Psychosocial support of patients and their relatives is the expression of an ethical commitment (*Labouvie & Bode, 2006*) in view of the serious impact of the cancer and treatment on the life context and life perspective of the child/adolescent.

Psychosocial treatment measures also help to avoid psychological and social late effects and the resulting costs, and are therefore relevant in the health policy context (*Calaminus, 2000; Carlson & Bultz, 2003; Janicke & Hommel, 2016; Schumacher, 2004*).

Further research is needed for the quality development of care concepts, which are based on a continuing process of integrating research findings and clinical expertise. Research is needed for example on the effectiveness of specific interventions for quality of life and emotional adjustment, and the identification of risk factors regarding psychosocial reintegration.

The way seriously ill people are dealt with in everyday clinical practice – qualities such as supportive, confidence-building communication, respect, tolerance and dignity – plays an important role in coping with disease (*Cochinov, 2007*). These aspects should also be taken into consideration in research. Adaptation and communication processes of children, adolescents and young adults with life-threatening diseases, and of their relatives are influenced by diverse physical, emotional, social and spiritual factors. The evaluation of complex connections in the context of an interdisciplinary treatment concept that is oriented towards the bio-psychosocial disease model is methodologically more difficult than the assessment of clearly defined interventions, and requires the further development of differentiated research methods (*Farin & Antes 2000*).

The guideline presented here is intended to serve the drafting of quality standards and the guaranteeing of psychosocial care for children, adolescents and young adults with cancer and their families. It is meant as a contribution towards greater transparency and as a practical guide. The overall aim is to support the further development and specification of good clinical practice in paediatric oncology and haematology.

Alongside the systematic research of other guidelines and current scientific literature, a *review* was conducted as part of the renewed update of the guideline (2019). Psychosocial personnel from the field of paediatric oncology and haematology were asked to *assess the usefulness of the guideline* and also to describe the *barriers to implementing the content of the guideline*. The results of this survey are very valuable with regard to the further implementation of the guideline in clinical practice and are described in detail in appendix E.

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