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Palliative Care and End-of-Life Care in Children

Child Health Nursing

Principles of paediatric palliative care, pain and symptom management, emotional support, family counselling, bereavement care and ethical considerations.

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CHAPTER 25 / CHILD HEALTH NURSING 25. Palliative Care and End-of-Life Care in Children

1. Definition and aims

Paediatric palliative care is active holistic support for children with serious or life-limiting illness and their families. It can start at diagnosis and occur with disease-directed treatment. Objectives are pain and symptom relief, quality of life, participation, family support and care aligned with goals.

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2. Assessment and symptom management

Symptom	Nursing response
Pain	Use developmental self-report/behavioural scale, assess cause, prescribed weight-based analgesia and non-drug comfort, reassess sedation and breathing.
Breathlessness	Position, reduce distress, assess reversible causes/goals, prescribed oxygen or symptom therapy.
Nausea/constipation	Assess medications and causes; prescribed antiemetics/laxatives, mouth care and nutrition as tolerated.
Fatigue and feeding	Preserve enjoyable activities, rest, avoid forcing intake near end of life; individualized feeding plan.
Anxiety or agitation	Familiar people, child-friendly explanations, calm environment and assessment for pain/delirium.

3. Communication, ethics and family

Communicate honestly in age-appropriate terms, ask what child and family understand and value, use shared decision-making with appropriate consent/assent. Discuss goals and legally appropriate limits/resuscitation decisions with responsible team; do not equate comfort care with abandonment. Provide spiritual/cultural support by preference, sibling inclusion, memory-making when desired and psychosocial support. Bereavement care acknowledges varied grief reactions and offers follow-up.

4. Nursing role

Coordinate home/hospital teams, symptom and emergency plans, medication safety, accessible equipment, respite and support. Ensure privacy, dignity and ongoing comfort in dying; document decisions, symptom assessments, medicines and response; after-death care follows law/policy and family preferences.

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5. Important Examination Questions

Long Answer Questions

1. 1. Explain paediatric palliative care principles and nursing responsibilities.

Short Answer Questions

1. 1. Describe pain assessment
2. 2. discuss family and sibling support
3. 3. explain assent in serious illness.

Very Short Answer Questions (with answers)

1. 1. Can palliative care coexist with cancer treatment? - Yes.
2. 2. What is bereavement? - Experience of loss after death.

6. Quick Revision

- Treat the child and support the family.
- Manage symptoms actively.
- Respect evolving autonomy and goals of care.

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B.SC. NURSING / CHAPTER-WISE STUDY NOTES

7. Conclusion

Treat the child and support the family. Manage symptoms actively. Respect evolving autonomy and goals of care.

NURSE'S CONTENT / CHILD HEALTH NURSING 43

B.SC. NURSING / CHAPTER-WISE STUDY NOTES

Practice questions

Choose one best answer. The answer key and explanations follow the questions.

1. When can paediatric palliative care begin?

A. At diagnosis alongside disease-directed treatment
B. Only after all disease-directed treatment stops
C. Only in the final hours of life
D. Only after discharge to home

2. Which response best addresses fatigue and feeding near the end of life?

A. Force intake to meet a fixed daily target
B. Preserve enjoyable activities and use an individualized feeding plan
C. Remove all enjoyable activities to conserve energy
D. Continue feeding without assessing tolerance

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3. Which communication approach supports the child and family during serious illness?

A. Avoid discussing their understanding

B. Exclude a developmentally able child from every discussion

C. Ask what they understand and value using age-appropriate honesty

D. Equate comfort care with abandonment

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Answer key and explanations

1. A - At diagnosis alongside disease-directed treatment

Palliative care can accompany disease-directed treatment from diagnosis.

2. B - Preserve enjoyable activities and use an individualized feeding plan

Care emphasizes comfort, enjoyable activity and individualized feeding.

3. C - Ask what they understand and value using age-appropriate honesty

Honest, developmentally appropriate communication supports shared goals and decisions.

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