

Synthesis of health promotion concepts in children's palliative care

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Websites and databases searched	Google Scholar; ASSIA; Psych Info; DARE; Cinahl; Synopsis; Medline; BioMed Central and websites for European Journal of Palliative care: World; Health Organisation; Department of Health England; Department of Health, Ireland; Welsh Assembly Government; European Association for Palliative Care; International Children's Palliative Care Network.; Scottish and Irish Government websites; Royal College of Paediatrics and Child Health; Royal College of Nursing; National Institute for Health and Care Excellence; Scottish Intercollegiate Guideline Network; Children's charity sites - Together for short Lives; True Colours Trust; Hospice care UK; CLIC/Sargent; Macmillan; Barnardos.
Search terms	("paediatric palliative care" OR "child* palliative care" OR "ped* palliative care" OR "end of life" AND "child*" OR paed* "parent*" OR "hospice" OR "bereavement" OR "death" or "life limiting illness" or "terminal" AND "health promotion" AND "concept*" OR "framework" OR "model" OR "theory" OR "policy")
Inclusion criteria	<p>Inclusion: Policies, guidelines & models with UK influence, relevant commissioned reviews and evaluations listed in the website or data base. Any paper reporting social, physical, psychological, economic environmental and multi-disciplinary factors/ trends influencing children's palliative care relevant to the UK. Papers focused on wellbeing and on promoting health and quality of life in life limited children. Papers referring to philosophical and conceptual development of children's palliative care and its defining features. May be international and relevant to UK.</p> <p>English language papers</p> <p>Time frame- Jan 2000-Dec 2018</p> <p>Exclusion – Adult orientated policy, guidelines, models, letters & circulars .</p>

Supplemental file 1. Summary of search strategy

Conceptual framework of an illness journey (McNamara- Goodger & Feudtner, 2012)	Multiple levels of influence from health promotion (World Health Organisation , 1986)	The model of palliative care in the perinatal setting (Balaguer, Martin-Ancel, Ortigoza-Escobar et al., 2012)	Themes for the best fit framework derived from synthesis of the 3 models
<u>Entering</u> Initial concern & life threatening or life shortening diagnosis. Psychological, social, educational, spiritual and other quality of life effects Impact on family. Healthcare utilization.	<u>Build healthy policy & Create a supportive environment & Strengthen Community action</u> The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.	<u>Family centred care & maternal bond</u> Assist mother, father and family in coping with tragic pre-natal diagnosis. Emphasis on information provision for decision making.	<u>Life limiting diagnosis and classification of illness</u> Type of diagnosis /breaking bad news. Eligibility & access to various levels of care / service. <u>Collaboration and continuity across levels and locations of care;</u> Access to 24/7 advice and support for parents as carers- Levels of care and typology of care- universal, generic palliative, Specialist palliative, hospice, respite. Communication and multi-disciplinary working across levels of care. Location of care- home, hospice, school, hospital. Extended social network/ support- extended family, friends.
<u>Progression of disease and symptoms</u> Psychological, social, educational, spiritual and other quality of life effects. Ongoing effects on family. Healthcare utilization.	<u>Develop personal skill</u> Enabling people to learn (throughout life) to prepare themselves for all stages and to cope with chronic illness and injuries is essential. This must be facilitated in school, home, work and community settings.	<u>Antenatal period</u> Care and support are initiated early following a pre-natal diagnosis. Holistic treatment of mother and support for both parents.	<u>Supportive child and family centred care</u> Supportive, flexible family centred care. Family as main unit of care - parents carrying out complex procedures and technological care. <u>Integrated care containing palliative and curative concepts</u> Advanced planning with families over a variety of timeframes. Respite and short breaks. Access to 24/7 advice and support for parents as carers.
<u>Exiting</u> Approaching end of life – death & bereavement. Psychological, social, educational, spiritual and other quality of life effects Impact on family. Healthcare utilization.	<u>Re orientate health services & moving to the future</u> The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services. Reorienting health services also requires stronger attention to health research, as well as changes in professional education and training.	<u>Integrated care</u> Integrated obstetric and paediatric palliative care, neonatal care. <u>Symptom control</u> Neonatal palliative care initiated at birth. Obstetric care delivered as part of this, holistic approach to support of mother.	<u>End of life and terminal care concepts</u> Quality of life for parents and siblings. Promoting health, enjoyment and achievement, making a positive contribution- the child as a developing individual. <u>Death of child and bereavement</u> Choice of place of death and family's satisfaction with end of life care. Fear of dying- parents and child (developmental considerations). Siblings.

Supplemental file 2 A priori framework- iteration of children's palliative care & health promoting concepts

Supplemental file 3.

AACODS Credibility Appraisal Checklist

Reference of source				
	Domains	Yes	No	Comments
Authority	Is the evidence from a reputable organisation?			
Accuracy	What are the aims of the evidence? Is its basis clear? Has it been peer reviewed?			
Coverage	Are all limits clearly stated?			
Objectivity	Does the evidence seem balanced in presentation?			
Date	Is the date provided?			
Significance	In the reviewer's opinion is the evidence of interest ?			