Psychosocial Care
in Paediatric Oncology and Haematology

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# TABLE OF CONTENTS

1  INTRODUCTION / BACKGROUND 5  
   1.1  Definition of psychosocial care 6  
   1.2  Goals and areas of responsibility 6  

2  STRUCTURE AND FRAMEWORK 6  
   2.1  Basic principles of psychosocial care 7  
   2.2  Organisation and structure 7  
   2.3  Quality assurance and documentation 7  

3  STRESS FACTORS AND RESOURCES 7  
   3.1  Stressors related to disease 7  
      3.1.1  Disease-specific somatic stressors 8  
      3.1.2  Disease-specific psychosocial stressors 8  
   3.2  Non-disease-related stressors 8  
      3.2.1  Non-disease-related psychosocial stressors 8  
   3.3  Personal and social resources 9  

4  DIAGNOSTICS 9  
   4.1  Diagnostic areas and procedures 10  
      4.1.1  Initial diagnostics 10  
      4.1.2  Ongoing diagnostics 10  
      4.1.3  Final diagnostics 10  
      4.1.4  Special diagnostics 11  

5  INDICATION AND LEADING SYMPTOMS 13  
   5.1  Leading symptoms 15  
   5.2  Indications for basic and intensified psychosocial care 16  

6  THERAPY / INTERVENTIONS 16  
   6.1  Basics 16  
      6.1.1  Psychosocial Interventions 16  
      6.1.2  Basic and intensified psychosocial care 17  
   6.2  Phase-specific psychosocial interventions 17  
      A.  Diagnosis phase / Beginning of therapy 18  
      B.  Treatment phase 18  
      C.  Remission phase / Follow-up care 18  
      D.  Recurrence phase/ Progression 19  
      E.  Palliative phase / Death and dying 19  
   6.3  Evidence basing of the effectiveness of selected psychosocial interventions 19
PSYCHOSOCIAL CARE IN PAEDIATRIC ONCOLOGY AND HAEMATOLOGY

1 INTRODUCTION / BACKGROUND

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. 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% of all those affected. The high rates of cure for children and adolescents demand extremely intensive treatment, usually associated with serious physical side effects.

The strain caused by the disease and the treatment is linked with intense emotional stress for the patient and his relatives and can lead to psychological illness. The diagnosis of cancer in childhood and adolescence means a prolonged and extreme emotional situation. It gives rise to profound changes in family life and is accompanied by a considerable degree of psychosocial pressure for all the family members. The physical, social, emotional and cognitive development of the children and adolescents is endangered. For the patient, the family represents the essential resource for coping with the disease and its treatment, and therefore needs professional psychosocial support.

The individual psychological and social pressures are reflected in a range of publications and personal accounts of those affected. The experiences of former patients and their relatives play an important role in the process of developing psychosocial concepts. The complexity of the pressures on the patient and his relatives requires care that integrates psychological, social and art therapy services, and also cooperates with the clinic's school and pastoral care service.

In German-speaking countries a range of experience-based treatment concepts for various areas of care have been developed (13, 40, 46), and a model for standardised care (30) and a national guideline (43) have been drawn up over the past years. At the international level, from 1993 onwards, guidelines and recommendations on a broad spectrum of psychosocial topics have been continually developed through a committee of the SIOP (Société Internationale d'Oncologie Pédiatrique) and other organisations (6, 11, 45). In the Anglo-American world, various concepts of care for children with cancer and their families have been created (8, 31). The common basis for all these concepts is orientation towards the family, the strengthening of resources and resistance, and multiprofessional supportive therapy oriented to the process of the disease.

The development of medical and psychosocial follow-up care and transitional concepts for former child and adolescent cancer sufferers has gained increasing importance in recent years. Results of studies on late effects and quality of life (10, 33, 37) point to physical, emotional, cognitive and social consequences of the disease and treatment for a proportion of patients. Psychosocial problems are also evident among parents and siblings (27, 29, 49). Specific psychosocial follow-up care services are particularly necessary for high-risk groups, such as patients with brain tumours and patients who need a radical operation or a stem-cell transplant (18, 47).
1.1 Definition of psychosocial care

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.

Cooperation with the medical team is central to psychosocial care in paediatric oncology and haematology. The emphasis is on supporting the resources of the patient and his family during the crisis of the disease, during therapy and – possibly – during dying, death and mourning. The core of this care concept is a supportive and informative relationship that is oriented towards the physical, emotional, social and developmental capabilities of the sick child /adolescent and his social environment and takes the individual style, and ability to cope and adjust into account.

1.2 Goals and areas of responsibility

This gives rise to the following goals and areas of responsibility for the adaptation of the patient and his family to the disease:

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
- Arranging continuing out-patient supportive measures and therapies
- Counselling aimed at the reintegration of the patient in kindergarten, school and vocational training

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 long-term social, emotional and cognitive late effects/developmental disorders

2 STRUCTURE AND FRAMEWORK

Psychosocial care is characterised by defined basic principles, structural-organisational (pre)conditions, and conditions of quality assurance and documentation that are supported by various national and international concepts. It is carried out by specialists from a range of professions (22), requires a clearly defined allocation of responsibilities and ongoing interdisciplinary communication within the team. The psychosocial staff perform specific activities according to their professional qualifications. In addition, there are interdisciplinary, overlapping areas of responsibility.
2.1 Basic principles of psychosocial care

- Holistic approach to treatment (7,32,34,39)
- Preventive approach to treatment (5,39)
- Family orientation (1,2,4,6,7,9,39,45)
- Centred on the individual (2,4,5,6,11,34,39,44,45)
- Resource-oriented (7,11,35,39,45)
- Supportive therapy (7,11,34,35,39,45)
- Process orientation towards course of disease (6,11,34,35,39,45)
- Interdisciplinary cooperation (2,5,6,7,11,34,39,44,45)
  Maintenance of basic ethical attitudes (1,11,16,45)

2.2 Organisation and structure

- Psychosocial care as a standard element in paediatric oncology and haematology (6,7,11,19,20,32,39)
  - Psychosocial service as an integral part of medical treatment and follow-up care
  - Basic care for all patients/families with intensified care as required
  - Availability and general accessibility to psychosocial care services

- Conditions regarding personnel, time, premises and administration (5,11,19,20,32,39)
  - multidisciplinary psychosocial team
  - clearly defined clinical and administrative tasks
  - staffing oriented towards need for care
  - premises that ensure privacy
  - funding for patient information, play and therapy materials, tests, questionnaires
  - well-equipped play room
  - age-appropriate activities for children and adolescents

2.3 Quality assurance and documentation

- Qualifications of psychosocial staff (6,11,39)
  - Staff with specialist training as:
    Psychologists, educators, social education workers, social workers, art and music therapists,
    play specialists, teachers, pastors
  - Interdisciplinary knowledge of diseases, stress reactions, disease concepts etc.
  - Ability to build up relationships based on trust and to deal with crisis situations etc.

- Ongoing training and supervision (5,11,32,39)
- Documentation of status and process (5,6,11,32,39)
- Evaluation and research (11,32)
  - Updating of care standards
  - Networking/linking clinical-somatic and psychosocial research

3 STRESS FACTORS AND RESOURCES

Oncological illnesses have psychological and social implications. In the patient and his family, they are determined by the form and intensity of physical and emotional stress arising from the disease. In addition, secondary stress factors that are not related to the illness, such as unfavourable sociocultural or psychosocial conditions, can be present in one or more family members and further complicate dealing with the disease and treatment. (15, 38).

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, cahexia etc.)
- Late effects of the disease and treatment (growth disturbances, fertility, cognitive performance etc.)
- Recurrence of tumour, 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 for the child's parents
- Organisational problems (e.g. care of siblings, distance from clinic)
- Separation from family, friends, schoolmates/school
- 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 no explained by the disease or the necessity of the treatment or, have not originally arisen 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
- 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 of major importance for patients with regard to dealing with the disease situation. Coping with disease is an active process that includes the utilisation of existing resources and also the development of new behaviours and additional resources. Since the 1980s, research has concentrated increasingly on questions of resilience, 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. 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 for coping successfully with disease. (9).

Stable coping factors - both short and long-term - have been found in the majority of families of young cancer patients (26). These include the following factors (21, 23, 28, 50):

- Family cohesion
- Social integration of the family
- Reliable emotional bonds
- Competent parenting behaviour
- Open communication
- Optimistic attitude, trust
- Favourable disease concepts
- Active problem-solving behaviour
- Fighting spirit
- Acquisition of information
- Distraction strategies
- Self-encouragement
- Determination
- Religiosity
- Search for a deeper meaning

Protective factors that have been identified for the siblings of childhood cancer patients include (25, 51):

- Open and honest communication about the disease
- Involving siblings in the process of the disease and patient care
- Adequate information about the disease and treatment

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, burdens 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>
</table>
| Initial contact on evaluation | - Presentation of psychosocial care provision  
- Start of detailed diagnosis |

- Psychosocial anamnesis
  - Sociodemographic data
  - History of disease
  - Patient's and family's anamnesis
  - Evaluation of resources
  - Coping with disease

- Examination
- Basic documentation (e.g. PSAPOH data sheet)
- Profile of resources and burdens
- Family genogram
- Questionnaire on health-related quality of life

- Complementary diagnostics (patient) on suspicion of psychological disturbance
- Complementary diagnostics (family) on suspicion of social conflict 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>
</table>
| Status survey of psychosocial situation | - Screening, exploration  
- Adjustment to disease (patient and family)  
- Home care situation  
- Psychol. results of child/adolescent |
| 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
- Complementary diagnostics (patient) in case of developmental, intelligence- and neuropsychological disturbances

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### 4.1.4 SPECIAL DIAGNOSTICS

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

The indication for psychosocial interventions is based on the considerable emotional burdens on the patient and the family, arising from confrontation with a serious, life-threatening disease. These burdens 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 (17). 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 - as distinct from the pathological stress reactions and adjustment disorders in terms of ICD 10 and DSM IV (42). 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, it is adequate in expressions and intensity. The reaction includes symptoms of depressive mood, anxieties, 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 (36).

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 graphic illustrates the diagnostic distinction between persistent stress reactions and acute stress reactions and adjustment disorders in ICD 10.
Fig. 1: Diagnostic decision tree (42)
Alongside the indication for the treatment of the patient, there is also an *indication for the social pedagogic and/or psychological support of the relatives* within the framework of family-oriented psychosocial care. This is based on the crucial importance of parental support for the implementation of treatment and the disease adaptation of the patient (48).

The indication for social pedagogic care of the family is primarily given in social conflict situations, to secure the parental functions of protection and support for the patient and his siblings, and to maintain the family's socioeconomic basis during treatment. The indication for psychological care of relatives is given in the case of emotional problems and a high level of psychological stress in coping with the disease and treatment. It is also necessary in the case of unfavourable coping mechanisms and interaction disorders which can place a serious strain on the patient.

### 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 consequences of the disease. In particular, they include:

- Behavioural problems and changes
- Emotional problems (anxiety symptoms, depressive symptoms etc.)
- Developmental problems or disturbances
- Compliance problems (e.g. in dealing with medical requirements)
- Body image problems due to visible and non-visible body changes
- Cognitive problems (attention and concentration problems etc.)
- Somatoform reactions (e.g. appetite disorders, sleep disturbances etc.)
- Social isolation due to prolonged stays in hospital (e.g. for SCT)
- Social conflict situation, problematic life circumstances
- Interaction problems (communication problems between family members etc.)
- Unfavourable individual and familial mechanisms for coping with disease
- Other marked changes in behaviours and reactions

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


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 ( F43.0)
- Post traumatic stress disorder (e.g. chronic traumatisation) (F43.1).  
- Adjustment disorders (regressive, aggressive or depressive reaction) ( F43.2)
- Emotional disorders with separation anxiety (F93.0)
- Fatigue syndrome (cf. F 48.0)
- Depressive episode (F32)
- Phobic disorders and other anxiety disorders (F 40/41)
- Compulsive disorders (F 42)
- Dissociative disorders (F44)
- Somatoform disorders (F45)
- Combined disorders of social behaviour and emotions (F92)
- Personality and behavioural disorder due to disease, damage or functional disorder of the brain (F07)
- other symptoms
5.2 Indications for basic and intensified psychosocial care

The indication for psychosocial care of the patient and his family is based on assessments made in the diagnostic process and the resulting classifications.

Indications for basic psychosocial care are primarily stressors that result from the disease and treatment, the so-called disease-related stressors. Secondary, non-disease-related factors in the sense of psychological (pre-existing) stress in one or more members of the family, or unfavourable sociocultural or psychosocial framework conditions are less relevant.

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 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. They are phase-specific and can be planned according to the course of the disease and the therapy. On the other hand, acute changes in the course of the disease can occur, and the psychosocial worker should react flexibly and immediately to these.

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
6.1.2 Basic and intensified psychosocial care

All patients should receive basic psychosocial care. In cases of high total strain, basic care is complemented by intensified care provision according to the indication. Psychosocial care is given continuously and in particular at the beginning of treatment and in crisis situations. Patients and relatives are contacted by the psychosocial services worker and care is offered within a short time frame.

Basic care should comprise:

**Diagnosis**
- Initial contact immediately after diagnosis/admission
- Psychosocial anamnesis (in the first 4 weeks)
- Social and psychological counselling
- Psychoeducative measures
- 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.

Patients who exhibit additional non health-related stress factors, such as unfavourable socioeconomic and familial circumstances and the lack of a social network normally receive a higher degree of social counselling and support, family and couples counselling and child guidance and supportive therapy. Patients with considerable health-related stressors normally receive increased interventions from the areas of crisis intervention, supportive therapy, relaxation techniques, art therapy, play and creative pedagogy, psychotherapy and palliative support (41).

6.2 Phase-specific psychosocial interventions

Psychosocial diagnostics and interventions should be oriented towards individual needs, which can change according to different phases in the disease and treatment. These needs can be acute. In the individual phases of the disease there are different focuses for care.

In all phases, it can become necessary to adapt the care strategy to meet current needs in the sense of crisis intervention. In psychosocial care, crisis intervention means a temporary intervention in situations or circumstances that are threatening, or cause significant stress or trauma.
The following explanations are oriented towards day-to-day clinical observations.

A. Diagnosis phase / Beginning of therapy
- *Psychosocial diagnostics*: Assessment of family burdens and resources and current need for support
- *Supportive therapy*: Support in dealing with the diagnosis, help in shifting focus from fear of death towards struggle for life, help with development to a realistic assessment of disease, promotion of adjustment to disease, empathic acceptance, reassurance and listening
- *Help in the form of information and orientation*: Material dealing with disease, treatment and consequences of treatment for the patient and relatives, information on support groups, charities etc., information for teachers and fellow students of patient and siblings
- *Social welfare counselling and support*: Help with reorganising everyday life, employment situation and financing household/basic needs; if necessary, involvement of social services

B. Treatment phase
- *Supportive therapy*: Encouragement, strengthening focus on healthy aspects, help in activating emotional and social resources, motivation for active cooperation, clarifying fantasies about disease and treatment, reducing anxieties and uncertainty, support in maintaining social contacts during treatment
- *Help in the form of information and orientation*: age-appropriate information, preparation for and follow-up after operations, radiotherapy, SCT, etc. (brochures, books, videos etc.), special counselling for adolescents regarding fertility etc., establishing contact with parents an patients in similar situation to provide encouragement, support of contact to self-help groups, charities, umbrella organization DLFH etc.
- *Social welfare counselling and support*: Help with organising outpatient home care, coordination of different provisions for support, help with obtaining medical aids, organisation of home and clinic tuition
- *Artistic therapies*: Activities aimed at promoting emotional expression
- *Family and couples counselling, parental guidance*: Help in dealing with the patient and his siblings, strengthening ability to communicate and autonomy in the family
- *Psychotherapy*: Measures aimed at reducing fear of medical treatment and emotional stress, promotion of a positive body image and autonomy, particularly in adolescents
- *Play and creative pedagogy*: Making the clinic stay more comfortable, using play to process it, diversion, relaxation, building up trust

C. Remission phase / Follow-up care
- *Supportive therapy*: Help in cause of fear of late effects or recurrence, development of protection from feelings of guilt, support to help parents regain energy, help in coping with disability, organisation of appropriate therapeutic programmes, supporting the development of a positive view of the future
- *Social welfare counselling and support*: Organisation of rehabilitation to reduce physical and emotional exhaustion in the patient and family members (family oriented, neurological etc.)
- *Family and couples counselling, parental guidance*: Strengthening the patient's self-responsibility, helping to reduce the special role of the sick child, support for reintegration of the patient in kindergarten, school, vocational training and employment, encouraging the integration of disease-related experiences into the personal life story
- *Psychotherapy*: Promotion of age-appropriate emotional processing of the disease trauma and physical effects, building up the patient's confidence and trust in his abilities, reduction of anxiety and adjustment disorders in the patient and relatives
D. Recurrence phase/ Progression

- **Supportive therapy**: Building up motivation and confidence, promotion of coping mechanisms, concentration on life in spite of changed prognosis, development of an appropriate future perspective, help and encouragement, confirmation of what has been achieved

- **Social welfare counselling and support**: intensified social support to ease the family's burden

- **Family and couples counselling, parental guidance**: Reduction of parental feelings of guilt, help in maintaining the social network for the patient, special focus on the situation of siblings, promotion of open communication

- **Artistic therapies**: Expression of feelings, experience of strengths and capabilities

- **Psychotherapy**: Support in dealing with fear of death and dying

- **Play and creative pedagogy**: creative and play activities, activation, promotion of sense of achievement, pleasure and relief from distress

E. Palliative phase / Death and dying

- **Supportive therapy**: Help with planning the last phase of life, strengthening parents' protection function, providing space for anticipatory grief

- **Social welfare counselling and support**: Promotion of a supportive network for home care, organisation of outpatient care in the home, if necessary, hospice

- **Artistic therapies**: finding child-appropriate forms of leave-taking, finding expression for fantasies and imagination

- **Palliative support**: Support in coping with fear, loss, pain and grief, interdisciplinary, culturally appropriate care, support during dying, home visits, follow-up care of grieving families, organisation of contact to centres for grieving relatives

6.3 Evidence basing of the effectiveness of selected psychosocial interventions

Based on a systematic research of the literature, studies on the effectiveness of selected psychosocial interventions were examined using the Downs & Black criteria (14) and evidence evaluation was undertaken in accordance with the recommendations of the Center of Evidence based Medicine, Oxford, or the Medical Centre for Quality Assurance (ÄZQ). In order to be classified as a meaningful study, the research had to fulfil minimum criteria with regard to sample size, randomisation, blinding, validity and other aspects. *

Oriented towards various goals, for psychosocial interventions, the following areas were selected: interventions involving information and orientation, interventions providing emotional and social support, interventions providing support in practical and financial questions, interventions aimed at securing implementation of therapy and cooperation, interventions for specific symptoms within the framework of medical measures, and interventions regarding prevention and rehabilitation.

At present there are few studies of the areas of intervention referred to above. In addition, they often have methodological flaws so that only a relatively small number of studies fulfil the criteria of level 1 and 2 evidence. On this basis, no evidence-based recommendations can be made for the interventions referred to above.

A considerable amount of clinically relevant scientific literature, e.g. studies with low sample size, anecdotal reports and qualitative studies, was excluded due to strict methodological criteria. Essential qualities of dealing with people with life-threatening diseases in the day-to-day clinical situation – such as supportive and trust-strengthening communication, respect, tolerance and dignity (12) – are not considered here. They have special importance for the patients and their relatives and require differentiated research methods appropriate to the complexity and process character of coping with disease.

* Detailed explanations are to be found in the method report of the guideline at: http://www.awmf.org/leitlinien/detail/ll/025-002.html
7 FOLLOW-UP CARE AND REHABILITATION

In paediatric oncology and haematology in Germany, the implementation of special inpatient family and youth-oriented rehabilitation measures (24) are an integral part of the treatment concept (see also: Leitlinie Rehabilitation in der pädiatrischen Onkologie (http://www.awmf.org/uploads/tx_szeleitlinien/070-007).

Screening of the further psychosocial development and 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 late effects
- Measures to aid social, school and workplace integration
- Organisation of further help for coping with disease and strengthening self-esteem
- Measures aimed at prevention of psychosomatic, emotional and social damage

The measures presented help to cope with the disease and to prevent late effects and are therefore important in terms of health policy.

The standardisation of psychosocial care in the treatment of children and adolescents with cancer is an important contribution to good clinical practice, greater transparency and practical guidelines, and is constantly being further developed and specified.

The S3- guideline "Psychosocial Care in Paediatric Oncology and Haematology" by PSAPOH/GPOH is published as an unabridged version and with additional literature to individual chapters including diagnostic procedures at http://www.awmf.org/leitlinien/detail/ll/025-002.html. The unabridged version was agreed in consensus with the panel of experts. This text is an adapted version.

8 LITERATURE


