

Leitliniensynopse

Um die zentralen Inhalte der vorliegenden Leitlinie mit den Inhalten ähnlicher Leitlinien vergleichen zu können, erfolgte eine Recherche und ein Abgleich mit internationalen Leitlinien. Die Leitlinienrecherche ergab, dass für den Bereich der psychosozialen Versorgung in der pädiatrischen Onkologie vorrangig die internationalen Guidelines der SIOG zu berücksichtigen sind. Diese wurden ab 1993 bis 2005 jährlich durch ein Komitee der internationalen Fachgesellschaft herausgegeben. Hinsichtlich der Aussagen der SIOG- Guidelines sind weitgehende Übereinstimmungen mit der hier erstellten Leitlinie zu finden.

Um weitere vergleichende Aussagen machen zu können, wurden darüber hinaus noch zwei bekannte Leitlinien zur allgemeinen psychosozialen Versorgung von Krebspatienten aus Australien und den USA miteinbezogen. Beide Leitlinien beziehen sich allerdings ausschließlich auf erwachsene Krebspatienten und sind deshalb von ihren Aussagen her nur bedingt vergleichbar, da vor allem der Einbezug der Gesamtfamilie nicht berücksichtigt wird. Ergänzend wurde auch die deutsche AWMF- Leitlinie zur stationären Rehabilitation krebskranker Kinder und ihrer Familien untersucht.

Diese internationalen Leitlinien wurden hinsichtlich ihrer Aussagen zu den Kernfragen der vorliegenden Leitlinie geprüft; die Ergebnisse finden sich in der vorliegenden Leitliniensynopse. Berücksichtigt man die Tatsache, dass sich die meisten Aussagen auf erwachsene Krebspatienten beziehen, so ergeben sich auch dazu keine diskrepanten Aussagen.

Fragestellungen:

Bereich	Fragestellung
BELASTUNGSFAKTOREN	Welche körperlichen, psychischen und sozialen Belastungen werden bei krebskranken Kinder und ihren Angehörigen beschrieben? Wie werden sie definiert?
RISIKOFAKTOREN	Welche (krankheitsunabhängigen) Belastungen werden beschrieben, die den Umgang mit der Erkrankung erschweren können?
RESSOURCEN UND SCHUTZFAKTOREN	Welche Faktoren fördern die Krankheitsadaptation bei Patient und Angehörigen?
DIAGNOSTIK	Wie werden die Belastungen und Ressourcen sowie die Krankheitsadaptation erfasst?
INDIKATIONSSTELLUNG	Bei welchen Belastungen/ Störungen muss psychosoziale Versorgung einsetzen?
INTERVENTIONEN	Welche Formen von Beratung und Therapie bei lebensbedrohlichen Erkrankungen werden angeboten zur Krankheitsbewältigung sowie zur Stärkung der Ressourcen von Patient und Familie?

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1. BELASTUNGSFAKTOREN

Fragestellung: Welche körperlichen, psychischen und sozialen Belastungen werden bei krebskranken Kinder und ihren Angehörigen beschrieben? Wie werden sie definiert?

Leitlinie	Körperliche Belastungen	Soziale Belastungen Patient	Seelische Belastungen Patient	Belastungen Eltern	Belastungen Geschwister
SIOP	<ul style="list-style-type: none"> - childhood cancer and treatment 	<ul style="list-style-type: none"> - isolation from normal activities 	<ul style="list-style-type: none"> - emotional crisis at the time of diagnosis (1) - challenge of relationship between all members of the family (1) - anxiety and fear (6) - misunderstanding and uncertainty about the merits of medication (9) - fear of amputations or other disfiguring treatments (9) - frustration with the length of treatments (9) 	<ul style="list-style-type: none"> - emotional crisis at the time of diagnosis (1) - challenge of relationship between parents (1) - a feeling of guilt for not having done everything (6) - psychological distress (6) - severe depression (6) - fear of losing their parental role (9) 	<ul style="list-style-type: none"> - challenge of relationship between siblings (1) - feeling of isolation (7) - feelings of guilt (7) - fear to get sick themselves (7) - school problems (7) - somatic complaints (7) - "acting out" (7) - loss of childhood (7) - loss of normal parent time and support (7) - loss of family cohesion (7) - changes in normal family routines (7) - additional chores within the family (7) - illness-related financial losses (7) - anger, sadness (7) - uncertainty about future (7)
NHMRC Australien (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - chemotherapy-induced nausea and vomiting - pain - fatigue - female fertility and pregnancy issues - male fertility issues - lymphoedema - disfigurement - odour - incontinence - bowel problems - cognitive Problems - communication difficulties - nutritional deficiencies - lack of appetite - oral symptoms 	<ul style="list-style-type: none"> - curtailment of activities they enjoy - perceived lack of support from family and friends - social impairment - financial problems - loss of income - difficulties with domestic chores or self care - problems with the practical aspects of advanced disease - disruption of social relationships - Unability to perform activities of daily living 	<ul style="list-style-type: none"> - being in a state of shock - feeling out of control - being angry, fearful or helpless - grief and loss - distress and fear - impact on self-concept - impact on body-image - sexual problems - interpersonal problems - problems with developing new sexual relationships after diagnosis - stress and adjustment reactions - severe emotional distress - anxiety - depression 	<p>Partners:</p> <ul style="list-style-type: none"> - stress level comparable or higher than that of patients - sometimes experience less support than patients - sometimes higher level of depression - difficulties with child care - unclear role and power structures - feeling of emotional exhaustion 	<p>Children of cancer patients:</p> <ul style="list-style-type: none"> - distress - usual support sources are disrupted - feelings of guilt - worries about the vulnerability of adults - disruption to social network - changes in role expectation

	<ul style="list-style-type: none"> - swallowing difficulties - respiratory symptoms - general health condition 		<ul style="list-style-type: none"> - suicide - post-traumatic stress disorder - challenge to confront their mortality - spiritual issues - struggle between independence and dependence - feeling of isolation 		
NCCN Distress Management (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - cancer and treatment - pain - poor sleep - poor appetite - nausea/vomiting - medication 	<ul style="list-style-type: none"> - severe financial problems - illness-related problems - concrete needs according to housing, food, financial problems, assistance with activities of daily living, transportation - employment/school/ career concerns - cultural/ language problems - family and caregiver availability 	<ul style="list-style-type: none"> - excessive worries - fear - unclear thinking - sadness - despair - spiritual crisis - poor concentration - periods of increased vulnerability to distress - signs and symptoms of normal fear about the future and uncertainty - concerns about illness - sadness about loss of usual health - anger, feeling out of control - hyper-vigilance - treatment decisions, quality of life issues and transition in care - problems in coping and communication - functional changes including body image and sexuality - End of life / bereavement 	Partners: <ul style="list-style-type: none"> - severe family problems - problems in dealing with children - problems in dealing with partner - family and social conflict / isolation 	Children of patients: <ul style="list-style-type: none"> - severe family problems
Rehabilitation in der päd. Onkologie	<ul style="list-style-type: none"> - Folgemorbiditäten, insbesondere ZNS und Bewegungsapparat - Behinderung 	<ul style="list-style-type: none"> - gestörtes Sozialverhalten 	<ul style="list-style-type: none"> - schwere psychische Reaktionen und Belastungen - Lebensbedrohung - Stationäre Krankenhausbehandlung - Ängste - Lernstörungen 	<ul style="list-style-type: none"> - schwere psychische Reaktionen im Familiensystem 	

2. RISIKOFAKTOREN

Fragestellung: Welche (krankheitsunabhängigen) Belastungen werden beschrieben, die den Umgang mit der Erkrankung erschweren können?

Leitlinie	Krankheitsunabhängige Belastungen Patient	Krankheitsunabhängige Belastungen Eltern
SIOP	<ul style="list-style-type: none"> - conflicts between older children/ adolescents and their parents (6) - religious beliefs, that may view pain and suffering as acceptable and even inevitable, if believed to the will of a Supreme Being. (9) 	<ul style="list-style-type: none"> - lack of resources (9) - cultural-religious differences may negate any trusting relationship with the treating physicians (9) - pre-existing and continuing family conflicts. (9)
NHMRC Australien (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - lack of social support - single, separated, divorced or widowed - economic adversity - history of psychiatric problems - cumulative stressful live events - history of alcohol or other substance abuse - younger patients - older patients - alcoholism - geographical isolation - rural lifestyle - homosexual orientation 	Partners/ family: <ul style="list-style-type: none"> - poor marital or family functioning - considerable financial strain before diagnosis
NCCN Distress Management (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - distress - behaviour symptoms - psychiatric history/medications - body image/sexuality - impaired capacity - psychiatric disorder (panic disorder, depression...) → psychiatric disorder in cancer - signs and symptoms of active abuse/ addition 	

3. RESSOURCEN UND SCHUTZFAKTOREN

Fragestellung: Welche Faktoren fördern die Krankheitsadaptation bei Patient und Angehörigen?

Leitlinie	Innerpsychische Faktoren Patient	Externe Faktoren Patient	Innerpsychische Faktoren Eltern	Externe Faktoren Eltern
SIOP		- valid informed consent (10)		- valid informed consent (10)
NHMRC Australien (ausschließlich auf Erwachsene bezogen!)	<ul style="list-style-type: none"> - emotional sharing of concerns - use of humour 	- adoption of a healthy diet and lifestyle		
Rehabilitation in der päd. Onkologie	<ul style="list-style-type: none"> - entwicklungsfördernde und vertrauensvolle Eltern-Kind-Beziehung - Familienorientierung 			

4. DIAGNOSTIK

Fragestellung: Wie werden die Belastungen und Ressourcen sowie die Krankheitsadaptation erfasst?

Leitlinie	Zeitpunkte der Diagnostik	Screening- Instrumente	Diagnostik psychischer Beeinträchtigungen	Diagnostik sozialer Beeinträchtigungen
SIOP	- at diagnosis (9)	- team develops own set of warning signs (9)	- factors predictive of a tendency toward non-compliance (9)	
NHMRC Australien (ausschließlich auf Erwachsene bezogen!)	<ul style="list-style-type: none"> - at time of diagnosis and recurrence - during advanced stage of disease - poorer prognosis - more treatment side-effects - greater functional impairment and disease burden - experiencing chronic pain - fatigue 	<ul style="list-style-type: none"> - effective communication is central to the identification of each individual's needs - general health questionnaire (GHQ) - Rotterdam Symptom Checklist (RSCL) - Hospital anxiety and depression scale (HADS) 	<ul style="list-style-type: none"> - identify unmet needs of patient and family - monitoring the emotional and psychological impact of cancer to the patient - asking about suicidal thoughts - asking about anxiety and depression - assessment of the degree of psychological distress resulting from physical symptoms - identify and document high risk factors - ask a patient about their general psychological and emotional well-being - ask about specific clinical issues including anxiety, depression, interpersonal functioning, coping with physical symptoms, body image and sexuality 	- check the extent of support available to the patient

<p>NCCN Distress Management (ausschließlich auf erwachsene Patienten bezogen!)</p>	<ul style="list-style-type: none"> - at their initial visit - at appropriate intervals - and as clinically indicated especially with changes in disease status (remission, recurrence, progression) <p><i>At periods of increased vulnerability:</i></p> <ul style="list-style-type: none"> - Finding out the diagnosis - Awaiting treatment - Change in treatment modality - End of treatment - Discharge from hospital following treatment - Stresses of survivorship - Finding a suspicious symptom - Medical follow-up and surveillance - Treatment failure - Recurrence/Progression - Advanced cancer - End of life 	<ul style="list-style-type: none"> - multidisciplinary committee tailors standards to institutional setting /clinical assessment <ul style="list-style-type: none"> - brief screening for distress (screening tool (0-10) in clinics) - problem list 	<ul style="list-style-type: none"> - excessive worries - fear - unclear thinking - sadness - despair - severe family problems - spiritual crisis - family problems - emotional Problems - spiritual and religious concerns 	<ul style="list-style-type: none"> - practical problems - severe financial problems
<p>Rehabilitation in der päd. Onkologie</p>			<ul style="list-style-type: none"> - individuelle psychische Belastungen und Probleme - Verhaltensauffälligkeiten - Schulschwierigkeiten 	<ul style="list-style-type: none"> - familiäre Störungen

5. INDIKATIONSSTELLUNG

Fragestellung: Bei welchen Belastungen/ Störungen muss psychosoziale Versorgung einsetzen?

Leitlinie	Basisversorgung für alle Patienten/ Familien	Intensivierte Versorgung Patient	Intensivierte Versorgung Eltern	Intensivierte Versorgung Geschwister	„Psychiatrisches Konsil“
SIOP		<ul style="list-style-type: none"> - psychological pain (6) - signs of non-compliance and refusal of treatment (9) 	<ul style="list-style-type: none"> - signs of family or parental dysfunction (6) - non-comprehension (9) - low socioeconomic status (9) - failure to follow simple instructions (9) - abandonment of treatment (9) 	<ul style="list-style-type: none"> - If siblings are potential bone-marrow donors (7) 	
NHMRC Australien (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - ensuring medical information is understood and retained - communicating in a quiet and private environment - responding to patterns of behaviour that may compromise treatment and cure - provide information about all aspects of the illness and the treatment - increase understanding - discuss difficult issues - providing support and emphasizing hopefulness - facilitating involvement in decision-making and choice - providing procedural and sensory information about difficult procedures - provide psychosocial support prior to potentially life-threatening procedures - check the extent of support available to the patient - provide additional support or access to support - talk about financial situation, provide financial support if necessary 	<ul style="list-style-type: none"> - existential concerns - psychological problems - body-image concerns - sexual difficulties - interpersonal problems - concerns for new relationships - severe emotional, stress and adjustment difficulties - anxiety - depression - traumatic symptoms - chemotherapy induced nausea and vomiting - pain - fatigue - fertility/pregnancy - lymphoedema - disfigurement - odour - communication difficulties - nutritional deficiencies - respiratory symptoms - significant psychological distress - significant physical impairment - severe physical symptoms - cultural and linguistic 			Clinical psychologist/ Psychiatrist: <ul style="list-style-type: none"> - anxiety - depression - suicidal ideation - PTSD - Body-image concerns - Sexuality concerns - Interpersonal problems - Severe emotional problems - Physical symptoms

	<ul style="list-style-type: none"> - help to arrange travel and accommodation - ensure continuity of care - identification of a coordinator of care 	diversity			
NCCN Distress Management (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - Clinical evidence of mild distress or score of less than 5 on screening tool. - Mild distress represents what the panel termed “expected distress” symptoms : part of normal response to a cancer diagnosis and treatment - Periods of increased vulnerability to distress - Signs and symptoms of normal fear and worry of the future and uncertainty - Concerns about loss of usual health - Anger, feeling out of control - Stable or diminished distress 	<ul style="list-style-type: none"> - Clinical evidence of moderate to severe distress or score of 5 or more on screening tool - Increased or persistent distress 	<ul style="list-style-type: none"> - Clinical evidence of moderate to severe distress or score of 5 or more on screening tool - Increased or persistent distress 	<ul style="list-style-type: none"> - Clinical evidence of moderate to severe distress or score of 5 or more on screening tool - Increased or persistent distress 	Clinical psychologist/ Psychiatrist: Psychiatric disorders <ul style="list-style-type: none"> - anxiety - mood disorder - adjustment disorder - anxiety disorder - substance-related disorder - personality disorder - dementia - delirium - other medical causes - behavioural problems - suicidal ideation - body image concerns - sexuality concerns - severe emotional problems - physical symptoms
Rehabilitation in der päd. Onkologie			<ul style="list-style-type: none"> - psychische Störungen - Spannungsreduktion und Angstbewältigung - Verhaltensstörungen (Einnässen, Einkoten) - Problematisches Essverhalten - Problematisches Bewegungsverhalten - Problematischer Alkohol- und Nikotingenuss - Nervosität und Konzentrationsschwäche 		

6. INTERVENTIONEN

Fragestellung: Welche Formen von Beratung und Therapie bei lebensbedrohlichen Erkrankungen werden angeboten zur Krankheitsbewältigung sowie zur Stärkung der Ressourcen von Patient und Familie?

Leitlinie	Psychologische Interventionen Patient	Soziale Interventionen Patient	Psychologische Interventionen Eltern	Soziale Interventionen Eltern	Interventionen Geschwister
SIOP	<ul style="list-style-type: none"> - Children should be helped to understand the illness and their response to the illness. They must be helped to accept the necessary treatment and they should be reassured that the acute treatment consequences can usually be effectively dealt with (1,9) - They should, whenever possible and at their appropriate level of development, actively participate in programs and other interaction processes aimed at promoting their participation in the decisions concerning their own health care (1) - Children need to understand in an age-appropriate manner, the new dimension of life (4) - Specific plan of care for each individual child (6) - Listening to the child's needs (6,9) - Include all family members in decision making (6,9) - Control physical and psychological pain (6) - Open communication between all family members and health care staff from the beginning (6,9) 	<ul style="list-style-type: none"> - Child should be encouraged to keep up with schoolwork (1) - At home they have to have a home teacher (1) - After therapy meet with the family to review the past and plan the future (1) 	<ul style="list-style-type: none"> - parents should be helped to behave toward the affected child in the same way as toward healthy siblings (1) - parents should be helped to plan how to best use their own emotional and material resources and energies to deal with the disease and its treatment. (4) - This involves concerning their fears and vulnerabilities (like anxiety, fear of the unknown, guilt...) to positive outlook and maintaining as normal a lifestyle as possible in the face of extraordinary demands (4) - Parents must be prepared for changes in their family roles (4) - They should be helped to offer patient advocacy, cooperation and help for the treatment team and reassurance for the child. (4,9) - post-death follow-up visits for parents and siblings (6) - Talk with parents about the needs of siblings (7) - insisting on and implementing continuous communication between all family members and the entire health care team (9) 	<ul style="list-style-type: none"> - providing a place near the hospital where families can stay (6,9) - finding someone to help with the needs of the other family members (6,9) - giving financial help (6,9) - judicial interventions in case of treatment abandonment (9) 	<ul style="list-style-type: none"> - involve siblings from the very beginning (7) - keep siblings informed in an age-related manner (7) - sibling support groups (7) - explain that siblings are not responsible for the cause of cancer (7) - encourage parents to bring siblings to hospital (7)

NHMRC Australien (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - support - education - exercise - relaxation training - relaxation therapy - guided imagery - systematic desensitisation - problem solving - cognitive – behavioural therapy - crisis intervention - progressive muscle relaxation - meditation - psychotherapy - group therapy - family and/or couple therapy - telephone counselling - supportive psychotherapy - drug therapy 	<ul style="list-style-type: none"> - planning of returning to work - working with interpreters 	<ul style="list-style-type: none"> - interventions providing support for partners 		
NCCN Distress Management (ausschließlich auf erwachsene Patienten bezogen!)	<ul style="list-style-type: none"> - clarify diagnosis, treatment options and side effects - education - building trust - ensure the continuity of care - mobilize resources - consider medication to manage symptoms - support groups and/or individual counselling - relaxation, meditation - creative therapies (e.g., art, dance, music) - Exercise 	<ul style="list-style-type: none"> - Mobilize resources 	<ul style="list-style-type: none"> - Clarify diagnosis, treatment options and side effects - Mobilize resources - Family support and counselling 	<ul style="list-style-type: none"> - Mobilize resources 	<ul style="list-style-type: none"> - Family support and counselling