Psychosocial Care in Paediatric Oncology and Haematology

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Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH)
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LITERATURE
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) (128, 129, 192-197, 280-283) and by other organisations such as AAP, ACT, A(P)OSW, CAPO und ICCCPO (1, 5, 8, 9, 43, 276), 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, Askin & Moore, 2008).

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

<table>
<thead>
<tr>
<th>Psychosocial care in paediatric oncology follows an approach which ...</th>
<th>Used in similar form or in part in the following guidelines, consensus statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 ... is holistic</td>
<td>(9, 202, 216, 237)</td>
</tr>
<tr>
<td>2 ... is preventive</td>
<td>(10, 237)</td>
</tr>
<tr>
<td>3 ... is family-oriented</td>
<td>(6, 7, 8, 9, 43, 216, 237, 276)</td>
</tr>
<tr>
<td>4 ... is centred on the individual</td>
<td>(6, 7, 8, 10, 43, 216, 237, 272, 276)</td>
</tr>
<tr>
<td>5 ... is resource-oriented</td>
<td>(9, 43, 217, 237, 276)</td>
</tr>
<tr>
<td>6 ... is supportive</td>
<td>(9, 43, 216, 217, 237, 276)</td>
</tr>
<tr>
<td>7 ... is oriented towards the course of the disease</td>
<td>(8, 43, 216, 217, 237, 276)</td>
</tr>
<tr>
<td>8 ... is based on interdisciplinary cooperation</td>
<td>(7, 8, 9, 10, 43, 216, 237, 272, 276)</td>
</tr>
<tr>
<td>9 ... maintains certain basic ethical attitudes during treatment</td>
<td>(4, 43, 73, 276)</td>
</tr>
</tbody>
</table>

Note: The references relate to general psychooncological articles (8, 10, 43, 202, 216), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 9, 73, 85, 88, 217, 237, 272, 276).

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

<table>
<thead>
<tr>
<th>Structure und organisation</th>
<th>Used in similar form or in part in the following guidelines, consensus statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Psychosocial care as a standard in paediatric oncology</td>
<td>(8, 9, 43, 85, 88, 202, 237)</td>
</tr>
<tr>
<td>2 Conditions regarding personnel, time, premises and administration</td>
<td>(10, 43, 85, 88, 202, 237)</td>
</tr>
</tbody>
</table>

Note: The references relate to general psychooncological articles (8, 10, 43, 202), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 9, 73, 85, 88, 217, 237, 272, 276).

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

<table>
<thead>
<tr>
<th>Structure and organisation, quality assurance and documentation</th>
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</thead>
<tbody>
<tr>
<td>1 Qualification of psychosocial personnel</td>
<td>(8, 43, 237)</td>
</tr>
<tr>
<td>2 Further and advanced training</td>
<td>(10, 43, 202, 237)</td>
</tr>
<tr>
<td>3 Documentation</td>
<td>(8, 10, 43, 202, 237)</td>
</tr>
<tr>
<td>4 Evaluation and research</td>
<td>(43, 202)</td>
</tr>
</tbody>
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Note: The references relate to general psychooncological articles (8, 10, 43, 202, 216), and also specific articles on paediatric psychooncology (4, 5, 6, 7, 9, 73, 85, 88, 217, 237, 272, 276).

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 (Grave 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:

<table>
<thead>
<tr>
<th>Personal resources</th>
<th>Social resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>- optimistic attitude</td>
<td>- cohesion of family members</td>
</tr>
<tr>
<td>- favourable disease concepts</td>
<td>- socially integrated family</td>
</tr>
<tr>
<td>- positive experience of working through disease and death</td>
<td>- open communication within the family</td>
</tr>
<tr>
<td>- active problem-solving</td>
<td>- emotionally positive parent-child relationship</td>
</tr>
<tr>
<td>- fighting spirit</td>
<td>- competent parenting style</td>
</tr>
<tr>
<td>- search for information, openness for contact and creativity</td>
<td>- secure economic and legal circumstance</td>
</tr>
<tr>
<td>- positive self-perception, self-efficacy</td>
<td>- ability to seek and accept social support</td>
</tr>
<tr>
<td>- psychological stability</td>
<td></td>
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<tr>
<td>- religiosity and finding meaning</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Areas of examination</th>
<th>Examination methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial anamnesis</td>
<td>- Examination</td>
</tr>
<tr>
<td>- Sociodemographic data</td>
<td>- Basic documentation (e.g. PSAPOH data sheet)</td>
</tr>
<tr>
<td>- History of disease</td>
<td>- Profile of resources and stressors</td>
</tr>
<tr>
<td>- Patient's and family's anamnesis</td>
<td>- Family genogram</td>
</tr>
<tr>
<td>- Evaluation of resources</td>
<td>- Questionnaire on health-related quality of life</td>
</tr>
<tr>
<td>- Coping with disease</td>
<td></td>
</tr>
</tbody>
</table>

- Complementary diagnostics (patient) on suspicion of psychological disturbance
  - in-depth diagnostics
  - if necessary, consultation of specialist psychologist/psychiatrist

- Complementary diagnostics (family) on suspicion of social conflict situation
  - Interview (e.g. concerning socio-economic situation)

### 4.1.2 ONGOING DIAGNOSTICS

- phase-specific and disease-oriented
- in critical situations (e.g. medical complications)
- in transition situations (e.g. preparing for a transplant)

<table>
<thead>
<tr>
<th>Areas of examination</th>
<th>Examination methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Coping, compliance</td>
<td>- Screening, exploration</td>
</tr>
<tr>
<td>- Motivation for therapy</td>
<td>- Repetition of elements of initial diagnosis</td>
</tr>
<tr>
<td>- Phase-specific issues</td>
<td>- if necessary, special diagnostics</td>
</tr>
<tr>
<td>- Total family stress</td>
<td></td>
</tr>
<tr>
<td>- Psychol. results of child/adolescent</td>
<td></td>
</tr>
</tbody>
</table>

### 4.1.3 FINAL DIAGNOSTICS

<table>
<thead>
<tr>
<th>Areas of examination</th>
<th>Examination methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Status survey of psychosocial situation</td>
<td>- Screening, exploration</td>
</tr>
<tr>
<td>- Adjustment to disease (patient and family)</td>
<td>- Profile of resources and stressors</td>
</tr>
<tr>
<td>- Home care situation</td>
<td>- Questionnaire on health-related quality of life</td>
</tr>
<tr>
<td>- Psychol. results of child/adolescent</td>
<td></td>
</tr>
</tbody>
</table>

- Diagnostics for initiating inpatient/outpatient rehabilitation measures
  - Detailed psychosocial examination of patient and reference persons, Psychosocial referral report/opinion (e.g. special report forms of rehabilitation clinics)

- Assessment of support needs educational/workplace reintegration
  - 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
  - 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

<table>
<thead>
<tr>
<th>Areas of examination</th>
<th>Examination methods (current version)</th>
</tr>
</thead>
</table>
| Development          | - Bayley Scales of Infant Development (BSID-II)  
- Development test 6 month to 6 years (ET 6-6)  
- Vienna development test (WET)  
- Basis diagnostics of defined developmental disturbances in preschool age – Version II (BUEVA-II)  
- Wechsler Preschool and Primary Scale of Intelligence-III (WPPSI III) |
| Intelligence         | - Kaufman Assessment Battery for children (K-ABC)  
- Hamburg-Wechsler intelligence test for children (HAWIK IV)  
- Wechsler Adult Intelligence Scale (WAIS-IV)  
- Adaptive intelligence diagnostics - Version 2.1 (AID 2)  
- Intelligence- and development scales for children of 5-10 years (IDS)  
- Snijders-Oomen non-verbal intelligence test (SON-R) 2 ½-7, 5 ½-17  
- Coloured Progressive Matrices (CPM)  
- Standard Progressive Matrices (SPM) |
| Neuropsychological Screening | - Neuropsychological developmental screening (NES)  
- Neuropsychological screening for children 5-11 years (NPS 5-11)  
- Basic cognitive performance COGBAT |
| Attention and concentration, processing speed | - Test for concentration and executive functions for preschool children (KHV- VK)  
- Test battery for attentional performance for children (KITAP)  
- Test battery for attentional performance (TAP 2.3)  
- Continuous Performance Test (CPT)  
- Test battery for perceptual and attentional performance (WAF) in: Vienna test system  
- Test of Everyday Attention for Children – German version (TEA-Ch)  
- Assessment of concentration and attention in nursery school children (TEA-Ch-K)  
- Frankfurt attention inventory 2 (FAIR-2)  
- D-KEFS Trailmaking Test (D-KEFS TMT) |
| Perception, memory   | - Test for verbal learning - and memory abilities (VLMT)  
- Battery for Assessment in Children. Memory and learning abilities 6 to 16 years (BASIC-MLT)  
- Battery for assessment of working memory for children 5-12 years (AGTB 5-12)  
- Diagnostics for cerebral damage - II (DCS-II)  
- Developmental Scoring System for the Rey-Osterrieth Complex Figure (DSS ROCF) |
| Visual motor skills  | - Developmental Test of Visual-Motor Integration (VMI)  
- Frostig developmental test of visual perception – 2 (FEW 2)  
- Copying test for children (ATK)  
- Developmental Scoring System for the Rey-Osterrieth Complex Figure (DSS ROCF) |
| Fine motor skills    | - Motor performance series (MLS)  
- Purdue Pegboard (Minnesota Dexterity Test) |
<table>
<thead>
<tr>
<th>Domain</th>
<th>Tests/Measurements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive functions</td>
<td>- Game of zoo&lt;br&gt;- Tower of London (TL-D)&lt;br&gt;- Wisconsin-Card-Sorting-Test (WCST)&lt;br&gt;- Computer assisted Card-Sorting-Test (CKV)&lt;br&gt;- Battery for assessment of working memory for children of 5-12 years (AGTB 5-12)</td>
</tr>
<tr>
<td>Speech/auditive perception</td>
<td>- Developmental test of speech for children 2 years and 3-5 years (SETK 2; SETK 3-5)&lt;br&gt;- Level of speech for children at the age of 5-10 years (SET 5-10)&lt;br&gt;- Basic reading and writing competencies – a phonological awareness test (BAKO 1-4)&lt;br&gt;- Regensburg test for verbal fluency (RWT)</td>
</tr>
<tr>
<td>School performance/academic achievement</td>
<td>- Salzburg reading and writing test II (SLRT-II)&lt;br&gt;- Hamburg writing test (HSP 1-9)&lt;br&gt;- Salzburg reading screening for schoolclasses 5-8 (SLS 5-8)&lt;br&gt;- Test for reading comprehension for children of schoolclass 1-6 (ELFE 1-6)&lt;br&gt;- Test for assessment of numerical and calculating abilities from preschool to 3rd grade (TEDI-MATH)&lt;br&gt;- Testing method of dyscalculation (ZAREKI-II)&lt;br&gt;- Eggenberg test of calculation/mathematics I+2+/3+/4+</td>
</tr>
<tr>
<td>Health-related quality of life</td>
<td>- Paediatric Quality of Life Questionnaire (PEDQOL)&lt;br&gt;- Questionnaire on child and adolescent quality of life (KINDL-R, CAT-Screen)&lt;br&gt;- Questionnaire on adolescent quality of life (LKJ)&lt;br&gt;- Health questionnaire (SF 36)&lt;br&gt;- Health Utility Index (HUI)&lt;br&gt;- Ulmer quality of life inventory for parents (ULQIE)&lt;br&gt;- Familial stress questionnaire (FaBel)&lt;br&gt;- Child Health Questionnaire (CHQ-PF 28) – short version for parents&lt;br&gt;- Giessen -Description of complaints for children and adolescents (GBB-KJ)</td>
</tr>
<tr>
<td>Behaviour/ emotional health/psychosocial functionality</td>
<td>- Strengths and Difficulties Questionnaire (SDQ-Deu)&lt;br&gt;- Child Behaviour Checklist (CBCL), Youth Self Report (YSR)&lt;br&gt;- Behavior Rating Inventory of Executive Function (BRIEF)&lt;br&gt;- Questionnaire on cognitive processing for children of 4-6 years (KOPKI 4-6)&lt;br&gt;- Diagnostic System of Mental Disorders - ICD-10 und DSM-IV for children and adolescents – II (DISYPS-II)&lt;br&gt;- Interviews on emotional distress in children and adolescents (IBS-KJ)&lt;br&gt;- Anxiety Test for Children II (KAT-II)&lt;br&gt;- Depression inventory for children and adolescents (DIKJ)&lt;br&gt;- Depression inventory for children (DTK)&lt;br&gt;- Questionnaire on emotional regulations in children and adolescents (FEEL-KJ)&lt;br&gt;- Personality questionnaire for children of 9-14 years (PFK 9-14)&lt;br&gt;- Children's Self-Report and Projective Inventory (CSRPI)&lt;br&gt;- Questionnaire on experiencing and coping with distress in childhood and adolescence (SSKJ 3-8)&lt;br&gt;- Questionnaire on coping with distress (SVF-KJ)&lt;br&gt;- Questionnaire on learning motivation for school children of classes 4-6. and 7-13. (FLM 4-6, FLM 7-13)&lt;br&gt;- Sceno-Test ; Animal family drawing test (FIT)</td>
</tr>
</tbody>
</table>
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**

**Reaction to severe stressor:**
Symptoms do not exceed the expected level in manifestation, degree and duration

**Persistent stress reaction**

**Causal connection given:**
stressor and symptoms coincide

**Symptoms generally appear within minutes of the event and decrease within two to three days**

- yes -> Acute stress reaction (F43.0)
- no

**Delayed or protracted reaction to a stressful event with a latency of weeks to months**

- no

**Disorders that generally occur within a month of the stressful event and do not usually last for longer than six months**

- yes -> Adjustment disorder (F43.2)
- no

**Occurrence of symptoms immediate or delayed. They can be present intermittently or continuously, the causal connection always remains**

- yes

**Causal connection between stressor and symptoms can but does not have to be present.**

- no

**Other emotional, affective or social behaviour disorders e.g. e.g. anxiety disorder (F40/41), depressive episodes (F32), somatoform disorders (F45)**

---

Fig.1: Diagnostic decision tree (261)
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.awmf.org/leitlinien/aktuelle-leitlinien/ll-liste/deutsche-gesellschaft-fuer-kinder-und-jugendpsychiatrie-psychosomatik-und-psychotherapie.html). (179)

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

#### Persistent stress reaction

<table>
<thead>
<tr>
<th>Individual experience of stress:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is influenced by:</strong></td>
</tr>
<tr>
<td>- Additional stressors arising from the personal and social circumstances of patient and family.</td>
</tr>
<tr>
<td>- Functionality of available resources.</td>
</tr>
</tbody>
</table>

#### Leading symptoms:

- Peculiarities of feeling and behaviour including behavioural changes.
- Emotional problems, in particular depressive symptoms, despair or sadness, anxiety symptoms, and feelings of vulnerability, restlessness and drivenness.
- Somatoform reactions such as stomach ache, headache, fever or sleep and appetite disorders.
- Cognitive symptoms such as concentration problems, attention problems, heightened vulnerability to disturbance.
- Interaction problems and social isolation.
- Development problems incl. regression to an earlier stage of development.
- Compliance problems / coping problems with tendency to denial.
- Body image disorders.

#### Diagnostics:

- Detailed exploration (incl. exploration of attachment figures).
- Observation of behaviour.
- Profile of resources and stressors.
- Further diagnostics: tests, questionnaires etc.

#### Indication for basic psychosocial care with counselling and treatment

Stress factors are primarily disease- and treatment-related.

#### Indication for intensified psychosocial care

Indications for intensified care are increased disease-related primary stressors (unfavourable prognosis, complications, recurrence etc.) and comprehensive or significant stressors in several non-disease-related secondary areas.

#### Indication for intensified psychosocial care incl. possible specialist psychological and specialist psychiatric treatment and/or medication

- Acute stress reaction (F43.0).
- Posttraumatic stress disorder (F43.1).
- Adjustment disorders (F43.2).
- Behaviour problems with physical disorders and factors (F5).
- Eating disorders (F50).
- Combined disorders of social behaviour and emotions (F92 or also F43.24./25).
- Emotional disorder in childhood especially emot. disorder with separation anxiety (F93.0).
- Phobic, panic and other anxiety disorders (F40/41).
- Depressive episodes (F32).
- Compulsive disorders (F42).
- Somatoform disorders (F45).
- Dissociative disorders (F44).
- Fatigue syndrome (F48).
- Personality and behavioural disorders due to brain disease, damage or dysfunction (F07).

---

Fig. 2. Indication for psychosocial care of the patient in paediatric oncology/haematology (261)
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 (Leiss et al., 2012). 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

<table>
<thead>
<tr>
<th>Stress factors</th>
<th>Demand on the patient/family</th>
<th>Stress reaction</th>
<th>Psychosocial interventions for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strange, frightening surroundings</td>
<td>Understanding the meaning of the life-threatening nature of the disease</td>
<td>Disease symptoms, pain</td>
<td>Psychosocial diagnostics</td>
</tr>
<tr>
<td>Unfamiliar, painful and frightening examinations</td>
<td>Admission and understanding information on the disease and treatment</td>
<td>Irritation and uncertainty due to hospital and treatment</td>
<td>Obtaining history</td>
</tr>
<tr>
<td>Intensive implementation of a diagnostic programme</td>
<td>Enduring anxiety and uncertainty</td>
<td>Fear of separation from the parents</td>
<td>Recording understanding of the disease by the patient and his parents, clarifying unanswered questions</td>
</tr>
<tr>
<td>Confrontation with the life-threatening nature of the diagnosis</td>
<td>Admission and understanding information on the disease and treatment</td>
<td>Age-specific reactions to the diagnosis e.g. fear of dying, helplessness, anger, grief, despair</td>
<td>Evaluating stress factors and resources</td>
</tr>
<tr>
<td>Loss of parental security</td>
<td>Enduring the (unexpressed) worries and tensions of the parents</td>
<td>Inability to understand what is happening</td>
<td>Clarifying individual need for care</td>
</tr>
<tr>
<td>Sudden change in entire circumstances due to admission to hospital e.g. separation from social and school environment</td>
<td>Cooperation with diagnostic and therapeutic procedures</td>
<td>Resistance to threatening feelings</td>
<td>Neuropsychological diagnostics in case of threatened CNS impairment</td>
</tr>
<tr>
<td>Abrupt, sometimes emergency beginning of treatment</td>
<td>Dealing with changes in everyday life (strange surroundings, people, procedures))</td>
<td>Psychological disorders see ICD-10 Chapter V (F)</td>
<td>Identification of language and cultural barriers</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unclear preliminary diagnoses, lengthy history of disease</td>
<td>Development of hope, confidence and trust in the medical treatment</td>
<td>Premonitions and worries</td>
<td>Information, help with orientation</td>
</tr>
<tr>
<td>Uncertainty, waiting for results</td>
<td>Giving the sick child support, security and reliable closeness</td>
<td>Diagnosis shock and fear of the future</td>
<td>Additional information on disease, treatment and consequences of treatment</td>
</tr>
<tr>
<td>Confrontation with the life-threatening diagnosis and the imminent therapy</td>
<td>Making decisions about the treatment</td>
<td>Overwhelmed by feelings (fear of the child’s death, impotence, helplessness, anger, grief, feelings of guilt, despair,)</td>
<td>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, <a href="http://www.discern.de">www.discern.de</a>)</td>
</tr>
<tr>
<td>Uncertain treatment outcome</td>
<td>Gaining orientation in the processes of the treatment system</td>
<td>Resistance to threatening feelings, numbness, denial</td>
<td>Support in processing complex information</td>
</tr>
<tr>
<td>Existential collapse of the family’s world</td>
<td>Acquiring knowledge of the disease and treatment</td>
<td>Limited ability to absorb information, confusion</td>
<td>Information for teachers and fellow students of the patient and siblings</td>
</tr>
<tr>
<td>Lack of prerequisites for understanding disease and treatment</td>
<td>Working through diagnosis, therapy and prognosis</td>
<td>Fears that their whole world will collapse, fear of losing control</td>
<td>Encouraging patient and relatives to actively seek information</td>
</tr>
<tr>
<td>Discrepancy in coping styles within the family</td>
<td>Parents’ double role of giving and needing support</td>
<td>Concern for siblings</td>
<td>Supportive therapy</td>
</tr>
<tr>
<td>Insufficient language skills</td>
<td>Controlling and coping with own emotions</td>
<td>Overtaxed by complicated medical issues</td>
<td>Strengthening parents’ confidence in their ability to learn and cope</td>
</tr>
<tr>
<td>Uncertainty regarding existing systems of meaning and belief</td>
<td>Honest discussion of the diagnosis within the family, age-appropriate information for siblings</td>
<td>Need for information/avoidance of information</td>
<td>Explaining that strong emotional reactions (fear, impotence, helplessness, anger, feelings of guilt) are normal</td>
</tr>
<tr>
<td>Alien cultural environment</td>
<td>Restructuring of family’s everyday life</td>
<td>Effort at maintaining appearance of naturalness and strength towards the children</td>
<td>Promoting cooperation during medical procedures (role-play, relaxation, distraction)</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>Dealing with the threatening situation</td>
<td>Psychological disorders see ICD-10 Chapter V (F)</td>
<td>Family, couples and parenting counselling</td>
</tr>
<tr>
<td>Unclear, threatening situation</td>
<td></td>
<td></td>
<td>Supporting family members in dealing with the emotional reactions to the medical diagnosis</td>
</tr>
<tr>
<td>Sudden change in everyday life</td>
<td></td>
<td></td>
<td>Counselling family members so they can support the patient in frightening and painful medical and nursing procedures</td>
</tr>
<tr>
<td>Sudden separation from family members</td>
<td></td>
<td></td>
<td>Encouraging open communication</td>
</tr>
</tbody>
</table>

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### 6.2.2 Treatment phase

<table>
<thead>
<tr>
<th>Stress factors</th>
<th>Demand on the patient/family</th>
<th>Stress reaction</th>
<th>Psychosocial interventions for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
<td>Supportive therapy</td>
</tr>
<tr>
<td>Prolonged and frequent stays in hospital</td>
<td>Learning to understand the need for medical and nursing procedures</td>
<td>Fear of medical procedures</td>
<td>Reducing fear and uncertainty</td>
</tr>
<tr>
<td>Long waiting times in hospital</td>
<td>Development of a hopeful attitude</td>
<td>Anger and rebellion against medical procedures</td>
<td>Promoting trust and confidence</td>
</tr>
<tr>
<td>Separation from other family members</td>
<td>Getting used to everyday life in hospital</td>
<td>Lack of cooperation / refusal e.g., to take tablets,</td>
<td>Giving encouragement, strengthening ability to see</td>
</tr>
<tr>
<td>Loss of personal privacy while in hospital</td>
<td>Active cooperation with medical and nursing procedures</td>
<td>blood samples, physical examinations</td>
<td>healthy aspects</td>
</tr>
<tr>
<td>Diagnostic procedures, e.g., LP, MRT, BT</td>
<td>Coping with repeated painful or frightening procedures</td>
<td>Fear that the disease is incurable, fear of late</td>
<td>Supporting and mobilising individual resources, e.g,</td>
</tr>
<tr>
<td>Numerous therapeutic procedures, e.g., taking tablets, infusions, mouth care</td>
<td>Putting up with diverse side effects</td>
<td>effects/fear of the future</td>
<td>inner strengths and endurance</td>
</tr>
<tr>
<td>Changes in appearance, e.g., hair loss, Cushing, cachexia</td>
<td>Coping emotionally with physical changes, making contacts in spite of visible stigmas</td>
<td>Aversion to foods and smells</td>
<td>Strengthening inner-family cohesion</td>
</tr>
<tr>
<td>Side effects, e.g., mucositis, fever, nausea, pain, physical weakness</td>
<td>Expressing feelings and state when undergoing medical and nursing procedures</td>
<td>Feelings of shame and loss of self-esteem with</td>
<td>Motivation for active cooperation</td>
</tr>
<tr>
<td>High danger of infection</td>
<td>Dealing with the loss of social contacts and age-appropriate leisure activities, e.g.,</td>
<td>regards to physical changes, e.g., changes to</td>
<td>Promoting the understanding of therapy, clearing up</td>
</tr>
<tr>
<td>Unclear, suspicious symptoms</td>
<td>sport, going to the disco</td>
<td>hair and skin, Cushing, cachexia</td>
<td>fantasies about disease</td>
</tr>
<tr>
<td>Serious physical impairments/complication e.g., necessity for intensive care</td>
<td>In adolescents, dealing with the loss of independence and autonomy</td>
<td>Desire for lasting physical contact with parents,</td>
<td>Arranging meetings with other parents to provide</td>
</tr>
<tr>
<td>Witnessing recurrence, dying and death of fellow patients</td>
<td>Developing new interests and hobbies</td>
<td>fear of separation and loss</td>
<td>encouragement and exchange experiences</td>
</tr>
<tr>
<td>Isolation in hospital, e.g., in case of infectious pathogens</td>
<td></td>
<td>Grief at lack of contact with siblings, friends and</td>
<td></td>
</tr>
<tr>
<td>Mood swings due to medication, e.g., corticosteroid therapy</td>
<td></td>
<td>schoolmates, homesickness</td>
<td></td>
</tr>
<tr>
<td>Loss of physical integrity</td>
<td></td>
<td>Disappointment at having to give up sport and hobbies</td>
<td></td>
</tr>
<tr>
<td>Temporary or permanent mental impairment or personality changes, e.g.,</td>
<td></td>
<td>Grief at separation from or loss of pets</td>
<td></td>
</tr>
<tr>
<td>Organic psychosyndrome</td>
<td></td>
<td>Emotional exhaustion, depressive mood</td>
<td></td>
</tr>
<tr>
<td>Significant limitation of independence and autonomy</td>
<td></td>
<td>Feelings of dependence and impotence, helplessness,</td>
<td></td>
</tr>
<tr>
<td>Lack of contact to friends, isolation</td>
<td></td>
<td>excessive adjustment</td>
<td></td>
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<tr>
<td>Exclusion from educational-vocational development</td>
<td></td>
<td>Aggression, anger, despair</td>
<td></td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td>Regressive behaviour</td>
<td></td>
</tr>
<tr>
<td>High care demands on the parents</td>
<td>Patient is accompanied by one of the parents in hospital</td>
<td>Social withdrawal</td>
<td></td>
</tr>
<tr>
<td>Frequent changes in treatment modalities</td>
<td>Willingness to learn nursing procedures and take on responsibility</td>
<td>Disturbed sleep, nightmares</td>
<td></td>
</tr>
<tr>
<td>Insufficient sleep, rest and recreation</td>
<td>Flexible adjustment of the family routine to the course of treatment, e.g., organising</td>
<td>Denial non-acceptance of the life-threatening nature</td>
<td></td>
</tr>
<tr>
<td></td>
<td>care for siblings</td>
<td>of the disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Change in interfamilial tasks and roles</td>
<td>In adolescents: termination of therapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Motivating the patient to cooperate actively, e.g., with regard to eating, drinking,</td>
<td>Psychological disorders see ICD-10 Chapter V (F)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>taking tablets</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Carrying out nursing procedures on their own at home</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Constant supervision of the patient, observation of his state of health</td>
<td></td>
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</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High care demands on the parents</td>
<td>Fears that the disease is incurable, fear of late effects and procession</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequent changes in treatment modalities</td>
<td>Exhaustion, chronic stress, overtaxing due to multiple demands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insufficient sleep, rest and recreation</td>
<td>Social withdrawal</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Feelings of guilt, worries, search for a meaning</td>
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<tr>
<td></td>
<td>Aggressive behaviour and reproaches</td>
<td></td>
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<tr>
<td></td>
<td>Anticipatory grief</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depressivity, pessimistic attitude, suicidal tendency</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disturbed sleep, heart and circulatory problems and other symptoms</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Information, help with orientation**
- 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

**Psychosocial diagnostics**
- 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

**Social welfare counselling and support**
- 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

**Family, couples and parenting counselling**
- 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

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<table>
<thead>
<tr>
<th>Siblings</th>
<th>Chapter V (F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of regular regime, security and parental attention</td>
<td>Measures accompanying treatment to help the patient and relatives cope with the disease</td>
</tr>
<tr>
<td>Accommodation away from home</td>
<td>Psychological preparation before and after medical and nursing procedures e.g. LP, operations, SCT, radiotherapy, MIBG</td>
</tr>
<tr>
<td>Loss of carefree childhood</td>
<td>Psychological measures for controlling and coping with pain</td>
</tr>
<tr>
<td></td>
<td>Measures for strengthening the autonomy and self esteem of the patient</td>
</tr>
<tr>
<td></td>
<td>Measures for reducing anxiety and stress, e.g. relaxation techniques, cognitive techniques, hypnotherapy</td>
</tr>
<tr>
<td></td>
<td>Help in dealing with family feelings of guilt and blaming</td>
</tr>
<tr>
<td></td>
<td>Measures for strengthening parents’ competence in dealing with the patient and siblings</td>
</tr>
<tr>
<td></td>
<td>Support in dealing with questions concerning the meaning of life, spirituality, dying and death</td>
</tr>
<tr>
<td>Ability to evaluate threatening physical symptoms</td>
<td>Art therapies</td>
</tr>
<tr>
<td>Empathy with the patient’s situation</td>
<td>Opportunity to encourage emotional expression</td>
</tr>
<tr>
<td>Clear and constant parenting style towards the sick child</td>
<td>Measures for strengthening self-confidence and autonomy</td>
</tr>
<tr>
<td>Standing up for the individual needs of the child in the clinic and social environment (Advocacy)</td>
<td>Working through conflict situations on the symbolic level (sounds, images)</td>
</tr>
<tr>
<td>Balancing the needs of all family members</td>
<td>Creative work to ease fears, provide distraction and reduction of pain, support in developing coping strategies</td>
</tr>
<tr>
<td>Adequate emotional and social care of siblings</td>
<td>Opportunities for nonverbal communication and interaction</td>
</tr>
<tr>
<td>Providing siblings with ongoing information about the course of the disease</td>
<td>Promotion of creative abilities to support “healthy” aspects</td>
</tr>
<tr>
<td>Adequate time for individual regeneration and time for the parental relationship</td>
<td>Play and creative pedagogy</td>
</tr>
<tr>
<td>Expressing and dealing with parents’ own feelings</td>
<td>Creation of an atmosphere that promotes trust</td>
</tr>
<tr>
<td>Ability to accept support</td>
<td>Playful processing of the treatment situation</td>
</tr>
<tr>
<td>Siblings</td>
<td>Measures aimed at distraction, relaxation and pleasure</td>
</tr>
<tr>
<td>Dealing with diminished parental time</td>
<td>Activating the child’s abilities and resources</td>
</tr>
<tr>
<td>Adjustment to changing care-givers and accommodation</td>
<td>Providing sense of achievement and promoting quality of life</td>
</tr>
<tr>
<td>Dealing with fears and loneliness</td>
<td>Support of age-appropriate development</td>
</tr>
<tr>
<td>Scaling back their own needs, wishes and interests</td>
<td>Measures aimed at promoting contact with other children</td>
</tr>
<tr>
<td></td>
<td>Organising patients’ birthdays, holidays, seasonal festivals</td>
</tr>
<tr>
<td></td>
<td>Organisation of events (e.g. visit by clowns, theatre performances)</td>
</tr>
<tr>
<td></td>
<td>Individual activities for bed-ridden patients</td>
</tr>
</tbody>
</table>

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### Remission phase/ Follow-up care

<table>
<thead>
<tr>
<th>Stress factors</th>
<th>Demand on the patient/family</th>
<th>Stress reaction</th>
<th>Psychosocial interventions for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td>• Maintenance therapy/ ambulatory therapy, e.g. for leukemia</td>
<td>• Denial coping strategies</td>
<td>• Encouraging the processing and integration of the disease-related experiences into the personal life history</td>
</tr>
<tr>
<td></td>
<td>• Surveillance diagnostics</td>
<td>• Fear of recurrence</td>
<td>• Supporting the patient in casting off his “sick role”</td>
</tr>
<tr>
<td></td>
<td>• Temporary or possibly permanent physical impairments e.g. wheelchair use</td>
<td>• Problems with self-esteem in case of disease-related physical, emotional and mental impairments</td>
<td>• Support in dealing with fear of relapse</td>
</tr>
<tr>
<td></td>
<td>• Reduced general resilience and stamina, slowing down</td>
<td>• Difficulties with (re-)integration in kindergarten and school, social anxiety</td>
<td>• Promoting the autonomy and self-confidence of the patient</td>
</tr>
<tr>
<td></td>
<td>• Late effects of the disease and treatment, e.g. organ damage, functional disturbances and disabilities</td>
<td>• Psychological disorders see ICD-10</td>
<td><strong>Psychosocial diagnostics / Final diagnostics</strong></td>
</tr>
<tr>
<td></td>
<td>• Decline in cognitive performance, e.g. attention, memory, concentration</td>
<td>Chapter V (F)</td>
<td>• Final consultation on psychosocial situation</td>
</tr>
<tr>
<td></td>
<td>• Isolation due to loss of social contacts</td>
<td>Fear of recurrence</td>
<td>• Clarifying how individual members of the family process the disease</td>
</tr>
<tr>
<td></td>
<td>• Altered appearance, physical and social stigmas</td>
<td>Chronic fear of recurrence, “Damocles sword”</td>
<td>• Clarifying care at home</td>
</tr>
<tr>
<td></td>
<td>• Catching up on missed lessons</td>
<td>Fear of stressful check-up results</td>
<td>• Diagnostics for implementing in/outpatient rehabilitation measures</td>
</tr>
<tr>
<td></td>
<td>• Need to repeat a school year, changing schools</td>
<td>Lasting uncertainty about the planability of life</td>
<td>• Initiation of complementary diagnostics if inadequate processing of disease/psychological disorder is suspected in the patient</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td>• Loss of “security” due to the termination of therapy</td>
<td>Emergence of emotions that have previously been controlled or suppressed</td>
<td>• referral to child and adolescent psychiatrist and psychotherapist</td>
</tr>
<tr>
<td></td>
<td>• Loss of the protective hospital environment</td>
<td>Massive physical and emotional exhaustion</td>
<td>• Initiation of complementary diagnostics if developmental, intelligence impairments, neuropsychological impairments are suspected</td>
</tr>
<tr>
<td></td>
<td>• Lack of a guarantee of a cure/ fear of check-ups</td>
<td>Chronification of physical complaints, e.g. backache</td>
<td>• Clarifying needs and supporting patient on transfer to adult follow-up care</td>
</tr>
<tr>
<td></td>
<td>• Unclear results, questionable signs of recidivi city</td>
<td>Long-term limitations to quality of life</td>
<td><strong>Organisation of follow-up care/ Social welfare support</strong></td>
</tr>
<tr>
<td></td>
<td>• Uncertainty about reversibility of patient’s emotional, mental and physical impairments</td>
<td>Psychological disorders see ICD-10</td>
<td>Arranging family-oriented and/or neurological inpatient rehabilitation measures or arrangement of rehabilitation measures specifically for adolescent patients / help in claiming costs from insurance</td>
</tr>
<tr>
<td></td>
<td>• Discrepant coping styles in the family</td>
<td>Chapter V (F)</td>
<td>• Counselling patients, parents, kindergarten teachers and school teachers on the patient’s reintegration in kindergarten, school, training and employment</td>
</tr>
<tr>
<td></td>
<td>• Shock at recurrence and death of fellow patients</td>
<td>Siblings</td>
<td>• Preparing for a return to school in cooperation with clinic tutors and home tutors and the child’s school</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>• Impossibility of restoring the family situation as it was prior to the illness</td>
<td>• High expectations of a return to normality</td>
<td>• Preparation and arrangement of targeted remedial measures in case of developmental delays and late effects in the patient</td>
</tr>
<tr>
<td></td>
<td>• Expression of their own interests and needs</td>
<td>Desire for “compensation”</td>
<td>• Preparation and drafting of sociomedical and psychosocial reports</td>
</tr>
<tr>
<td></td>
<td>• Normalisation of sibling relationships</td>
<td>Disappointment at the lasting changes in the family due to the illness</td>
<td>• Arranging seminars, events and camps for patients, parents and siblings</td>
</tr>
<tr>
<td></td>
<td>• Dealing with personal maturity processes</td>
<td>Persistent jealousy, anxiety, feelings of guilt</td>
<td><strong>Family, couples and parenting counselling</strong></td>
</tr>
<tr>
<td></td>
<td>• Regaining trust and confidence</td>
<td>Problems at school</td>
<td>• Counselling on age-appropriate emotional processing of the trauma of disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychological disorders see ICD-10</td>
<td>• Counselling on dealing with late effects, e.g. loss of extremities, infertility, growth disturbances, diminished capacity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chapter V (F)</td>
<td>• Counselling on measures to aid the emotional and physical regeneration of the parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Counselling on parenting issues regarding patient and siblings</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Encouraging parents to support the independence of adolescent patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Encouraging or if necessary arranging further psychiatric-psychotherapeutic treatment of patient, parents and/or siblings if indicated</td>
</tr>
</tbody>
</table>

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### 6.2.4 Recurrence / Progression

<table>
<thead>
<tr>
<th>Stress factors</th>
<th>Demand on the patient/family</th>
<th>Stress reaction</th>
<th>Psychosocial interventions for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td><strong>Accepting the renewed treatment while knowing about the stressors associated with it</strong></td>
<td><strong>Fear of death</strong></td>
<td>The spectrum of psychosocial interventions is as for the diagnosis and treatment phase.</td>
</tr>
<tr>
<td></td>
<td><strong>Dealing with prolonged difficult living conditions and limitations</strong></td>
<td><strong>Profound uncertainty and emotional instability</strong></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td><strong>Dealing with loss of control and fear of death</strong></td>
<td><strong>Loss of faith in the treatment and hope of cure</strong></td>
<td>Areas of intervention are:</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Significant separation anxiety</strong></td>
<td>- Supportive therapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- Information, help with orientation</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Regressive behaviour</strong></td>
<td>- Family, couples and parenting counselling</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Demanding, dominant behaviour, low tolerance of frustration</strong></td>
<td>- Social welfare support</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Aggressive behaviour towards parents and siblings</strong></td>
<td>- Psychotherapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Child protects parents from his own fears</strong></td>
<td>- Art therapies</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Refusal of treatment procedures</strong></td>
<td>- Play and creative pedagogy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>For further stress factors see initial treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>For further demands, see initial treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>For further reactions see initial treatment</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td><strong>Regaining hope</strong></td>
<td><strong>Psychological disorders, see ICD-10 Chapter V (F)</strong></td>
<td>Interventions: see treatment phase</td>
</tr>
<tr>
<td></td>
<td><strong>Dealing with worse prognosis</strong></td>
<td></td>
<td>For further stress factors see initial treatment</td>
</tr>
<tr>
<td></td>
<td><strong>Absorbing and processing complex information</strong></td>
<td></td>
<td>For further demands, see initial treatment</td>
</tr>
<tr>
<td></td>
<td><strong>Renewed adjustment of family life to the treatment situation</strong></td>
<td></td>
<td>For further reactions see initial treatment</td>
</tr>
<tr>
<td></td>
<td><strong>Open communication about prognosis and further treatment possibilities</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 6.2.5 Palliative phase / Death and dying

<table>
<thead>
<tr>
<th>Stress factors</th>
<th>Demand on the patient/family</th>
<th>Stress reaction</th>
<th>Psychosocial interventions for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confrontation with increasing deterioration of health</td>
<td>Dealing with symptoms</td>
<td>Fear of isolation, separation anxiety</td>
<td>Supportive therapy / palliative care</td>
</tr>
<tr>
<td>Symptoms of disease, e.g. pain, shortness of breath, bleeding</td>
<td>Recognising the increasing hopelessness</td>
<td>Fear of dying, fears of death</td>
<td>- Continuous offering of care for patient and relatives</td>
</tr>
<tr>
<td>Loss of function in areas of everyday life</td>
<td>Dealing with emotional responses to the progression of the disease and the process of dying</td>
<td>Feelings of meaninglessness, impotence, despair</td>
<td>- Help in planning the last phase of life</td>
</tr>
<tr>
<td>Physical decline, loss of strength</td>
<td>Dealing with loss of control and fear of death</td>
<td>Switching between hope and fear</td>
<td>- Supporting parents in decision for palliative care at home</td>
</tr>
<tr>
<td>Experience of existential threat</td>
<td>Hope of achievable goals (sympathetic closeness, comfort and pain relief)</td>
<td>Emotional uncertainty, irritation</td>
<td>- Strengthening the parents' protective function in the process of leave-taking</td>
</tr>
<tr>
<td>Experience of separation, loneliness and isolation</td>
<td>Taking leave of family and friends</td>
<td>Inner withdrawal, silence, excessive protection of relatives</td>
<td>- Emphasising the importance of physical contact, presence of the parents and nonverbal communication</td>
</tr>
<tr>
<td>Experiencing relatives' shock</td>
<td>Recognising and expressing wishes</td>
<td>Protracted mental-emotional maturity</td>
<td>- Encouraging an open, honest and protective handling of patient's and siblings' questions concerning dying and death</td>
</tr>
<tr>
<td>Unanswered questions about dying and life after death</td>
<td>Making unfinished things possible</td>
<td>Symbolic expression of inner processes</td>
<td>- Changing the goal of hope, enhancing trust</td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shock caused by the unavoidability of death</td>
<td>Recognising the increasing hopelessness</td>
<td>Expression of desire not to be forgotten</td>
<td>- Involving siblings in the dying and grieving process</td>
</tr>
<tr>
<td>Feeling of uncertainty due to the imminent dying process</td>
<td>Making a dignified death possible</td>
<td>Psychological disorders see ICD-10 Chapter V (F)</td>
<td>- Giving space for anticipatory grief, encouragement to allow the inexpressible</td>
</tr>
<tr>
<td>Confrontation with the child's increasing suffering</td>
<td>Conveying closeness, security and mutual trust</td>
<td></td>
<td>- Support in coping with fear, loss, pain and grief</td>
</tr>
<tr>
<td>Extreme, unforeseeable strain, day and night</td>
<td>Maintaining calm and openness</td>
<td></td>
<td>- Taking individual, cultural and religious concepts and traditions in dealing with dying and death into account</td>
</tr>
<tr>
<td>Discrepant coping styles in the family</td>
<td>Leave-taking, allowing the dying child to go his way</td>
<td></td>
<td>- Making grief support for parents and siblings extending beyond the death of the child</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heightened perception of the family's grief and despair</td>
<td>Coping emotionally with fear, loss, pain and grief</td>
<td></td>
<td>- Consultation with the relatives of the dead child in the clinic</td>
</tr>
<tr>
<td>Experiencing the changes in the health of the sick sibling</td>
<td>Allowing the dying child to participate in life as much as possible</td>
<td></td>
<td>- Arranging contact to institutions and support groups for grieving relatives</td>
</tr>
<tr>
<td>Incomprehensible, frightening life situation</td>
<td>Recognising the needs of the child, understanding messages and signals</td>
<td></td>
<td>- Making leave-taking from people close to patient possible</td>
</tr>
<tr>
<td>Threatening fantasies about dying and death</td>
<td>Realising the value of the moment in life, conscious planning for the remaining time</td>
<td></td>
<td>- Arranging rehabilitation for grieving families</td>
</tr>
<tr>
<td>Building “bridges” for remembering the child</td>
<td>Dealing with questions on the meaning of life</td>
<td></td>
<td><strong>Psychosocial diagnostics</strong></td>
</tr>
<tr>
<td>Meeting everyday demands/ maintaining ability to function</td>
<td>Building “bridges” for remembering the child</td>
<td></td>
<td><strong>Continuous assessment of the state of the whole family, and their need for support</strong></td>
</tr>
<tr>
<td>Restructuring life circumstances</td>
<td>Meeting everyday demands/ maintaining ability to function</td>
<td></td>
<td><strong>Social welfare support</strong></td>
</tr>
<tr>
<td>Recognising the siblings in their pain</td>
<td>Restructuring life circumstances</td>
<td></td>
<td>- Finding out about resources for local palliative care</td>
</tr>
<tr>
<td>Recognising the siblings' need for normality in life</td>
<td>Recognising the siblings in their pain</td>
<td></td>
<td>- Promoting a supportive network for care at home</td>
</tr>
<tr>
<td>Finding warmth and security</td>
<td>Recognising the siblings' need for normality in life</td>
<td></td>
<td>- Collaboration in an interdisciplinary, multidisciplinary helpers conference / drawing up a plan for crises and emergencies</td>
</tr>
<tr>
<td>Allowing themselves to have conflicting feelings</td>
<td>Developing concepts on connection to the dying sibling after death</td>
<td></td>
<td>- Arranging ambulatory care in the patient’s home or if necessary, hospice care</td>
</tr>
<tr>
<td>Developing concepts on connection to the dying sibling after death</td>
<td><strong>Psychosocial interventions for patient and family</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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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).

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 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

<table>
<thead>
<tr>
<th>Studies/Reviews</th>
<th>Degree of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.3.1 Interventions aimed at information and aids to orientation</td>
<td></td>
</tr>
<tr>
<td><em>Interventions for children and adolescents with cancer</em></td>
<td></td>
</tr>
<tr>
<td>Scott et al. (2004a) (SR)</td>
<td>III</td>
</tr>
<tr>
<td>Scott et al. (2004b) (SR)</td>
<td>III</td>
</tr>
<tr>
<td><em>Interventions for the parents of children and adolescents with cancer</em></td>
<td></td>
</tr>
<tr>
<td>Heiney et al. (1989)</td>
<td>III</td>
</tr>
<tr>
<td>Kazak et al. (2005)</td>
<td>II</td>
</tr>
<tr>
<td>6.3.2 Interventions aimed at emotional and social support</td>
<td></td>
</tr>
<tr>
<td><em>Interventions for children and adolescents with cancer</em></td>
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</tr>
<tr>
<td>Barrera et al. (2002a)</td>
<td>III</td>
</tr>
<tr>
<td>Heiney et al. (1988)</td>
<td>III</td>
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<tr>
<td>Hinds (2000)</td>
<td>III</td>
</tr>
<tr>
<td><em>Interventions for the parents of children and adolescents with cancer</em></td>
<td></td>
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<tr>
<td>Chesney &amp; Chesler (1993)</td>
<td>III</td>
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<tr>
<td>Heiney et al. (1989)</td>
<td>III</td>
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<tr>
<td>Hoekstra Weebers (1998)</td>
<td>I</td>
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<tr>
<td>Sahler et al. (2002)</td>
<td>II</td>
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<tr>
<td>Sahler et al. (2005)</td>
<td>II</td>
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<tr>
<td>Pai et al. (2006) (MA)</td>
<td>III</td>
</tr>
<tr>
<td><em>Interventions for the siblings of children and adolescents with cancer</em></td>
<td></td>
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<tr>
<td>Barrera et al. (2002b)</td>
<td>III</td>
</tr>
<tr>
<td>Houtzager et al. (2001)</td>
<td>III</td>
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<tr>
<td>Packman et al. (2004)</td>
<td>III</td>
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<tr>
<td>6.3.3 Interventions aimed at support in practical and financial questions</td>
<td></td>
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<tr>
<td>Goodenough (2004)</td>
<td>III</td>
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<tr>
<td>6.3.4 Interventions aimed at securing therapy and cooperation</td>
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<tr>
<td><em>Interventions for children and adolescents with cancer</em></td>
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<tr>
<td>Klosky et al. (2004)</td>
<td>lb</td>
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</table>
Table 4 (continued)

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

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

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

³ 3rd revised version of S1-Guideline (see AWMF) published as a book (according to publisher, includes evidence degree for recommendations)
⁴ http://www.awmf.org/leitlinien/detail/ll/051-010.html
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 (Children’s Oncology Group, COG 2008, www.survivorshipguidelines.org). 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, Vannatta, Gerhardt, Wells & Noll 2007; Michel, Rehholz, von der Weid, et al., 2010; Moyer, Willard, Gross et al. 2012) 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, Schulte & Barrera 2010), 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, Barrera, Atenasu, & Pinto 2009). For patients with neuro-cognitive sequelae there is a special need for interventions that focus not only on learning disabilities, but also on strengthening emotional end social ressources (Butler, Sahler, Askins et al., 2008; Barrera & Schulte, 2009; Bruce, Newcombe & Chapman, 2012). Parents and siblings also exhibit later psychosocial problems (van Dongen Melmann, 1995; Kusch et al., 1999; Taib et al. 2003; Kazak et al. 2004, Prchal 2009; Meyler, Guerin, Kiernan et al. 2010) 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 (178) 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 in patient neurological rehabilitation measures.

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.krebkindermachsorge.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 Kindercrabstiftung (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.
The special aspects of emotional distress and suffering in adolescent patients with resulting specific needs in treatment and consultation (AYAO PRG - Adolescent and Young Adult Oncology Progress Review Group, 2006; Seitz, Besier & Goldbeck, 2009; Larsson, Mattson & von Essen, 2010), as well as the increasing number of adolescent and young adult survivors of cancer in childhood with considerable physical and psychological health risks (Schultz, Ness & Whitton et al., 2007; Zebrack, Mills & Weitzman, 2007; Krull, Huang., Garney et al., 2010), clearly indicate the need for interlinked multiprofessional concepts in follow-up care. The interdisciplinary check-up centre at the university children’s hospital in Freiburg offers advice and preventive care for young people after cancer treatment (www.uniklinik-freiburg.de/kinderklinik/live/fachabteilungen/klinik4/was/nachsorge.html) and is a model for this form of care in German speaking countries.

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 biopsychosocial 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.
LITERATURE

1. ACT -Association for Children with Life-Threatening or Terminal Conditions and their Families. (1998). ACT-Charter. ACT Orchard Lane, Bristol


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