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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) within the framework of quality assurance measures for the improvement and further development of the acute treatment and follow-up care of children and adolescents with cancer. Clinical practice guidelines, i.e. the scientifically based explanation 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, structured procedure in the psychosocial care 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. They aim to give the members of the multiprofessional psychosocial team orientation, based on the best possible evidence currently available, and to make the practice of care transparent for doctors, the nursing team, patients and their relatives.

Issues 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” (*Schröder et al., 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 method report*).

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 of selected issues
- Adaptation of statements and recommendations in international guidelines
- Consensus recommendations of the representative panel of experts

The method 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.

* The method report is currently available only in German

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 20-year background of experience for which concepts and structures for everyday practice have been developed (*Creutzig et al, 2004*). Medical advances in the treatment of malignant diseases in childhood and adolescence which have been made since the 1970s make recurrence-free survival possible for 70-75% of all those affected (*Creutzig et al, 2002; Berthold et al, 2006*). The high rates of cure for children and adolescents demand extremely intensive treatment, usually associated with serious physical side effects.

The disease- and treatment-related stress is associated with a high degree of suffering for the patient and his relatives. It 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 all the family members.

The family represents the essential source of support for the patient in coping with the disease and its treatment and therefore requires professional psychosocial support. (*Wittmeyer, Kaufmann & Lampert, 1990; Vance & Eiser, 2004*), 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 (*e.g. Kelly, 1986; Bruns, 1992; Bartig & Hofmann et al., 1998; Steiner & Eulerich-Gyamerah, 2003; Barkmann, Blohm & Wallner, 2006*).

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, kindergarten teachers, school teachers and pastors into the medical treatment setting was begun (*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 et al., 1989*) multiprofessional psychosocial care services were 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 et al. 1991*). Paediatric oncology and haematology thus took on a pioneering role in the psychosocial care of chronically sick children and adolescents and their families.

In German-speaking countries, a range of experience-based treatment concepts for various areas of care have been developed, (*Kokoschka, 1984; Thiel, 1990; Griessmeier & Bossinger, 1994; Häberle & Niethammer, 1995; Topf et al., 1997; Lilienthal et al., 2001; Labouvie, Hasan & Bode, 2003; di Gallo, 2004; Schröder et al., 1996; Schreiber-Gollwitzer, Schröder & Niethammer, 2002*), a model for standardised care was evaluated (*Kusch et al., 1997; Labouvie, 2005*), and national guidelines drawn up (*Schröder et al., 2006*). The central elements of psychosocial care such as counselling and therapeutic activities were described within the framework of a multi-centre study in Germany (*Schreiber-Gollwitzer et al., 2003; Mechels, 2008*), and the structural quality was examined in a nationwide survey (*Griessmeier et al., 2003*).

Care concepts for dying children and their families were developed in close cooperation with the medical treatment team, taking the special requirements of the palliative situation into account (*Niethammer, 1999, 2008; Kochendörfer, 2002; Mundle, 2002; Ritter, 2003; Führer & Zernikow, 2005; Führer, Duroux & Borasio, 2006*). In the light of medical progress, ethical questions pose a particular challenge for the organisation of the patient's dying and, as it were, final phase of life (*v. 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 detection of risk factors in the adaptation process after the end of treatment (*Stam et al., 2006, Eiser, 2007*).

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) (*100, 101, 157-162, 225-228*) and by other organisations such as AAP, ACT, A(P)OSW, CAPO und ICCCPO (*6, 1, 10, 11, 33, 223*), for example. Various care concepts for child cancer patients and their families also emerged in Anglo-American countries (*Chesler et al., 1993; Bearison & Mulhern, 1994; Lauria et al., 1996; Lauria et al., 2001*).

The common basis of all the concepts is family orientation, the strengthening of resources and resistance, and a multiprofessional supportive therapy which is oriented towards the disease process (*Holland & Rowland, 1990; Noeker & Petermann, 2002*). The consensus among experts in the field of psychosocial oncology is that a resource-oriented approach is preferable to a psychopathological view, and this 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 in improving well-being and adaptation to disease of the patients and their relatives, and in reducing stress factors (*Kazak 2005*).

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 the patient and his family 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 out-patient 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

2.0 Definition of psychosocial care

(1) Psychosocial care in paediatric oncology and haematology* encompasses all the clinical and scientific research activities concerning the evaluation and treatment of individual, familial, social and social welfare/entitlement issues relevant to the disease and their influence on coping, as well as the development of concepts aimed at the continuous improvement of treatment.

(2) Psychosocial care in paediatric oncology and haematology is conducted in cooperation with the medical treatment team. The emphasis is on supporting the resources of the patient and his family in the course of the disease, during therapy, follow-up care and, if the need arises, during dying, death and mourning. The basis for this is a supportive and informative relationship with the child and his family and social environment. It is oriented towards the physical, emotional, social and developmental potential of the sick child or adolescent and his social environment and takes individual styles and ability to cope and adjust into account.

* The short form "paediatric oncology" is often used in the following text.

2.1 Basic principles of psychosocial care

The basic principles of psychosocial care in paediatric oncology and haematology are described in the following chapter 2.1. They are supported by various national and international concepts for psychosocial care in (paediatric) oncology and children in hospital. An overview is given in table 1. The points listed in column 2 will be explained in more detail in the text that follows.

Table 1: Basic principles of psychosocial care and related publications

	Psychosocial care in paediatric oncology follows an approach which ...	Used in similar form or in part in the following guidelines, consensus statements
1	... is holistic	(11, 166, 175, 189)
2	... is preventive	(8, 189)
3	... is family-oriented	(5, 7, 10, 11, 33, 175, 189, 223)
4	... is centred on the individual	(5, 7, 8, 10, 33, 175, 189, 219, 223)
5	... is resource-oriented	(11, 33, 176, 189, 223)
6	... is supportive	(11, 33, 175, 176, 189, 223)
7	... is oriented towards the course of the disease	(10, 33, 175, 176, 189, 223)
8	... is based on interdisciplinary cooperation	(5, 8, 10, 11, 33, 175, 189, 219, 223)
9	... maintains certain basic ethical attitudes during treatment	(4, 33, 57, 223)

Note: The references relate to general psychooncological articles (8, 10, 33, 166, 175), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 11, 57, 67, 72, 176, 189, 223, 219).

2.1.1 Holistic approach to treatment

(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 illness, stressors and psychosocial risk factors should also be considered.

(5) The patients' and relatives' efforts to cope should be regarded as the expression of existing competencies. They should be examined to see how far they are suited to supporting the long-term adaptation process.

2.1.2 Prevention

(6) Early psychosocial support should be aimed at the prevention of psychological sequelae and co-morbidities in the patient and his relatives. It should also serve to prevent social, emotional and cognitive sequelae/developmental disorders.

(7) Psychosocial care should serve to prevent social isolation, social difficulties and excessive familial stress.

2.1.3 Family orientation

(8) Children need emotional support and security. 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 care of the patient.

(10) The child's cancer and treatment mean persistent psychosocial stress for the parents and siblings. Psychosocial care encompasses information and advice, and support to lighten the family's emotional load.

(11) The 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.

2.1.4 Centered on the individual

(12) Psychosocial care fundamentally requires an individual approach; in particular, the age and development stage of the child/adolescent, the heterogeneity of oncological diseases and their treatment and also the differing familial resources and previous stress factors should be taken into account.

(13) Information which complements the information and advice given by the physician is repeatedly offered to the patient after and in the course of the diagnosis. This information should be given 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- and child-appropriate individual support and guidance during the carrying out of medical procedures and 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 taken into consideration. In the case of language difficulties, a professional interpreter should be engaged when important topics need to be clarified.

2.1.5 Resource-oriented

(16) Psychosocial care aims to promote functional coping mechanisms in the patient and family taking into account the age-appropriate development of the patient. This strengthens resistance to disease and treatment-related stress factors.

(17) Psychosocial care uses individual interests and skills to promote the personal resources of the patient and his family, for example, self-esteem, an optimistic attitude, hope, 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 the patient to take part appropriately in his social environment (peer group, school, clubs etc.) and maintain social relationships within the framework of his illness and treatment situation.

2.1.6 Supportive therapy

(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 permit the establishment of a stable, supportive relationship with the patient and his relatives.

(23) Psychosocial care should allow adequate time for building and maintaining trust in the treatment and promote the compliance of the patient and his 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 personnel if conflicts arise.

2.1.7 Orientation towards the course of the disease

(26) Psychosocial care is oriented towards the process of the disease and treatment and monitors the need for psychosocial care in consultation with medical personnel, the patient and his relatives.

(27) The form and extent of psychosocial interventions should be oriented towards the psychological and physical state of the patient and take his subjective problems and needs during the course of the disease into account.

2.1.8 Interdisciplinary cooperation

(28) Psychosocial care in an acute hospital is based on close interdisciplinary cooperation with the medical and nursing staff. Regular consultation in the form of case, ward and departmental meetings should take place to coordinate patient care and work organisation.

(29) 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.

(30) Psychosocial care is committed to networking inpatient and outpatient, acute and rehabilitative therapy measures, e.g. after termination of intensive therapy or on transfer to adult oncology.

(31) Psychosocial care coordinates and links support from non-professional helpers, parents' associations, and donors and others, taking into account the well-being of the sick children/adolescents and their families.

2.1.9 Maintenance of basic ethical attitudes

(32) Psychosocial personnel respect the integrity and dignity of the patient and his relatives and support their right to self-determination.

(33) 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.

(34) Psychosocial care respects the right of the patient and his relatives to adequate treatment independently of their cultural and ethnic background and religion.

(35) Psychosocial care is based on a benevolent and supportive attitude which shows respect for adaptive and psychologically essential defence mechanisms.

(36) 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.

(37) Psychosocial care should support the patient's health-related quality of life in the planning and implementation of treatment measures.

(38) Patients should receive information on their disease and treatment that is appropriate for their age and development.

(39) Adolescent patients should be involved in information and in the decision-making process concerning treatment.

(40) Psychosocial care should support open communication between parents, patient and siblings and encourage truthfulness in dealing with the disease and treatment.

(41) Psychosocial care supports the family in finding an individual and dignified approach to the last phase of life and death of the patient.

(42) Psychosocial interventions for children and adolescents should be implemented in consultation with and with the agreement of the parents.

(43) Psychosocial care accepts the right of the child, adolescent or relatives to refuse the psychosocial interventions offered.

2.2 Organisation and structure

Guiding principles of the structure and organisation of psychosocial care in paediatric oncology and haematology are described in the following chapter 2.2. They are supported by various national and international concepts of psychosocial care in (paediatric) oncology and children in hospital. Table 2 gives an overview of these. The points listed in column 2 are explained in detail in the text which follows.

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

	Structure und organisation	Used in similar form or in part in the following guidelines, consensus statements
1	Psychosocial care as a standard in paediatric oncology	(10, 11, 33, 67, 72, 166, 189)
2	Conditions regarding personnel, time, premises and administration	(8, 33, 67, 72, 166, 189)

Note: The references relate to general psychooncological articles (8, 10, 33, 166, 175), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 11, 57, 67, 72, 176, 189, 219, 223).

2.2.1 Psychosocial care as a standard in paediatric oncology and haematology

(44) 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.

(45) For the patient, psychosocial care involves basic care and, when necessary, intensified care.

(46) Psychosocial care is generally available and accessible. It should meet the needs of the children and adolescents and their relatives.

2.2.2 Conditions regarding personnel, time, premises and administration

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

(48) Areas of responsibility and competence of individual psychosocial personnel should be defined in writing and brought into line with current professional standards and guidelines.

(49) The psychosocial service should be headed by a trained psychologist, an educator with a psychotherapy qualification, a social worker with a psychotherapy qualification, a child and adolescent psychotherapist, a child and adolescent psychiatrist, or a paediatrician with a suitable psychological qualification.

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

(51) Psychosocial personnel should have rooms at their disposal that guarantee the necessary privacy for counselling and therapy. They should be easy to reach for relatives and patients using wheelchairs and infusomats, for example.

(52) Adequate funds should be available to psychosocial workers for patient information, play, therapy and testing materials, and literature, for example.

(53) The ward should have a well-equipped play room and age-appropriate activities for children and adolescents.

(54) Psychosocial care should advocate a child and family-friendly hospital environment which promotes the resources of patients, relatives and personnel.

2.3 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 2.3. They are supported by a range of national and international concepts of psychosocial care in (paediatric) oncology and of children in hospital; table 3 gives an overview of these. The points listed in column 2 are explained in detail in the text which follows.

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

	Structure and organisation, quality assurance and documentation	Used in similar form or in part in the following guidelines, consensus statements
1	Qualification of psychosocial personnel	(10, 33, 189)
2	Further and advanced training	(8, 33, 166, 189)
3	Documentation	(8, 10, 33, 166, 189)
4	Evaluation and research	(33, 166)

Note: The references relate to general psychooncological articles (8, 10, 33, 166, 175), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 11, 57, 67, 72, 176, 189, 219, 223).

2.3.1 Qualification of psychosocial staff

(55) In acute hospitals, psychosocial care in paediatric oncology should be provided by psychologists, educators, social education workers, social workers, art and music therapists, kindergarten teachers, school teachers and pastors with specialist training.

(56) In addition to specialist training, psychosocial staff should have the following interdisciplinary skills:

- Knowledge of cancer, its treatment and late effects in childhood and adolescence
- Knowledge of age- and culture-appropriate 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
- Expert 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 the 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 promoting mental hygiene

2.3.2 Further training

(57) Psychosocial personnel should take part regularly in further and advanced training courses.

(58) Psychosocial personnel should receive regular supervision from an external supervisor in order to reflect on their work on a professional basis and find their own ways of dealing with stress.

(59) Psychosocial personnel should offer information and further training, for example, for therapists outside the clinic, for teachers and voluntary helpers.

2.3.3 Documentation

(60) In the context of status and process documentation, psychosocial care in paediatric oncology should include the systematic and continuous recording of stress factors and resources of patients and families and the documentation of psychosocial interventions, stress factors and resources.

(61) 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.

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

2.3.4 Evaluation and research

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

(64) Psychosocial research issues should be integrated into clinical-somatic research.

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 stress factors. The typical stress factors and impairments have been demonstrated in numerous scientific studies (*Dahlquist et al., 1996; Eiser, 1998; Fuemmler et al., 2002; Kazak et al., 1995; Kröger, 2005; Mulhern et al., 1993; Noeker & Petermann, 2002; Tsimicalis et al., 2005; van Dongen-Melman, 1995; Wittmeyer & Kaufmann, 1989; Woodgate, 2000*) 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 (*Hürter, 1990; Kazak, 1992; Kusch et al., 1996*).

3.1 Stressors related to disease

Stress factors related to disease comprise all the conditions and demands that arise due to the disease and the therapy. They are subdivided into disease-specific somatic and disease-specific psychosocial stress factors.

3.1.1 Disease-specific somatic stressors

- Diagnostic measures (lumbar punctures, diagnostic imaging, taking of blood samples etc.)
- Therapeutic measures (taking tablets, mouth care, preparation for surgery etc.)
- Side effects of treatment (infections, vomiting, hair loss, Cushing etc.)
- Operations, chemo-, radio- and high dosage therapy, stem cell transplant (SCT) etc.
- Radical surgical procedures associated with loss of function (amputations etc.)
- Severe physical impairment (intensive care, pain, cachexia etc.)
- Late effects of the disease and treatment (growth disturbances, fertility, cognitive performance etc.)
- Recurrence of tumours, progression of the disease
- Palliative treatment situation

3.1.2 Disease-specific psychosocial stressors

- "Diagnosis shock" (emotional coping with reaction to diagnosis and prognosis)
- Dealing with painful or frightening procedures
- Fear of incurability of the disease and late effects
- Restriction of lifestyle due to treatment regime
- Dealing with the loss of physical and mental abilities
- Dealing with a changed physical image
- Loss of autonomy and self-esteem, feelings of guilt
- Exhaustion of relatives involved in care (chronic stress situation)
- High care demands on the child's parents
- Organisational problems (e.g. care of siblings, distance from clinic)
- Separation from family, friends, schoolmates
- Stress for the parents' marital relationship
- Increased financial expense e.g. travel to the clinic, the doctor, the therapist
- Serious economic hardships, threatened loss of employment

3.2 Non-disease-related stressors

Non-disease-related stressors 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 disease – from the familial, personal or socioeconomic conditions of the patient and his family. They can constitute a significant risk factor with regard to the demands of dealing with the illness.

3.2.1 Non-disease-related psychosocial stressors

e.g.

- Socioeconomic stress factors (unemployment, financial difficulties, housing problems etc.)
- Language and cultural problems, uncertain legal position (unclear residency status, inadequate language skills etc.)
- Lack of social support and family cohesiveness
- Problematic coping strategies and unfavourable health behaviour
- Prior somatic or mental illness of the patient or relatives
- Previous development disturbances or deficits
- Problematic parenting style
- Single parent
- See further diagnoses in ICD-10

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 the patient in helping him 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 (*Mc Cubbin & Mc Cubbin, 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 the patient and his relatives (*Grawe et al., 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 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 personal 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 (*Eiser, 1990; Lawford & Eiser, 2001; Luthar et al., 2000; Petermann, Noeker & Bode, 1987; Stam, Grootenhuis & Last, 2001; Warschburger & Petermann, 2002*). These are on the one hand personal resources and on the other hand social resources of the child/adolescent and his family. Social support within and outside the family, positive self perception, sense of coherence, optimism and a beneficial parenting climate are among the resources identified as having a protective effect on coping successfully with disease (*Bettge & Ravens-Sieberer, 2003*).

Stable coping factors, both short and long-term, have been found in the majority of families of young cancer patients (*Kupst, 1992; Kazak et al., 2003*). The following factors have been identified as promoting coping: Familial integration und 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 et al., 1994; Horwitz & Kazak, 1990; Kazak et al., 1997; Patenaude & Kupst, 2005; Woodgate, 1999 a, 1999b*).

The following factors are summarised in an overview of various studies (*Kusch et al., 1996*): extended families, cohesion of family members, families with several children, socially integrated families, previous experiences of disease and death that have been processed positively, optimistic attitude of the family, religiosity of the family, open communication within the family, competent parenting style, proximity to the clinic.

Protective factors that have been identified for the siblings of childhood cancer patients include: open and honest communication about the disease (*Eiser & Havermans, 1994*), involving siblings in the process of the disease and patient care, and adequate information about the disease and treatment (*Houtzager, Grootenhuis & Last, 1999; Zeltzer et al., 1996*).

The following factors play an important role in everyday clinical practice:

Personal resources	Social resources
<ul style="list-style-type: none"> - optimistic attitude - favourable disease concepts - positive experience of working through disease and death - active problem-solving fighting spirit - search for information, openness for contact and creativity - positive self-perception, self-efficacy - psychological stability - religiosity and finding meaning 	<ul style="list-style-type: none"> - cohesion of family members - socially integrated family - open communication within the family - emotionally positive parent-child relationship - competent parenting style - secure economic and legal circumstance - ability to seek and accept social support

Indicators for the adjustment of the individual or family to the disease and its consequences and for further psychosocial development emerge from the complex interaction of demands, stressors and resources. They are fundamental for the planning of psychosocial treatment.

4 DIAGNOSTICS

Psychosocial diagnosis serves to evaluate individual stressors and to identify coping and adjustment strategies available to the sick child and his social sphere. It should take place at the beginning, during and at the end of treatment. For individual problems, a special diagnosis using appropriate standardised procedures should be carried out in order to obtain a differentiated evaluation of the relevant problems associated with the disease. The use of questionnaires and tests is oriented towards the results of the psychosocial anamnesis and examination. The procedures listed here reflect the current level of knowledge. They represent a recommendation.

4.1 Diagnostic areas and procedures

4.1.1 INITIAL DIAGNOSTICS	
<ul style="list-style-type: none"> Initial contact on evaluation 	<ul style="list-style-type: none"> Presentation of psychosocial care provision Start of detailed diagnosis
Areas of examination	Examination methods
Psychosocial anamnesis <ul style="list-style-type: none"> Sociodemographic data History of disease Patient's and family's anamnesis Evaluation of resources Coping with disease 	<ul style="list-style-type: none"> Examination Basic documentation (e.g. PSAPOH data sheet) Profile of resources and stressors Family genogram Questionnaire on health-related quality of life
→ Complementary diagnostics (patient) on suspicion of psychological disturbance	<ul style="list-style-type: none"> in-depth diagnostics if necessary, consultation of specialist psychologist/psychiatrist
→ Complementary diagnostics (family) on suspicion of social conflict situation	<ul style="list-style-type: none"> Interview (e.g. concerning socio-economic situation)

4.1.2 ONGOING DIAGNOSTICS	
<ul style="list-style-type: none"> phase-specific and disease-oriented in critical situations (e.g. medical complications) in transition situations (e.g. preparing for a transplant) 	
Areas of examination	Examination methods
<ul style="list-style-type: none"> Coping, compliance Motivation for therapy Phase-specific issues Total family stress Psychol. results of child/adolescent 	<ul style="list-style-type: none"> Screening, exploration Repetition of elements of initial diagnosis if necessary, special diagnostics

4.1.3 FINAL DIAGNOSTICS	
Areas of examination	Examination methods
<ul style="list-style-type: none"> Status survey of psychosocial situation <ul style="list-style-type: none"> Adjustment to disease (patient and family) Home care situation Psychol. results of child/adolescent 	<ul style="list-style-type: none"> Screening, exploration Profile of resources and stressors Questionnaire on health-related quality of life
<ul style="list-style-type: none"> Diagnostics for initiating inpatient/outpatient rehabilitation measures 	<ul style="list-style-type: none"> Detailed psychosocial examination of patient and reference persons, Psychosocial referral report/opinion (e.g. special report forms of rehabilitation clinics)
<ul style="list-style-type: none"> Assessment of support needs educational/workplace reintegration 	<ul style="list-style-type: none"> Evaluation of cognitive performance incl. assessment of learning difficulties, social and emotional integration ability (see "special diagnostics")
→ Complementary diagnostics (patient) on suspicion of inadequate adjustment/ psychological disturbance	<ul style="list-style-type: none"> see "special diagnostics" if necessary, referral to child psychiatry practice, child psychotherapy practice, counselling centres
→ Complementary diagnostics (patient) in case of developmental, intelligence- and neuropsychological disturbances	see "special diagnostics"

4.1.4 SPECIAL DIAGNOSTICS

Developmental, performance and behavioural diagnostics / neuropsychology / quality of life

- Special high-risk groups (e.g. ALL/AML patients undergoing cranial radiotherapy, intrathecal chemotherapy, brain tumour patients, patients with stem cell transplants)
- Special issues and for clarification of suspected diagnoses

Areas of examination	Examination methods
Intelligence	<ul style="list-style-type: none"> - Kaufman Assessment Battery for children (K-ABC) - Hamburg-Wechsler intelligence test for children (HAWIK III) - Hamburg-Wechsler intelligence test for adults (HAWIE-R) - Snijders-Oomen non-verbal intelligence test (SON-R) 2 ½-7, 5 ½-17 - Coloured Progressive Matrices (CPM) - Standard Progressive Matrices (SPM)
Visual motor skills	<ul style="list-style-type: none"> - Developmental Test of Visual-Motor Integration (VMI) - Developmental Test of Visual Perception (DTVP-2/-A)
Fine motor skills	<ul style="list-style-type: none"> - Motor performance series (MLS) - Purdue Pegboard (Minnesota Dexterity Test)
Perception, memory	<ul style="list-style-type: none"> - Fragmented picture test (FBT)
Attention and concentration	<ul style="list-style-type: none"> - Differential performance test-KE / KG (DL-KE / KG) - Test d 2 - Test battery for attentional performance (TAP) - Continuous Performance Test (CPT)
Development	<ul style="list-style-type: none"> - Development test 6 months to 6 years (ET 6-6) - Bayley Scales of Infant Development (BSID-II) - Vienna development test (WET) - Munich functional development diagnostics (MFED)
Health-related quality of life	<ul style="list-style-type: none"> - Questionnaire on child and adolescent quality of life (KINDL-R, CAT-Screen) - Questionnaire on adolescent quality of life (LKJ) - Paediatric Quality of Life Questionnaire (PEDQOL) - Health questionnaire (SF 36) - Health Utility Index (HUI) - Ulmer quality of life inventory for parents (ULQIE) - Familial stress questionnaire (FaBel) - Child Health Questionnaire (CHQ-PF 28) – short version for parents
Behavioural / psychosocial functionality	<ul style="list-style-type: none"> - Strengths and Difficulties Questionnaire (SDQ-Deu) - Child Behaviour Checklist (CBCL), Youth Self Report (YSR) - Anxiety questionnaire for schoolchildren (AFS) - Depression inventory for children and adolescents (DIKJ) - Thematic apperception test (TAT) - Sceno-Test ; Animal family drawing test (FIT)

5 INDICATION AND LEADING SYMPTOMS

The indication for psychosocial interventions is based on the considerable emotional burdens on the patient and the family, arising from confrontation with a serious, life-threatening disease. These stress factors can lead to reactions that vary in form and degree. The trauma of a life-threatening illness presents as an intensive experience of discrepancy between the threatening situational factors and individual coping capabilities, and is associated with feeling of helplessness and defenceless surrender (*Fischer & Riedesser, 1999*). The reaction of a child or his relatives to a severe, life-threatening illness should not principally be interpreted as a psychological disturbance, but the intensity of symptoms can turn it into one.

In paediatric oncology we therefore usually refer to so-called *persistent stress reactions* - i.e. adequate stress reactions that are appropriate to the event or occurrence that caused them with regard to expression and intensity (*Schreiber-Gollwitzer & Gollwitzer 2007*) - as distinct from the pathological stress reactions and adjustment disorders in terms of ICD 10 and DSM IV (*Dilling et al., 2004*). They are 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 referred to as distress (*Bultz & Holland, 2006; NCCN 2007*). Another model refers to the concept of 'Chronic Sorrow' (*Ahlström, 2007*).

Even if this persistent stress reaction does not constitute a pathological event in the narrow sense, an often considerable need to take action and give support exists 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, the subjective perception of stress and knowledge of the personal characteristics of the person concerned, is fundamental.

The following diagram illustrates the diagnostic distinction between persistent stress reactions, acute stress reactions and adjustment disorders in ICD 10.

Decision tree for differential diagnosis of reaction to a severe stressor or adjustment disorder

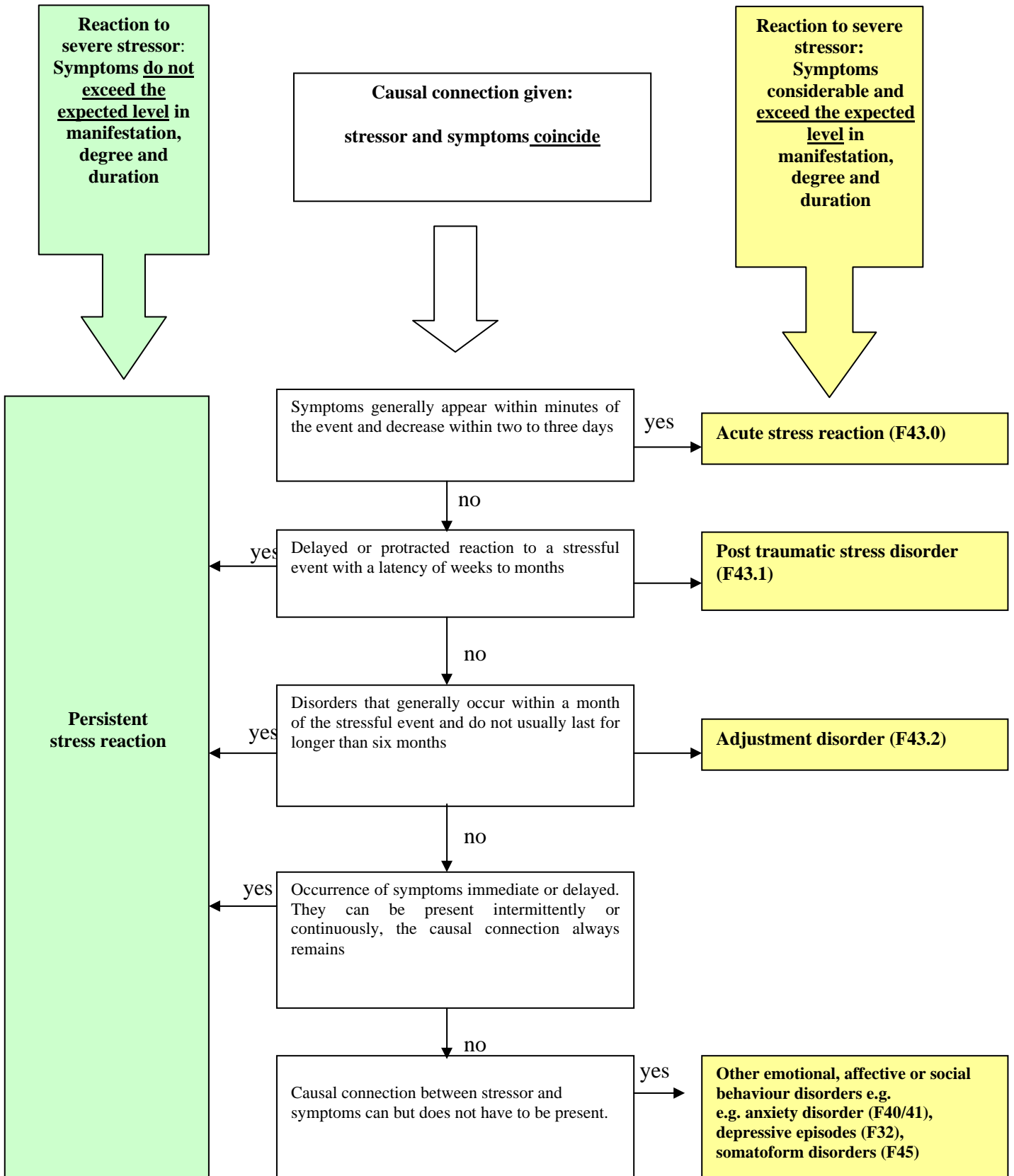


Fig.1: Diagnostic decision tree (212)

5.1 Leading symptoms

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

The distinction between an adequate and an excessive reaction of the patient to a severe stressor is not always clear.

The AWMF guidelines for child and adolescent psychiatry contain treatment paths for different disorders which should also be taken into consideration in the planning of psychosocial treatment (http://www.uni-duesseldorf.de/AWMF/II/II_028.htm). (149)

Fig. 2 explains the diagnostic and differential diagnostic considerations for the patient's treatment in an algorithm. The evaluation of the appropriateness of the reaction should take into account the severity of the stress factor on the one hand and the subjective experience of stress and knowledge of the individual's personality characteristics on the other hand (*Cox, 1994; Resch, 1999*).

Indication for psychosocial care of the patient in paediatric oncology/haematology

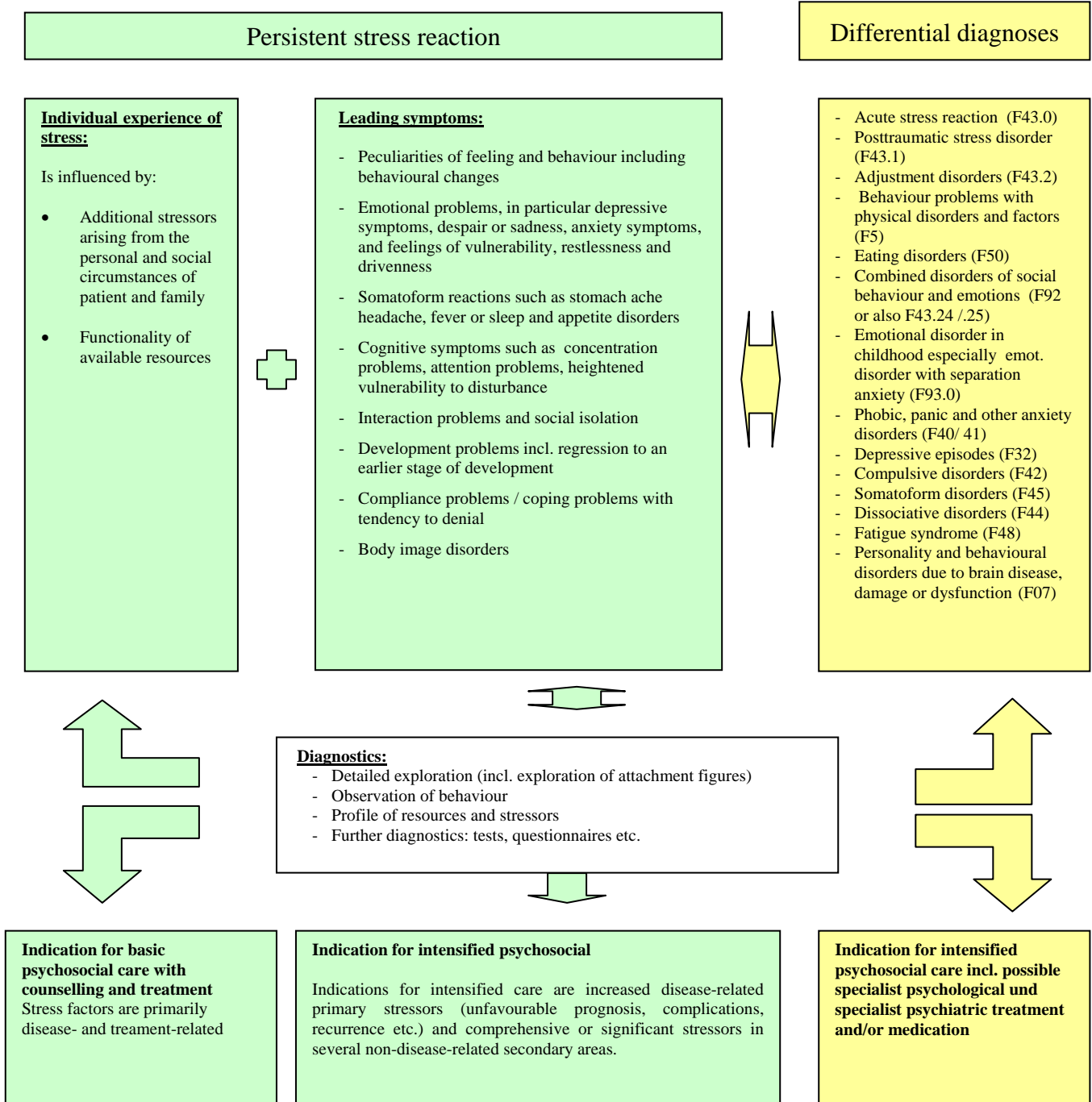


Fig. 2. Indication for psychosocial care of the patient in paediatric oncology/haematology (212)

The diagnoses and leading symptoms used in the algorithm are explained below.

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)

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 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 at all levels. Regression to an earlier stage of development is also possible (bed-wetting etc.).

Compliance problems (e.g. in dealing with medical demands)

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”. Knowledge of the cause for this behaviour is crucial.

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

The patient experiences his own appearance and the physical changes as stressful and focuses his 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 well-defined areas of 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 calm occur. Frequently, a massive overstrain lies behind the development of these physical symptoms. In clarifying these symptoms, the possibility that they are side-effects of the oncological therapy, for example pain that the patient experiences as particularly invasive and stressful, should be excluded. Similarly, rarely occurring complications of treatment should be excluded.

Social isolation due to prolonged stays in hospital (e.g. for SCT)

Frequent and sometimes prolonged stays in hospital and the resulting absence from school and the necessary withdrawal from social contacts due to immunosuppressive therapy limit the child's relationships with friends, school- 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

A spectrum of potential social, economic and cultural problems and problem constellations ranging from economic difficulties to unresolved residency status, from divorce to a family member needing constant care etc. These can be 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 etc.)

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

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

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

Acute stress reaction (e.g. threatened decompensation, crisis reaction)

A temporary disorder of considerable severity which occurs due to an extraordinary physical or mental strain 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)

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 (e.g. chronic traumatisation)

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

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

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

* Alongside the indication for treatment of the patient, 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 disease. (*Vance & Eiser, 2004*).

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 his siblings, and in maintaining the family's socio-economic basis. The family's socio-economic situation is a high risk factor in adaptation to the disease (*Kazak, 1992*).

The indication for the *psychological care of relatives* is given in the case of serious emotional problems in coping with the disease and treatment and high level of suffering due to the latent threat of death and fear of progredience. 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)
- Family breakdown due to separation and divorce (Z63)
- Problems related to lifestyle (Z72)
- State of total exhaustion (Z73)
- Family history of mental and behavioural disorders (Z81) *

(The passage marked from * to * has been expanded by the steering group to explain the indication for care of relatives)

5.2 Indication for basic and intensified psychosocial care

The findings obtained in the diagnostic processes lead to an assessment of the need for psychosocial care. The indications for **basic psychosocial care** are primarily stressors that result from the disease and the treatment, the so-called disease-related stressors. Non-disease-related secondary factors in the sense of (pre-existing) psychological problems of one or more family members or unfavourable sociocultural or psychosocial conditions are less relevant. The course of the disease and treatment is also characterised by critical points in time when an increased need for psychosocial care over and above the basic provision can arise.

Indications for **intensified care** are increased disease-related primary stressors (unfavourable prognosis, complications, recurrence etc.) 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 diminished psychosocial resources, unfavourable sociocultural conditions etc., or there may be substantial secondary psychological stressors in the sense of emotional disturbances of the patient or one or more members of the family.

High-risk groups for intense stress are for example:

- Patients with a poor or unclear prognosis
- Patients with recurrence of cancer
- Brain tumour patients
- Patients who require radical surgery, (e.g. amputation)
- Patients who receive a stem cell transplant (SCT)
- Patients in critical and transition situations
- Palliative care patients
- Patients with psychological problems or additional illnesses
- Families with a high level of non-disease-related psychosocial stressors
- Families in which a member is mentally or physically ill
- Single parents

6 THERAPY / INTERVENTIONS

6.1 Basics

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 patient and his relatives (see chapter 2).

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

6.1.1 Psychosocial interventions

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

(In italics the current OPS-Codes in the G -DRG-System, relevant to medical billing)

- Information, orientation / *Familien- Paar- und Erziehungsberatung*
- Psychosocial diagnostics / *(Neuro-) psychologische u. psychosoziale Diagnostik*
- Supportive* therapy / *Supportive Therapie*
- Crisis intervention / *Integrierte Psychosoziale Komplexbehandlung*
- Social counselling and support / *Sozialrechtliche Beratung*
- Family and couples counselling, parental guidance/ *Familien- Paar- und Erziehungsberatung*
- Preparation, follow-up and support for medical measures/ *Psychotherapie*
- Psychotherapy (e.g. conversational therapy, family and behavioural therapy, psychodynamic therapy) / *Psychotherapie*
- Relaxation techniques (e.g. breathing techniques, autogenic training, imagination) / *Psychotherapie*
- Artistic therapy (e.g. music and art therapy) / *Künstlerische Therapie*
- Play and creative pedagogy / *Supportive Therapie*
- Palliative support / *Palliativmedizinische Komplexbehandlung*
- Planning and initiation of outpatient and inpatient follow-up care and rehabilitation / *Nachsorgeorganisation*
- Organisation of reintegration in school and workplace / *Nachsorgeorganisation*
- Educating patients and relatives/ psychoeducation / *Schulungen*
- Coordination of inpatient and outpatient psychosocial care / *Nachsorgeorganisation*

* "Supportive therapy" refers to targeted therapeutic procedures of variable duration that are oriented towards the current disease problems of the patient and his family. The focus is on the emotional processing of the diagnosis and course of the disease, on confronting the disease, its consequences and the necessary therapy as well as the familial, individual, educational, workplace and social problems that result from it.

6.1.2 Basic and intensified psychosocial care

All paediatric oncology patients should receive basic psychosocial care. In cases of great psychosocial stress, basic care is complemented by intensified care in accordance with the indication. Outreach psychosocial care is given particularly at the beginning of treatment and in crisis situations. Patients and relatives are contacted by a member of the psychosocial service, and an offer of care is made within a short time frame. The degree of stress is subject to considerable fluctuation and is recorded continuously during the course of treatment.

Basic care should comprise:

Diagnosis

- Initial contact immediately after diagnosis/admission
- Psychosocial anamnesis (in the first 4 weeks)
- Social and psychological counselling
- Psychoeducative measures
- Ongoing diagnostics oriented towards the specific disease
- Supportive therapy / crisis intervention
- Individual and group artistic activities
- Play and creative pedagogy
- Organisation of rehabilitation measures
- Final interview
- Offer of aftercare/ follow-up

End of therapy

Intensified psychosocial care should be implemented in the case of severe stress and risk factors, and limited psychosocial resources. An individual treatment plan is drawn up. The interventions in this area are offered with higher frequency and continuously. They can focus on different aspects of care (*Schreiber-Gollwitzer et al., 2003*).

Intensified care should comprise:

1. Higher frequency interventions of basic care
2. Further interventions:
 - Family, couples and parenting counselling
 - Relaxation techniques
 - Art therapy
 - Psychotherapy
 - Palliative support

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*. In the context of psychosocial care, crisis intervention means a temporary intervention in situations or circumstances that are threatening, or cause significant stress or trauma. The interventions listed in tables 6.2.1. to 6.2.5 can be used as required by the event.

The following tables summarise potential disease-related stress factors, the demands made on patients, parents and siblings and their stress reactions, and also the focus on psychosocial interventions in individual phases. The tables are oriented to observations in everyday clinical practice. Epidemiological data of adequate quality are not available; the systematic recording of psychosocial factors, for example in the context of oncological registers/therapy optimisation studies, would be desirable.

6.2.1 Diagnosis phase / Beginning of therapy

Stress factors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p>Patient</p> <ul style="list-style-type: none"> • Strange, frightening surroundings • Unfamiliar, painful and frightening examinations • Intensive implementation of a diagnostic programme • Confrontation with the life-threatening nature of the diagnosis • Loss of parental security • Sudden change in entire circumstances due to admission to hospital e.g. separation from social and school environment • Abrupt, sometimes emergency beginning of treatment <p>Parents</p> <ul style="list-style-type: none"> • Unclear preliminary diagnoses, lengthy history of disease • Uncertainty, waiting for results • Confrontation with the life-threatening diagnosis and the imminent therapy • Uncertain treatment outcome • Existential collapse of the family's world • Lack of prerequisites for understanding disease and treatment • Discrepancy in coping styles within the family • Insufficient language skills • Uncertainty regarding existing systems of meaning and belief • Alien cultural environment <p>Siblings</p> <ul style="list-style-type: none"> • Unclear, threatening situation • Sudden change in everyday life • Sudden separation from family members 	<p>Patient</p> <ul style="list-style-type: none"> • Understanding the meaning of the life-threatening nature of the disease • Enduring anxiety and uncertainty • Admission and understanding information on the disease and treatment • Enduring the (unexpressed) worries and tensions of the parents • Cooperation with diagnostic and therapeutic procedures • Dealing with changes in everyday life (strange surroundings, people, procedures)) <p>Parents</p> <ul style="list-style-type: none"> • Development of hope, confidence and trust in the medical treatment • Giving the sick child support, security and reliable closeness • Making decisions about the treatment • Gaining orientation in the processes of the treatment system • Acquiring knowledge of the disease and treatment • Working through diagnosis, therapy and prognosis • Parents' double role of giving and needing support • Controlling and coping with own emotions • Honest discussion of the diagnosis within the family, age-appropriate information for siblings • Restructuring of family's everyday life • Giving information to relatives, school, employer <p>Siblings</p> <ul style="list-style-type: none"> • Dealing with the threatening situation 	<p>Patient</p> <ul style="list-style-type: none"> • Disease symptoms, pain • Irritation and uncertainty due to hospital and treatment • Fear of separation from the parents • Age-specific reactions to the diagnosis e.g. fear of dying, helplessness, anger, grief, despair • Inability to understand what is happening • Resistance to threatening feelings <p>• Psychological disorders see ICD-10 Chapter V (F)</p> <p>Parents</p> <ul style="list-style-type: none"> • Premonitions and worries • Diagnosis shock and fear of the future • Overwhelmed by feelings (fear of the child's death, impotence, helplessness, anger, grief, feelings of guilt, despair,) • Resistance to threatening feelings, numbness, denial • Limited ability to absorb information, confusion • Fears that their whole world will collapse, fear of losing control • Concern for siblings • Overtaxed by complicated medical issues • Need for information/avoidance of information • Effort at maintaining appearance of naturalness and strength towards the children • Psychological disorders see ICD-10 Chapter V (F) <p>Siblings</p> <ul style="list-style-type: none"> • Fear for the sick sibling • Profound feelings of uncertainty due to changes in the family • Separation anxiety <p>• Psychological disorders see ICD-10 Chapter V (F)</p>	<p>Psychosocial diagnostics</p> <ul style="list-style-type: none"> • Obtaining history • Recording understanding of the disease by the patient and his parents, clarifying unanswered questions • Evaluating stress factors and resources • Clarifying individual need for care • Neuropsychological diagnostics in case of threatened CNS impairment • Identification of language and cultural barriers <p>Information, help with orientation</p> <ul style="list-style-type: none"> • Additional information on disease, treatment and consequences of treatment • Handing out (age-specific) written and audiovisual information for patients, siblings and parents that meets the basic requirements for patient information material (e.g. DISCERN, www.discern.de) • Support in processing complex information • Information for teachers and fellow students of the patient and siblings • Encouraging patient and relatives to actively seek information <p>Supportive therapy</p> <ul style="list-style-type: none"> • Strengthening parents' confidence in their ability to learn and cope • Explaining that strong emotional reactions (fear, impotence, helplessness, anger, feelings of guilt) are normal • Help in taking the focus from fear of death to the struggle for life • Promoting cooperation during medical procedures (role-play, relaxation, distraction) <p>Family, couples and parenting counselling</p> <ul style="list-style-type: none"> • Supporting family members in dealing with the emotional reactions to the medical diagnosis • Counselling family members so they can support the patient in frightening and painful medical and nursing procedures • Encouraging open communication <p>Play and creative pedagogy</p> <ul style="list-style-type: none"> • Creation of an atmosphere that promotes trust, offering a continuing relationship • Occupying children during consultations and treatment planning, lightening parents' load • Giving orientation in connection with rooms, staff etc. <p>Social welfare counselling and support</p> <ul style="list-style-type: none"> • Counselling and help in reorganising day-to-day life and in claiming social benefits (employment situation, home-helps, care allowance, travelling expenses etc.) • Help in arranging for an attachment figure to accompany the patient • Arranging for schooling at home and in the clinic

6.2.2 Treatment phase

Stress factors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p>Patient</p> <ul style="list-style-type: none"> • Prolonged and frequent stays in hospital • Long waiting times in hospital • Separation from other family members • Loss of personal privacy while in hospital • Diagnostic procedures, e.g. LP, MRT, BT • Numerous therapeutic procedures, e.g. taking tablets, infusions, mouth care • Changes in appearance, e.g. hair loss, Cushing, cachexia • Side effects, e.g. mucositis, fever, nausea, pain, physical weakness • High danger of infection • Unclear, suspicious symptoms • Serious physical impairments/complication e.g. necessity for intensive care • Witnessing recurrence, dying and death of fellow patients • Isolation in hospital, e.g. in case of infectious pathogens • Mood swings due to medication, e.g. corticosteroid therapy • Loss of physical integrity • Temporary or permanent mental impairment or personality changes, e.g. organic psychosyndrome • Significant limitation of independence and autonomy • Lack of contact to friends, isolation • Exclusion from educational-vocational development <p>Parents</p> <ul style="list-style-type: none"> • High care demands on the parents • Frequent changes in treatment modalities • Insufficient sleep, rest and recreation 	<p>Patient</p> <ul style="list-style-type: none"> • Learning to understand the need for medical and nursing procedures • Development of a hopeful attitude • Getting used to everyday life in hospital • Active cooperation with medical and nursing procedures • Coping with repeated painful or frightening procedures • Putting up with diverse side effects • Coping emotionally with physical changes, making contacts in spite of visible stigmas • Expressing feelings and state when undergoing medical and nursing procedures • Dealing with the loss of social contacts and age-appropriate leisure activities, e.g. sport, going to the disco • In adolescents, dealing with the loss of independence and autonomy • Developing new interests and hobbies <p>Parents</p> <ul style="list-style-type: none"> • Patient is accompanied by one of the parents in hospital • Willingness to learn nursing procedures and take on responsibility • Flexible adjustment of the family routine to the course of treatment, e.g. organising care for siblings • Change in interfamilial tasks and roles • Motivating the patient to cooperate actively, e.g. with regard to eating, drinking, taking tablets • Carrying out nursing procedures on their own at home • Constant supervision of the patient, observation of his state of health 	<p>Patient</p> <ul style="list-style-type: none"> • Fear of medical procedures • Anger and rebellion against medical procedures • Lack of cooperation / refusal e.g. to take tablets, blood samples, physical examinations • Fear that the disease is incurable, fear of late effects/fear of the future • Aversion to foods and smells • Feelings of shame and loss of self-esteem with regards to physical changes, e.g. changes to hair and skin, Cushing, cachexia • Desire for lasting physical contact with parents, fear of separation and loss • Grief at lack of contact with siblings, friends and schoolmates, homesickness • Disappointment at having to give up sport and hobbies • Grief at separation from or loss of pets • Emotional exhaustion, depressive mood • Feelings of dependence and impotence, helplessness, excessive adjustment • Aggression, anger, despair • Regressive behaviour • Social withdrawal • Disturbed sleep, nightmares • Denial non-acceptance of the life-threatening nature of the disease • In adolescents: termination of therapy <p>• Psychological disorders see ICD-10 Chapter V (F)</p> <p>Parents</p> <ul style="list-style-type: none"> • Fears that the disease is incurable, fear of late effects and progredience • Exhaustion, chronic stress, overtaxing due to multiple demands • Social withdrawal, isolation • Feelings of guilt, worries, search for a meaning • Aggressive behaviour and reproaches • Anticipatory grief • Depressivity, pessimistic attitude, suicidal tendency • Disturbed sleep, heart and circulatory problems and other symptoms 	<p>Supportive therapy</p> <ul style="list-style-type: none"> • Reducing fear and uncertainty • Promoting trust and confidence • Giving encouragement, strengthening ability to see healthy aspects • Supporting and mobilising individual resources, e.g. inner strengths and endurance • Strengthening inner-family cohesion • Motivation for active cooperation • Promoting the understanding of therapy, clearing up fantasies about disease • Arranging meetings with other parents to provide encouragement and exchange experiences <p>Information, help with orientation</p> <ul style="list-style-type: none"> • Providing more detailed age-appropriate information, e.g. on operations, radiotherapy, SCT (brochures, books, videos, DVD, CDs etc.) • Special counselling for adolescents, e.g. on questions of fertility, sperm donation • Psychoeducative groups, e.g. parents' evenings, information events • Support in processing complex information • Arranging other forms of care, e.g. school, pastoral care, ambulatory counselling centres <p>Psychosocial diagnostics</p> <ul style="list-style-type: none"> • Continuous recording of state, social situation and current need for care of patient and relatives • Clarifying presence of current stress and adjustment disorders • If psychological disorders are suspected, consultation with psychological/psychiatric specialist • Neuropsychological diagnosis in case of threatened CNS impairment <p>Social welfare counselling and support</p> <ul style="list-style-type: none"> • Support for self-help, personal responsibility and autonomy of the family • Inclusion of external help to lighten the family's load • Arranging financial support • Support in claiming benefits from public agencies • Coordination of different support offerings • Preparation and help for discharge to home and for reintegration in school/employment • Provision of aids and appliances and arranging support • Arranging contact to self-help groups, booster clubs, charities, DLFH et al. • Counselling and help in reorganizing everyday life • Advice on inpatient family-oriented rehabilitation measures, or rehabilitation measures specifically for adolescent patients / help with making applications <p>Family, couples and parenting counselling</p> <ul style="list-style-type: none"> • Promoting adaptation to the disease- and treatment-related changes in family life • Support in decision-making and in dealing with invasive treatments • Help in dealing with conflicting interests and different coping styles in the family system

<ul style="list-style-type: none"> • Additional financial expense, economic hardship • Threatened loss of job • Parents have little time for siblings • Strain on partnership • Discrepant coping styles in the family • Loss of social contacts to friends and colleagues, professional development, leisure, holidays etc. • Persistent emotional strain, fear of progredience • Loss of personal privacy while in hospital • Witnessing recurrence, dying and death of fellow patients <p>Siblings</p> <ul style="list-style-type: none"> • Loss of regular regime, security and parental attention • Changed role in the family • Accommodation away from home • Loss of carefree childhood 	<ul style="list-style-type: none"> • Ability to evaluate threatening physical symptoms • Empathy with the patient's situation • Clear and constant parenting style towards the sick child • Standing up for the individual needs of the child in the clinic and social environment (Advocacy) • Balancing the needs of all family members • Adequate emotional and social care of siblings • Providing siblings with ongoing information about the course of the disease • Adequate time for individual regeneration and time for the parental relationship • Expressing and dealing with parents' own feelings • Ability to accept support <p>Siblings</p> <ul style="list-style-type: none"> • Dealing with diminished parental time • Adjustment to changing care-givers and accommodation • Dealing with fears and loneliness • Scaling back their own needs, wishes and interests 	<ul style="list-style-type: none"> • Conduct that is damaging to health, e.g. overeating, smoking, delaying their own medical treatment • Communication problems in the family/lack of mutual support by parents • Disappointment and lack of understanding towards partner • Parents' refusal of social support • Overprotection, spoiling of the patient • Symbiotic behaviour, lack of detachment from patient • Neglect of the patient, e.g. unreliable administering of medication, insufficient fluids, hygiene • Excessive demands on or neglect of siblings • Psychological disorders see ICD-10 Chapter V (F) <p>Siblings</p> <ul style="list-style-type: none"> • Feeling unloved and insignificant • Fear of separation and loss • Helplessness, uncertainty • Ambivalent feelings, e.g. jealousy, feelings of guilt, anger, worry about the patient • Excessive adjustment, protecting parents • Forced independence • Aggressive behaviour • Withdrawal behaviour • Poorer grades in school • Child's fear of becoming ill himself • Psychological disorders see ICD-10 Chapter V (F) 	<ul style="list-style-type: none"> • Strengthening inner-family communication, promoting exchange between other parents and siblings affected • Encouragement to express and deal with feelings arising from the disease and treatment • Support in maintaining family, neighbourhood and friend relationships/strengthening the support network • Indicating the necessity of parents' regeneration with regard to sleep, rest, nutrition • Counselling on stress factors and supportive handling of siblings • Strengthening confidence in parenting ability • Encouraging parents and counselling for the social environment, enabling the patient to have contact with other children within the limitations of the treatment • Help in maintaining the patient's social network • Encouragement in taking up further psychiatric-psychotherapeutic treatment of the patient, parents and/or siblings where indicated. If necessary arranging treatment <p>Psychotherapy</p> <ul style="list-style-type: none"> • Measures accompanying treatment to help the patient and relatives cope with the disease • Psychological preparation before and after medical and nursing procedures e.g. LP, operations, SCT, radiotherapy, MIBG • Psychological measures for controlling and coping with pain • Measures for strengthening the autonomy and self esteem of the patient • Measures for reducing anxiety and stress, e.g. relaxation techniques, cognitive techniques, hypnotherapy • Help in dealing with family feelings of guilt and blaming • Measures for strengthening parents' competence in dealing with the patient and siblings • Support in dealing with questions concerning the meaning of life, spirituality, dying and death <p>Art therapies</p> <ul style="list-style-type: none"> • Opportunity to encourage emotional expression • Measures for strengthening self-confidence and autonomy • Working through conflict situations on the symbolic level (sounds, images) • Creative work to ease fears, provide distraction and reduction of pain, support in developing coping strategies • Opportunities for nonverbal communication and interaction • Promotion of creative abilities to support "healthy" aspects <p>Play and creative pedagogy</p> <ul style="list-style-type: none"> • Creation of an atmosphere that promotes trust • Playful processing of the treatment situation • Measures aimed at distraction, relaxation and pleasure • Activating the child's abilities and resources • Providing sense of achievement and promoting quality of life • Support of age-appropriate development • Measures aimed at promoting contact with other children • Organising patients' birthdays, holidays, seasonal festivals • Organisation of events (e.g. visit by clowns, theatre performances) • Individual activities for bed-ridden patients
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6.2.3 Remission phase/ Follow-up care

Stress factors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p>Patient</p> <ul style="list-style-type: none"> Maintenance therapy/ ambulatory therapy, e.g. for leukaemia Surveillance diagnostics Temporary and possibly permanent physical impairments e.g. wheelchair use Reduced general resilience and stamina, slowing down Late effects of the disease and treatment, e.g. organ damage, functional disturbances and disabilities Decline in cognitive performance, e.g. attention, memory, concentration Isolation due to loss of social contacts Altered appearance, physical and social stigmas Catching up on missed lessons Need to repeat a school year, changing schools <p>Parents</p> <ul style="list-style-type: none"> Loss of "security" due to the termination of therapy Loss of the protective hospital environment Lack of a guarantee of a cure/ fear of check-ups Unclear results, questionable signs of recidivity Uncertainty about reversibility of patient's emotional, mental and physical impairments Discrepant coping styles in the family Shock at recurrence and death of fellow patients <p>Siblings</p> <ul style="list-style-type: none"> Impossibility of restoring the family situation as it was prior to the illness 	<p>Patient</p> <ul style="list-style-type: none"> Strengthening physical and psychological resistance Development of autonomy and self-confidence Resumption of social relationships Coping with personal maturity – discrepancy with peers Catching up on age-specific experiences/development processes Reintegration in everyday life at school and work Coping with functional limitations and disabilities Processing traumatic experiences and integrating them in the life history <p>Parents</p> <ul style="list-style-type: none"> Development of confidence in the future Giving space to profound fears and learning to live with them Strengthening their own physical and psychological resistance Regaining a positive attitude to health Consolidating family cohesion and the partnership Regaining confidence in parenting competence Abandoning the "special role" as the sick child Normalising everyday life Coping with the patient's impairments and late effects Organisation of aids and measures of support <p>Siblings</p> <ul style="list-style-type: none"> Expression of their own interests and needs Normalisation of sibling relationships Dealing with personal maturity processes Regaining trust and confidence 	<p>Patient</p> <ul style="list-style-type: none"> Denial coping strategies Fear of recurrence Problems with self-esteem in case of disease-related physical, emotional and mental impairments Difficulties with (re-)integration in kindergarten and school, social anxiety Psychological disorders see ICD-10 Chapter V (F) <p>Parents</p> <ul style="list-style-type: none"> Chronic fear of recurrence, "Damocles sword" Fear of stressful check-up results Lasting uncertainty about the planability of life Emergence of emotions that have previously been controlled or suppressed Massive physical and emotional exhaustion Chronification of physical complaints, e.g. backache Long-term limitations to quality of life Psychological disorders see ICD-10 Chapter V (F) <p>Siblings</p> <ul style="list-style-type: none"> High expectations of a return to normality Desire for "compensation" Disappointment at the lasting changes in the family due to the illness Persistent jealousy, anxiety, feelings of guilt Problems at school Psychological disorders see ICD-10 Chapter V (F) 	<p>Supportive therapy</p> <ul style="list-style-type: none"> Encouraging the processing and integration of the disease-related experiences into the personal life history Supporting the patient in casting off his "sick role" Support in dealing with fear of relapse Promoting the autonomy and self-confidence of the patient <p>Psychosocial diagnostics / Final diagnostics</p> <ul style="list-style-type: none"> Final consultation on psychosocial situation Clarifying how individual members of the family process the disease Clarifying care at home Diagnostics for implementing in/outpatient rehabilitation measures Clarifying need for support for reintegration in school/employment Initiation of complementary diagnostics if inadequate processing of disease/ psychological disorder is suspected in the patient ⇒ referral to child and adolescent psychiatrist and psychotherapist Initiation of complementary diagnostics if developmental, intelligence impairments, neuropsychological impairments are suspected Clarifying needs and supporting patient on transfer to adult follow-up care <p>Organisation of follow-up care/ Social welfare support</p> <ul style="list-style-type: none"> Arranging family-oriented and/or neurological inpatient rehabilitation measures or arrangement of rehabilitation measures specifically for adolescent patients / help in claiming costs from insurance Counselling patients, parents, kindergarten teachers and school teachers on the patient's reintegration in kindergarten, school, training and employment Preparing for a return to school in cooperation with clinic tutors and home tutors and the child's school Preparation and arrangement of targeted remedial measures in case of developmental delays and late effects in the patient Preparation and drafting of sociomedical and psychosocial reports Arranging seminars, events and camps for patients, parents and siblings <p>Family, couples and parenting counselling</p> <ul style="list-style-type: none"> Counselling on age-appropriate emotional processing of the trauma of disease Counselling on dealing with late effects, e.g. loss of extremities, infertility, growth disturbances, diminished capacity Counselling on measures to aid the emotional and physical regeneration of the parents Counselling on parenting issues regarding patient and siblings Encouraging parents to support the independence of adolescent patients Encouraging or if necessary arranging further psychiatric-psychotherapeutic treatment of patient, parents and/or siblings if indicated

6.2.4 Recurrence / Progression

Stress factors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p>Patient</p> <ul style="list-style-type: none"> • Renewed diagnostics and therapy procedures • Worsening of chances of cure and survival • Renewed limitation of physical, social and mental development due to the treatment • Witnessing parents' shock and despair <p>Parents</p> <ul style="list-style-type: none"> • Confrontation with the lack of success of treatment so far • Worsening of chances of cure and survival • Taking decisions on invasive or experimental treatments • Dealing with intensified therapy regimes, invasive operations etc. • Collapse of individual and family life plans • Discrepant coping styles in the family • Uncertainty concerning existing belief and meaning systems <p>Siblings</p> <ul style="list-style-type: none"> • Renewal of threatening situation and profound feeling of uncertainty • Threatened loss of the sibling • Witnessing parents' shock and despair 	<p>Patient</p> <ul style="list-style-type: none"> • Accepting the renewed treatment while knowing about the stressors associated with it • Dealing with prolonged difficult living conditions and limitations • Dealing with loss of control and fear of death <p>Parents</p> <ul style="list-style-type: none"> • Regaining hope • Dealing with worse prognosis • Absorbing and processing complex information • Renewed adjustment of family life to the treatment situation • Open communication about prognosis and further treatment possibilities • Renewed building of trust in medical treatment and personnel • Building up an appropriate perspective on the future • Mobilising new resources • Motivating and encouraging the patient for the new therapy • Open communication inside and outside the family, age-appropriate information for siblings <p>Siblings</p> <ul style="list-style-type: none"> • Dealing again with the threatening situation and profound feeling of uncertainty • Dealing with increased anxiety and grief • Increased scaling back of own needs regarding parents and siblings 	<p>Patient</p> <ul style="list-style-type: none"> • Fear of death • Profound uncertainty and emotional instability • Loss of faith in the treatment and hope of cure • Significant separation anxiety • Regressive behaviour • Demanding, dominant behaviour, low tolerance of frustration • Aggressive behaviour towards parents and siblings • Child protects parents from his own fears • Refusal of treatment procedures <p>• Psychological disorders, see ICD-10 Chapter V (F)</p> <p>Parents</p> <ul style="list-style-type: none"> • Shock, existential anxiety • Doubts about choice of medical treatment so far, loss of trust • Feelings of guilt or blaming • Unstable emotions (fluctuating between anger, despair and hope) • Exaggerated optimism or pessimism regarding the course of the disease • Exhaustion, weakness, inability to act • Resignation, anticipatory grief • Psychosomatic complaints • Increased resort to alternative/adjunct treatments, e.g. healer • Spoiling of the patient / problems with setting boundaries • Withdrawal from the patient • Symbiotic mother-child relationship <p>• Psychological disorders, see ICD-10 Chapter V (F)</p> <p>Siblings</p> <ul style="list-style-type: none"> • Fear of the sibling's death • Loss and separation anxiety <p>• Psychological disorders, see ICD-10 Chapter V (F)</p>	<p>The spectrum of psychosocial interventions is as for the diagnosis and treatment phase.</p> <p>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>Areas of intervention are:</p> <ul style="list-style-type: none"> • Supportive therapy • Information, help with orientation • Family, couples and parenting counselling • Social welfare support • Psychotherapy • Art therapies • Play and creative pedagogy
<p>For further stress factors see initial treatment</p>	<p>For further demands, see initial treatment</p>	<p>For further reactions see initial treatment</p>	<p>Interventions: see treatment phase</p>

6.2.5 Palliative phase / Death and dying

Stress factors	Demand on the patient/family	Stress reaction	Psychosocial interventions for patient and family
<p>Patient</p> <ul style="list-style-type: none"> • Confrontation with increasing deterioration of health • Symptoms of disease, e.g. pain, shortness of breath, bleeding • Loss of function in areas of everyday life • Physical decline, loss of strength • Experience of existential threat • Experience of separation, loneliness and isolation • Experiencing relatives' shock • Unanswered questions about dying and life after death <p>Parents</p> <ul style="list-style-type: none"> • Shock caused by the unavoidability of death • Feeling of uncertainty due to the imminent dying process • Confrontation with the child's increasing suffering • Extreme, unforeseeable strain, day and night • Discrepant coping styles in the family <p>Siblings</p> <ul style="list-style-type: none"> • Heightened perception of the family's grief and despair • Experiencing the attention focused on the dying child • Experiencing the changes in the health of the sick sibling • Incomprehensible, frightening life situation • Threatening fantasies about dying and death 	<p>Patient</p> <ul style="list-style-type: none"> • Dealing with symptoms • Recognising the increasing hopelessness • Dealing with emotional responses to the progression of the disease and the process of dying • Dealing with loss of control and fear of death • Hope of achievable goals (sympathetic closeness, comfort and pain relief) • Taking leave of family and friends • Recognising and expressing wishes • Making unfinished things possible • Filling the remaining time with life • Dealing with questions of the meaning of life • Finding images of transition <p>Parents</p> <ul style="list-style-type: none"> • Recognising the increasing hopelessness • Making a dignified death possible • Conveying closeness, security and mutual trust • Maintaining calm and openness • Leave-taking, allowing the dying child to go his way • Coping emotionally with fear, loss, pain and grief • Allowing the dying child to participate in life as much as possible • Recognising the needs of the child, understanding messages and signals • Realising the value of the moment in life, conscious planning for the remaining time • Dealing with questions on the meaning of life • Building "bridges" for remembering the child • Meeting everyday demands/ maintaining ability to function • Restructuring life circumstances • Recognising the siblings in their pain • Recognising the siblings' need for normality in life <p>Siblings</p> <ul style="list-style-type: none"> • Finding warmth and security • Allowing themselves to have conflicting feelings • Developing concepts on connection to the dying sibling after death 	<p>Patient</p> <ul style="list-style-type: none"> • Fear of isolation, separation anxiety • Fear of dying, fears of death • Feelings of meaninglessness, impotence, despair • Switching between hope and fear • Emotional uncertainty, irritation • Inner withdrawal, silence, excessive protection of relatives • Protracted mental-emotional maturity • Symbolic expression of inner processes • Expression of need for peace and concentration on essentials • Expression of desire not to be forgotten <p>• Psychological disorders see ICD-10 Chapter V (F)</p> <p>Parents</p> <ul style="list-style-type: none"> • Strong emotional reactions e.g. anxiety, anger, yearning, feelings of guilt, despair • Helplessness, overtaxing • Physical and mental exhaustion • Fear of confrontation with questions concerning dying • Clinging to illusions, excessive denial • Couple and family conflicts, family disintegration • Insecurity in dealing with grief in regard to social environment • Fear of psychological breakdown and self-abandonment • Doubts about previous beliefs, loss of meaning in life <p>• Inability to restructure life/pathological grief</p> <p>• Psychological disorders see ICD-10 Chapter V (F)</p> <p>Siblings</p> <ul style="list-style-type: none"> • Contradictory feelings towards the dying sibling, e.g. jealousy, anger, shame, yearning, feelings of guilt • Attempt at replacing the dead child • Attention-seeking, e.g. through symptoms of illness <p>• Psychological disorders see ICD-10 Chapter V (F)</p>	<p>Supportive therapy / palliative care</p> <ul style="list-style-type: none"> • Continuous offering of care for patient and relatives • Help in planning the last phase of life • Supporting parents in decision for palliative care at home • Strengthening the parents' protective function in the process of leave-taking • Emphasising the importance of physical contact, presence of the parents and nonverbal communication • Encouraging an open, honest and protective handling of patient's and siblings' questions concerning dying and death • Changing the goal of hope, enhancing trust • Involving siblings in the dying and grieving process • Giving space for anticipatory grief, encouragement to allow the inexpressible • Support in coping with fear, loss, pain and grief • Taking individual, cultural and religious concepts and traditions in dealing with dying and death into account • Grief support for parents and siblings extending beyond the death of the child • Consultation with the relatives of the dead child in the clinic • Arranging contact to institutions and support groups for grieving relatives • Making leave-taking from people close to patient possible • Arranging rehabilitation for grieving families <p>Psychosocial diagnostics</p> <ul style="list-style-type: none"> • Continuous assessment of the state of the whole family, and their need for support <p>Social welfare support</p> <ul style="list-style-type: none"> • Finding out about resources for local palliative care • Promoting a supportive network for care at home • Collaboration in an interdisciplinary, multidisciplinary helpers conference / drawing up a plan for crises and emergencies • Arranging ambulatory care in the patient's home or if necessary, hospice care • Arranging psychosocial support for parents and attachment figures , e.g. services to lighten the family's load, ambulatory hospice services • Help in claiming financial aid and help in organising the last phase of life <p>Information, help with orientation</p> <ul style="list-style-type: none"> • Providing age-adequate information material on death and dying for the patient, parents, siblings, teachers and school classes etc. • Promoting understanding for the age-appropriate expression of "knowledge" of dying and childlike fantasies about life after death • Support in seeking rituals of leave-taking and remembrance <p>Art therapies / play and creative pedagogy</p> <ul style="list-style-type: none"> • Finding age-appropriate forms of leave-taking • Expression and creation of inner world and images <p>Complementary measures</p> <ul style="list-style-type: none"> • Making school visits, attendance in class and contact with fellow students possible • Support in spiritual and religious questions • Pastoral care of patient and family, memorial services • Help in organising and planning funerals

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 method chosen here for the scientific foundation of psychosocial interventions entails the omission of a considerable amount of thematically relevant scientific and clinical literature (compare evidence criteria table 3 in method report*). This refers to the exclusion of small series, anecdotal reports, and qualitative studies. In view of the relatively small case number of child cancer patients in relation to adult cancer patients, there is currently a lower number of psychosocial studies in paediatric oncology which fulfil the criteria of evidence levels I and II.

The following description of the evidence for psychosocial interventions is oriented toward the various *goals* of the interventions. Accordingly, the following subchapters describe interventions concerning information and help with orientation (chap. 6.3.1), interventions concerning emotional and social support (chap. 6.3.2), interventions for support in practical and financial issues (chap. 6.3.3), interventions aimed at securing the patient's cooperation and therapy (chap. 6.3.4), interventions for specific symptoms in the context of medical procedures (chap. 6.3.5), and interventions for prevention and rehabilitation (chap. 6.3.6).

For the sake of clarity and to avoid redundancy between the subchapters as far as possible, subchapters 6.3.1 and 6.3.2 include interventions for the whole family (especially parents and siblings of the cancer patient); in the remaining subchapters, the interventions refer exclusively to the patient himself.

The methodology of evidence research and editing is outlined in the method report.

All the studies considered in sections 6.3.1 bis 6.3.6. have been compiled in an overview in table 4 at the end of this chapter. A more detailed description and evaluation of the studies considered here can be found in the appendix to the guideline* as *background information to evidence in chap. 6.3*. The methodology of the evidence research and editing, which forms the basis for this chapter, is described in the method report.

* The method report and the appendix to the guideline are currently available only in German

6.3.1 Interventions providing information and orientation

Interventions aimed at enhancing knowledge, understanding and communication regarding the disease

It is not possible to draw evidence-based conclusions from the empirical studies available on the effectiveness of interventions aimed at enhancing knowledge, understanding and communication regarding cancer in children and adolescents (*Scott et al., 2004a; Scott et al., 2004b*). There are too few studies available, and some of these are methodologically flawed.

Evidence that interventions such as computer-based learning, art therapy and social or school reintegration programmes can lead to improvements in knowledge and understanding, and in psychological and social behaviour variables is derived from a review of studies on the improvement of children's and adolescents' communication about their own disease (*Scott et al., 2004a*). A review of studies on the enhancement of children's and adolescents' communication about cancer in relatives (*Scott et al., 2004b*) 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 et al., 2005*)¹.

In a review of the treatment of children and adolescents with diabetes, theory-based behavioural interventions have proved effective with regard to psychosocial outcomes such as self-efficacy and communication skills (*Hampson et al., 2000*).

¹ IHCA's 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.

Discussions with parents, groups providing information and help with orientation for the parents of child and adolescent cancer patients

It is not possible to draw evidence-based conclusions from the available empirical research on the effectiveness of psychosocial interventions aimed at information and orientation of the parents of child and adolescent cancer patients (*Heiney et al., 1989; Kazak et al., 2005*), as there are too few studies, and some of these are methodologically flawed.

However, there is expert-based consensus that psychosocial interventions aimed at supporting the parents of children and adolescents with cancer in processing complex information, for example in discussions and groups, have proved to be effective in providing information and orientation.

6.3.2 Interventions for emotional and social support

Psychosocial interventions for the reduction of emotional distress/improvement of quality of life for children and adolescents with cancer

Interventions for children and adolescents

It is not possible to draw evidence-based conclusions from the available empirical research on the effectiveness of psychosocial interventions for emotional and social support (*Barrera et al., 2002a; Heiney et al., 1988; Hinds, 2000; Pai et al., 2006*), as there are too few studies, and some of these are methodologically flawed.

With regard to indirect evidence, targeted, specific psychosocial interventions such as cognitive behaviour therapy and supportive therapy, but also psychopharmacological interventions have proved effective for depressive symptoms in adult cancer patients (less so for clinical depression) (*Williams & Dale, 2006; Rodin et al., 2007*). In a Cochrane review, psychosocial interventions (primarily in the form of groups) in cases of advanced cancer (breast cancer) proved to be effective in the short term at best; longer-term effects were not found (*Edwards et al., 2004*).

In a review of the treatment of children and adolescents with diabetes, theory-based behavioural interventions have proved effective with regard to psychosocial outcomes such as self-efficacy and communication skills (*Hampson et al., 2000*).

Interventions for parents

It is not possible to draw evidence-based conclusions from the available empirical research on the effectiveness of psychosocial interventions for the emotional and social support of the parents of child and adolescent cancer patients or other areas of care (*Chesney & Chesler, 1993; Heiney et al., 1989; Hoekstra Weebers et al., 1998; Sahler et al., 2002; Sahler et al., 2005*) as there are too few studies, and some of these are methodologically flawed.

Interventions for siblings

It is not possible to draw evidence-based conclusions from the available empirical research on the effectiveness of psychosocial interventions for the emotional and social support of the siblings of child and adolescent cancer patients or other areas of care (*Barrera et al., 2002b; Houtzager et al., 2001; Packman et al., 2004*) as there are too few studies, and some of these are methodologically flawed.

6.3.3 Interventions for support in practical and financial issues

There are no empirical studies on the effectiveness of psychosocial interventions in practical and financial issues. A study by *Goodenough et al. 2004* on the predictors for claiming social-work 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 (see guideline “Information on Social Benefits” by Deutsche Leukämie Forschungshilfe (DLFH), www.kinderkrebsstiftung.de).

6.3.4 Interventions for securing therapy and cooperation

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

A comparative study without a TAU control (*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.

6.3.5 Interventions for specific symptoms in the context of medical procedures

Pain

Short-term medical interventions

The effectiveness of psychotherapeutic procedures with regard to pain reduction and anxiety in short-term medical interventions such as BMB and LP has been investigated in several studies, including some comparative studies (*Broome et al., 1998; Chen et al., 1999; Dahlquist et al., 2002; Dahlquist et al., 2005; Hawkins et al., 1998; Jay et al., 1995, Jay et al., 1991, Jay et al., 1987; Katz et al., 1987, Kuttner et al., 1988, Liossi & Haitira, 1999; Manne et al., 1994; Manne et al., 1990; Milling & Costantino (2000) (SR), Sander-Wint et al., 2002, Smith et al., 1989), Wall & Womack, 1989; Wild & Espie (2004) (SR)*) However, these studies have methodological flaws so that it is not possible to draw clear conclusions from them. The value of these procedures in short-term interventions has been qualified by more recent anaesthesiological procedures.

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

Chronic and severe acute pain

The recommendations of German organisations for paediatric oncology and haematology, pain and palliative medicine - Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH), Deutsche Gesellschaft zum Studium des Schmerzes (DGSS) and 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 et al., 2003*).

In adult oncology, there is evidence that educative interventions for patients and their relatives (e.g. information on pain management or pain diaries) can lead to improvements in pain management (*Allard et al., 2001*).

Nausea and vomiting during chemotherapy

Several comparative studies of psychotherapeutic (e.g. hypnotherapeutic) interventions give weak evidence of a reduction of nausea and vomiting during chemotherapy (*Hawkins et al., 1995, Jacknow et al., 1994, Zeltzer et al., 1991, Reed et al., 1987*). The value of these procedures has been relativised by newer antiemetic pharmacotherapeutic interventions. Particularly for nausea and vomiting with a strong psychogenic component, interventions such as hypnotherapy, behaviour therapy or art therapy are of value.

6.3.6 Interventions for prevention and rehabilitation

School reintegration programmes, social competence training for children/adolescents with recently diagnosed cancer

No recommendation can be drawn from the empirical studies (*Katz et al. 1988, Katz et al., 1992, Varni et al., 1993*) as there are too few of them and some of the research available has significant methodological flaws and is not applicable to the German system. In practice, innovative approaches such as school reintegration programmes with visits to the child's own school have proved helpful. Interventions of this kind should be evaluated in further studies. After a long period of isolation due to illness, inpatient rehabilitation provides an opportunity for gaining experience in peer groups and supports reintegration into everyday social and family life.

In the view of the group of experts, social contacts and school attendance should be maintained or continued as early as possible in order to avoid social isolation.

Interventions for acquired brain damage

No recommendations can be given on the basis of the empirical studies that are available. Studies (*Butler & Copeland, 2002, Van't Hooft et al., 2005*) refer exclusively to attention and memory training. There are too few studies, and those which are available have clear methodological flaws. Further studies with a higher methodological quality are needed.

Even the reference to indirect evidence from two Cochrane reviews concerning cognitive rehabilitation of memory and attention deficits after strokes in adults does not allow evidence-based recommendations to be made. However, there was evidence of an improvement in attention performance (*Majid et al., 2000; Lincoln et al., 2000*).

For illnesses and therapies such as brain tumours, intrathecal chemotherapy, cranial radiotherapy and high dose chemotherapy that can impair neuropsychological functions (*Mulhern et al., 2004; Prassopoulos et al., 1996; Moleski, 2002*), appropriate testing of these functions should be carried out before the beginning of treatment. Follow-up of concentration, attention, perception and memory performance etc. is of great significance for the early recognition and treatment of possible deficits, and for reintegration in school. Remedial measures should be planned interdisciplinarily, be targeted to individual needs and begin as early as possible. Speech therapy, ergotherapy and educational therapy should be considered for example, and also out- and inpatient rehabilitation.

Table 4: Effectiveness of psychosocial interventions in the treatment of children and adolescents with cancer and their relatives: direct evidence and degree of evidence

	Studies/Reviews	Degree of evidence
6.3.1 Interventions aimed at information and aids to orientation		
Interventions for children and adolescents with cancer	Scott et al. (2004a) (SR)	III
	Scott et al. (2004b) (SR)	III
Interventions for the parents of children and adolescents with cancer	Heiney et al. (1989)	III
	Kazak et al. (2005)	II
6.3.2 Interventions aimed at emotional and social support		
Interventions for children and adolescents with cancer	Barrera et al. (2002a)	III
	Heiney et al. (1988)	III
	Hinds (2000)	III
	Pai et al., (2006) (MA)	III
Interventions for the parents of children and adolescents with cancer	Chesney & Chesler (1993)	III
	Heiney et al. (1989)	III
	Hoekstra Weebers (1998)	I
	Sahler et al. (2002)	II
	Sahler et al. (2005)	II
	Pai et al. (2006) (MA)	III
Interventions for the siblings of children and adolescents with cancer	Barrera et al. (2002b)	III
	Houtzager et al. (2001)	III
	Packman et al (2004)	III
6.3.3 Interventions aimed at support in practical and financial questions		
	Goodenough (2004)	III
6.3.4 Interventions aimed at securing therapy and cooperation		
Interventions for children and adolescents with cancer	Klosky et al. (2004)	Ib

Table 4 (continued)

		Studies/Reviews	Degree of evidence
6.3.5	Interventions in the case of specific symptoms within the framework of medical procedures		
	Interventions in the case of short-term medical interventions such as BMB and LP	Broome et al. (1998) Chen et al. (1999) Dahlquist & Pendley (2005) Dahlquist et al. (2002) Hawkins et al. (1998) Jay et al. (1995) Jay et al. (1991) Jay et al. (1987) Katz et al. (1987) Kuttner et al. (1988) Lioffi & Haitira (1999) Manne et al. (1990) Manne et al. (1994) Milling & Costantino (2000) (SR) Sander-Wint et al. (2002) Smith et al. (1989) Wall & Womack (1989) Wild & Espie (2004) (SR)	III III III III III III Ib II III III II III III III III III III III III III
	Interventions in the case of chemotherapy	Hawkins et al. (1995) Jacknow et al. (1994) Redd et al. (1987) Zeltzer et al. (1991)	III II III III
6.3.6	Interventions aimed at prevention and rehabilitation		
	School reintegration programmes, social competence training for children/adolescents with recently diagnosed cancer	Katz et al. (1988) Katz et al. (1992) Varni et al. (1993)	III III II
	Attention and memory training in case of acquired brain damage	Butler & Copeland (2002) Van't Hooft et al. (2005)	III II

Note Literature marked with SR denotes a systematic review. MA denotes a meta analysis. Literature not otherwise marked refers to single studies. Further details can be found in the text or appendix Background information on evidence chap. 6.3.

6.4 Interventions for specific disorders/symptoms

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.

The relevant diagnosis groups together with sources in German-speaking countries are given in table 5. Guidelines for other diagnosis groups are available on the AWMF internet portal (www.awmf-online.de) and at www.leitlinien.de.

Table 5: Relevant psychological disorders and treatment guidelines

Diagnosis (ICD-10)	Guideline (available online)	Further guidelines
Personality and behavioural disorders due to brain disease, damage or dysfunction (F07)	Leitlinien der Deutschen Gesellschaft für Kinder- und Jugendpsychiatrie und -psychotherapie (S1) ²	Leitlinien zur Diagnostik und Therapie von psychischen Störungen im Säuglings-, Kindes- und Jugendalter (BAG et al., 2006) ³
Depressive episode (F32)		
Phobic disorders (F40)		
Other anxiety disorders (F41)		
Obsessive-compulsive disorders (F42)		
Acute stress reaction (F43.0)	Leitlinien der Deutschen Gesellschaft für Kinder- und Jugendpsychiatrie und -psychotherapie (S1) ²	
Posttraumatic stress disorder (F43.1)		
	Leitlinien Psychotherapeutische Medizin und Psychosomatik (S2) ⁴	
Adjustment disorder (F43.2)	Leitlinien der Deutschen Gesellschaft für Kinder- und Jugendpsychiatrie und -psychotherapie (S1) ²	
Dissociative disorders (F44)		
Somatoform disorders (F45)		
Mixed disorders of conduct and emotions (F92)		
Emotional disorders with separation anxiety (F93.0)		

² http://www.uni-duesseldorf.de/AWMF/II/II_028.htm

³ 3rd revised version of S1-Guideline (see AWMF) published as a book (according to publisher, includes evidence degree for recommendations)

⁴ <http://www.uni-duesseldorf.de/AWMF/II/051-010.htm>

7 FOLLOW-UP CARE AND REHABILITATION

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. Findings of late effects and quality of life studies (*Langer et al., 2002; Zebrack & Chesler, 2002; Moore, 2005; Oeffinger & Hudson 2004; Robison et al., 2005; Calaminus et al., 2007*) point to physical, emotional, cognitive and social consequences of the disease and treatment for some of the patients.

Specific psychosocial follow-up care is particularly necessary for high-risk groups such as brain tumour patients (*Fuemmler, Elkin & Mullins, 2002; Freeman et al., 2004; Mulhern et al., 2004*), and patients who need invasive surgery (*Eiser & Grimer, 1990; Felder-Puig et al., 2006*) or a stem cell transplant (*Günter, Karle & Klingebiel, 2001; Phipps et al., 2004; Tsimicalis, Stinson & Stevens, 2005*). Parents and siblings also exhibit later psychosocial problems (*van Dongen Melmann, 1995; Kusch et al., 1999; Taib et al. 2003; Kazak et al. 2004*) and require needs-related therapeutic measures.

Screening of the further psychosocial development and, if necessary, the initiation of complementary therapeutic interventions should be carried out within the framework of follow-up care in the acute clinic. Links with inpatient and outpatient institutions involved in follow-up care and also preparation for the transfer to late follow-up care in adulthood are necessary.

Aspects of psychosocial follow-up care are:

- Psychosocial follow-up within the framework of multidisciplinary aftercare
- Early planning and coordination of outpatient and inpatient rehabilitation
- Preparation and organisation of targeted support for cognitive and late effects
- Measures to aid social, school and workplace integration
- Measures aimed at the prevention of psychosomatic, emotional and social late effects
- Organisation of rehabilitation measure for grieving relatives

In paediatric oncology and haematology in Germany, the implementation of special family and youth-oriented inpatient rehabilitation measures (148) are an integral part of the treatment concept. Psychosocial aspects have a high value in these measures (*Häberle et al., 1991; Häberle et al., 1997; Mathes, 1998; Leidig et al., 2001*). Patients with serious neurological and neuropsychological impairments receive out- and inpatient neurological rehabilitation measures (147).

Additional options for promoting the process of coping with the disease and psychosocial reintegration have been established with the setting-up of advice centres (e.g. www.kinderkrebsnachsorge.de; www.phoenikks.de), the organisation of information events for patients with a range of symptoms, family seminars and youth meetings (e.g. PSAPOH, GPOH, DLFH) (*Kröger & Lilienthal, 2001; Kröger, 2005*). Camps (e.g. www.waldpiraten.de) support the exchange of experiences between patients and siblings of all age groups. Grief seminars are offered for parents and siblings of children who have died.

A wide range of age-appropriate information material on various topics is available for patients, former patients and their relatives. Special note should be made of material produced by the German childhood cancer foundation, Deutsche Kinderkrebsstiftung (www.kinderkrebsstiftung.de), and individual treatment centres as well as several handbooks and brochures from English-speaking countries (*Keene et al., 2000; Shiminsky Maher et al., 2002; Eiser et al., 2004; Petersen Broyd et al., 2006*).

Psychosocial care is an established part of intersectoral, multidisciplinary follow-up care and accompanies children and adolescents with cancer and their families from the initial discharge from hospital to the home environment and long after the end of therapy.

CONCLUDING REMARKS

In the context of a holistic treatment concept in paediatric oncology and haematology, psychosocial care supports humanitarian aspects in patient care (*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 the patient and his 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 perspective of the child.

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

Further research is needed for the quality development of care concepts 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 considered in research. Adaptation and communication processes of children and adolescents with life-threatening diseases and their families 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 and adolescents with cancer and their families. It is meant as a contribution towards greater transparency and as a practical guide. The aim is to support the further development and specification of good clinical practice in paediatric oncology and haematology as a whole.

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