

Synthesis of health promotion concepts in children's palliative care

Bennett, Virginia; Hain, Richard; Pritchard, Aaron; Noyes, Jane

International Journal of Palliative Nursing

DOI:

[10.12968/ijpn.2021.27.10.490](https://doi.org/10.12968/ijpn.2021.27.10.490)

Published: 17/12/2021

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Bennett, V., Hain, R., Pritchard, A., & Noyes, J. (2021). Synthesis of health promotion concepts in children's palliative care. *International Journal of Palliative Nursing*, 27(10), 490-503.
<https://doi.org/10.12968/ijpn.2021.27.10.490>

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INTRODUCTION

Palliative care for children and young people is an active and often nurse-led model of care that addresses the complex needs and high burden of symptoms associated with children's life-limiting conditions (see figure 1). This model promotes comfort and wellbeing so that the child and family are enabled to live life to the fullest (Rappoport, 2018; Together for Short Lives, 2017). Children's palliative care is an evolving field that is distinct from the adult model in that it places emphasis on the need for sustained and responsive support from diagnosis onwards over long durations, sometimes for the child's life. Whilst greater acceptance, understanding about the functions of children's palliative care is evident, there remains scope to develop understanding about the conceptual basis of the model.

An active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (World Health Organisation, 2019, p1).

Figure 1. Definition of children's palliative care

Globally there are an estimated 21.5 million children who would benefit from palliative care and of these 8 million who need specialised services (International Children's Palliative Care

Network (ICPCN), 2019). Such overwhelming need has accentuated the necessity for children's palliative care models to be redefined to help professionals and especially nurses understand what is required to enable all children who require palliative care to live well.

In the UK and countries with developed healthcare services the notable improvement of survival and improved quality of life of children in receipt of palliative care has been recognised (Fraser, Miller & Hain, 2012). Indeed, research has demonstrated that children with serious illness who are in receipt of palliative care have improved outcomes. However, despite this influence, the conceptual basis of children's palliative has remained largely under analysed.

As a holistic model, children's palliative care enshrines approaches that are tailored to provide support to mitigate the effects of disease in an age and developmentally appropriate way. This ensures that the negative impact of illness on the child's health and wellbeing is minimised and ensures the child's developmental continuum is protected. Such an approach appears to be conceptually rooted in a model of health promotion.

Health promotion

Health promotion is the process of enabling people to increase control over, and, to improve their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions (World Health Organisation, 2019). Building on these tenets The Ottawa Charter (World Health Organisation, 1986) (Figure 2) sought to promote greater individual and community responsibility for health through policy and has maintained its enduring purpose both practically and conceptually as a framework to address new emergent issues in public health such as children's palliative care. It was judged important to review whether health promotion conceptually influenced models, policies and guidelines with UK

influence as they create the context, influencing the mechanisms and outcomes of children's palliative care by capturing and setting priorities for practice and services.

Health promoting palliative care.

The notion of health promoting palliative care as model for adult care is well established and draws implicitly on concepts that can be attributed to a model of health promotion (Kellehear, 2005; Kellehear & O'Connor, 2008; Kellehear 2010; Rosenberg & Yates, 2010; Russell and Sander, 2013; Russell and Sander 2014). This model has most recently been extended and is also referred to as Public Health Palliative Care (Sallnow & Paul, 2015). However, Kellehear's (2005) model was not developed for children's palliative care and as such, caution must be taken when extrapolating theories developed for the adult domain to apply to children. Nevertheless, the idea of developing a model for children's palliative that draws on the tenets of the seminal work of Kellehear (1998;2005) has potential to extend professionals' understanding and guide practice in children's palliative care.

- Building healthy public policy
- Create supportive environments
- Strengthen community actions
- Develop personal skills
- Reorient health services
- Moving to the future

Figure 2 The Ottawa Charter, Five action areas and guiding principal (World Health Organisation, 1986)

Studies exploring the perspectives of children with palliative care needs and their families (Noyes, Hasting, Lewis *et al.*, 2013; Noyes, Pritchard, Rees, *et al.*, 2014; Noyes, Pritchard, Pritchard *et al.*, 2018) suggest that there may be conceptual relationships shared by models of health promotion and children's palliative care, but these relationships have not been formally articulated in current models of children's palliative care. The ideology of integrating children's palliative care with other care models is already receiving attention (Goldman, Hain and Lieben, 2012). Most naturalistically the move to integrated paediatric cancer and palliative care is well recognised (Waldman and Wolfe, 2013). The development of perinatal palliative care and the extension of the children's palliative care model to the unborn child and family is in its infancy in the UK (Murdoch, Carragher, MacNamara, 2013; Health Service Executive, Ireland, 2017). The benefits of sharing concepts of care between child psychiatry and children's palliative to reduce distressing emotional and psychological symptoms has also been reported (Muriel, Wolfe, Block, 2016) and the integration of children's palliative care into paediatric and neonatal intensive care where there has been in the past only cure-orientated care is increasingly reported (Carter and Craig, 2012; Longden, 2011; Longden, 2012). However, although these examples indicate the benefit of palliative care for children's health, there remain misconceptions about the conceptual basis of children's palliative care being a model focused mainly on death and end of life death. Such barriers have led to late adoption (Clercq *et al.* 2019) and children missing the benefits of palliative care.

It was judged important to explore whether relationships could be identified within the UK children's palliative care policy, models and guidelines as they have significant influence in the UK and wider in international settings, creating the context for children's palliative care, capturing and setting priorities for practice and services, and for guiding resource allocation from which care is operationalised. Importantly policy and guideline evidence are often more reflective of contemporary health care practice and was judged to have the potential to add depth of understanding about the conceptual basis of children's palliative care.

Aims of the review and best fit framework synthesis

To interpret whether health promotion shares a conceptual relationship with children's palliative care models, guidelines and policy, to synthesise the findings and use to inform a conceptual model that provided a fuller presentation of the conceptual basis children's palliative care.

The questions that guided the review were:

- Are health promotion concepts identifiable within the models, policies and guidelines with influence on children's palliative care in the UK?
- Where health promotion concepts are identified, what are their relationships and influence on the children's palliative care models, policies and guidelines?

REVIEW METHODS

An adapted best fit framework synthesis method guided the review process (Booth and Carroll, 2014; Booth, Sutton and Papaioannou, 2016; Carroll, Booth, Leaviss *et al.*, 2013).

Best fit framework synthesis is a two-staged methodological approach to the review of qualitative literature. It involved the development of a bespoke a priori framework alongside

a separately conducted search, collection and review of literature that is analysed and synthesised to extend the a priori framework. Chosen theories were reduced to their key elements and these formed the basis of a priori framework against which subsequent reviewed evidence was coded and synthesised to produce themes (Booth and Carroll, 2014; Carroll, Booth, Leaviss *et al.*, 2013). Relationships across the themes were generated and integrated into the final conceptual framework that represented a new model describing the attributes and functions of concepts shared by health promotion and children's palliative care (see figure 3).

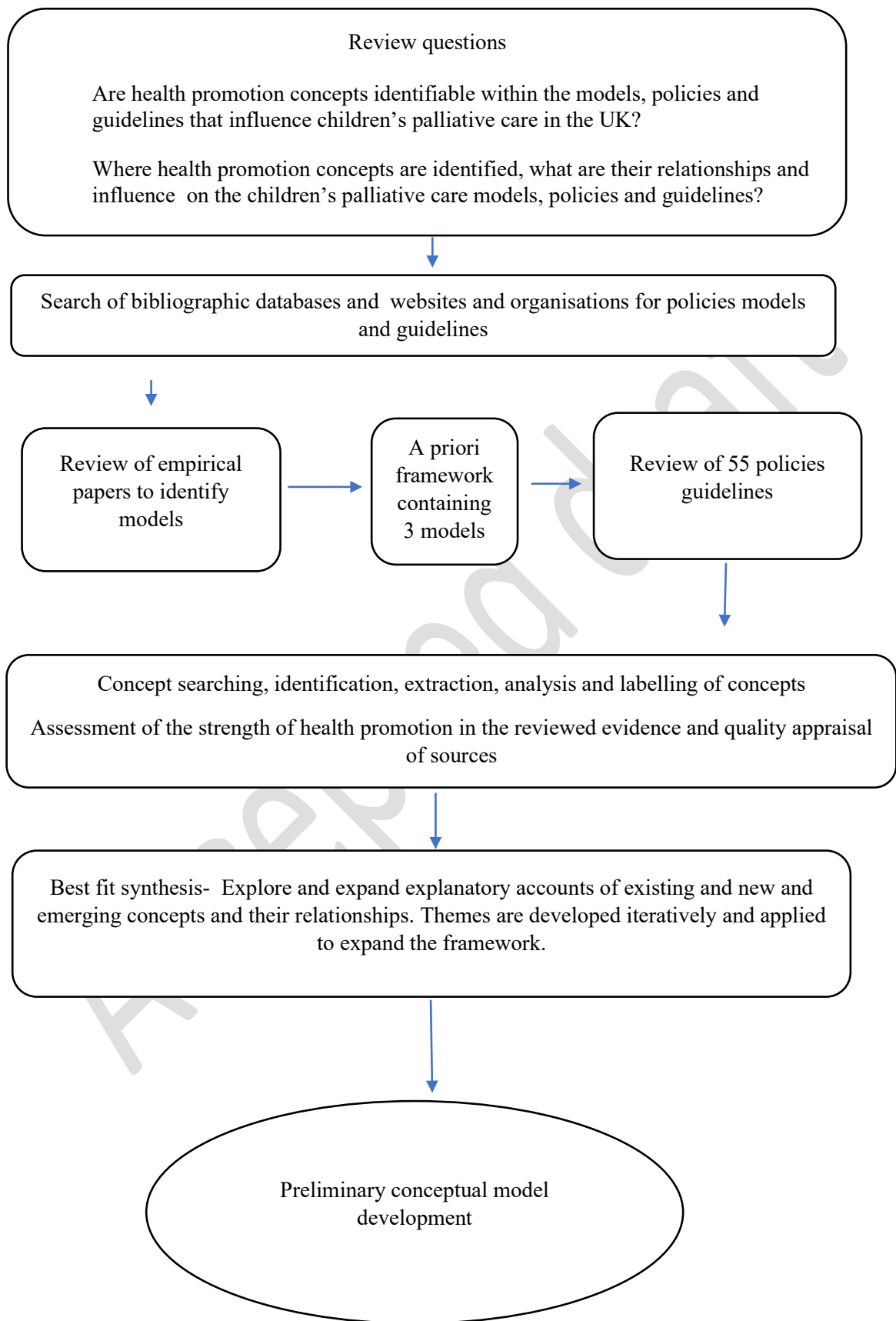


Figure 3. Flow diagram of best fit framework review process

As the aim was to identify whether a relationship between health promotion and children's palliative care concepts existed, the best fit synthesis method was suited as it provided a systematic, visible, purposeful framework to guide review and analysis of specific information. The deductive development and use of a theory informed a priori framework alongside an inductive, thematic review and synthesis provided potential for rich cross fertilisation of concepts across health promotion and children's palliative care whilst utilising a method thought to be more reproducible (Carroll, Booth, Leaviss *et al.*, 2013)

Search methods

Stage one search – a priori framework development. An extensive body of children's palliative care literature had been identified during a previous knowledge mapping exercise (BLINDED FOR PEER REVIEW), however, no description of the overlap between the concepts of health promotion and children's palliative care was identified. The original search strategy was extended using an adapted BeHEMoTh approach (Table1) (Booth , Sutton and Papaioannou, 2016). This search entailed adding the terms 'framework', 'conceptual model' and 'model' 'theory' and 'framework'.

Strategy	Terms
Be -Behaviour of interest	Health promotion, children's palliative care, child, end of life, life-limiting illness.
H -Health context	Variety of locations, home, hospice, hospital, relevant to the UK context.
E -Exclusions	Condition specific models, curative cancer focused models, evidence from very different health care systems with no UK influence.
MoTh -Models or theories	Empirical or grey literature, including theoretical, discussion papers. Evidence referring to the theory of palliative care or a framework for use in clinical practice. Any models, conceptual models, concepts, frameworks, pathways.

Insert: Table 1. Search strategy for best fit framework using BeHEMoTh approach

Stage one: a priori framework development.

The database search produced two sources that satisfied the inclusion criteria for children's palliative care models (Balaguer, *et al.*, 2012; McNamara- Goodger & Feudtner, 2012). As no model contained explicit reference to health promotion, concepts from a universal model of health promotion were amalgamated (World Health Organisation , 1986) with the themes generated from the two retrieved palliative care models (Balaguer, et al., 2012; McNamara-

Goodger & Feudtner, 2012) and an a priori framework was formed. (to view the iterative a priori framework, (see supplemental file 2).

Stage two search: Extending the framework.

A specific review of models, policy and guidelines concerned with delivery of children's palliative care followed stage one. Electronic database searches were undertaken for models, guidelines and policies that had influence on the UK children's palliative care context. The purpose was to identify whether they contained evidence of health promoting concepts. Free text and hand searches of individual websites were carried out using the search terms and synonyms. Practitioner, professional, voluntary and government websites provided a portfolio of evidence judged likely to contain policy and guidelines, however many of the electronic websites did not offer features that accommodated the use of truncation or Boolean logic and searches were labour intensive. All retrieved evidence was screened against the inclusion /exclusion criteria in and duplicates were removed. Evidence was downloaded directly from the websites. A request for full versions of policy documents were submitted to the Together for Short lives website to enable document download (see supplemental file 1 for a summary of the search strategy).

Stage two search outcome & quality appraisal:

The presence of health promoting concepts were identified in 55 policies and guidelines that met the inclusion criteria (See figure 4 for summary of search outcomes). Documents were critically appraised using the Authority, Accuracy, Coverage, Objectivity, Date and Significance (AACODS) checklist which identifies the key quality features in grey literature where specific research methods were absent (Tyndall, 2010) (supplemental file 3). The selected evidence met all 5 AACOD criteria for inclusion.

The 55 documents were then subject to a review specific assessment to ascertain the presence and strength of health promoting concepts. This involved the careful reading and the application of the key in Figure 5 across all the included models, policies and guidelines (see Table 2).

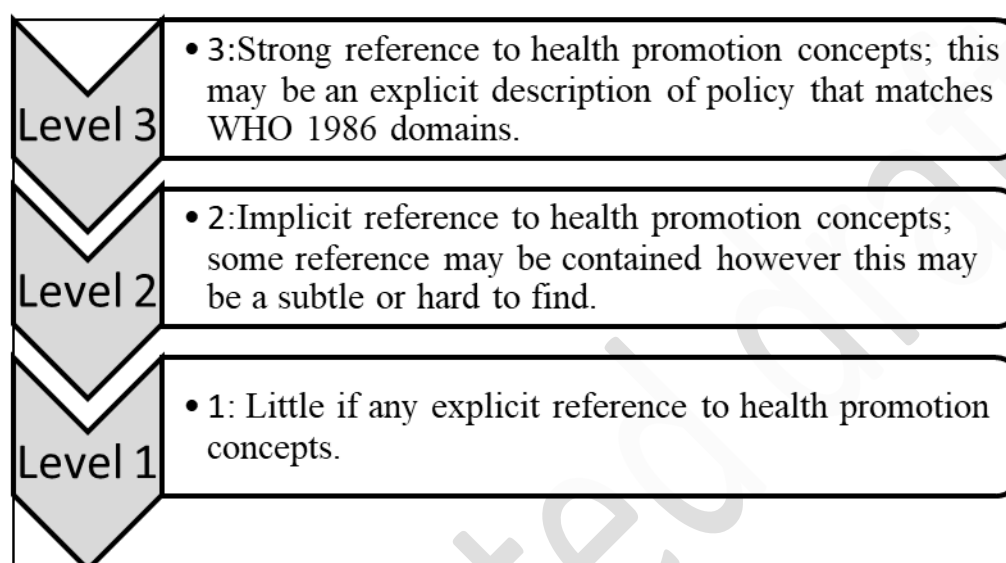


Figure 5: Criteria for assessing the strength of health promotion concepts within the reviewed guidelines and policy

Policy/ guideline	Building healthy policy	Create supportive environment	Strengthen community action	Develop personal skill	Re orientate health services	Moving to the future
National Institute for Clinical Effectiveness (NICE) (2016). End of life care for infants, children and young people with life limiting illness.	3	3	3	3	3	3
Together for Short Lives (2016a). Basic symptom control in paediatric palliative care.	2	3	2	3	2	2

Scottish Government (2016). Child's rights and wellbeing impact assessment for the strategic framework for action on palliative and end of life care (SFA).	3	3	3	3	3	3
Scottish Government (2015). Strategic framework for action on palliative and end of life care. The Scottish Government.	3	3	3	3	3	3
Together for Short Lives (2015a) Stepping Up; a good transition to adulthood for young people.	3	3	3	3	3	3
Together for Short Lives (2015b). Talking about sex, sexuality and relationships: Guidance and standards.	3	2	2	3	3	3
White, C., A. (2015). What matters to you about the future of palliative and end of life care in Scotland? (Engagement Document). National Advisory Group for Palliative and End of Life Care: Scottish Government.	3	3	3	3	3	3
Health Service Executive (Ireland) (2014). Palliative care needs assessment guidance.	3	2	2	2	2	3

National Institute for Clinical Effectiveness (NICE) (2014). Cancer services for children and young people.	3	3	3	3	2	3
Together for Short Lives(2014a). A guide to End of life care - care of children and young people before death, at the time of death and after death	3	3	2	3	2	3
Together for Short Lives (2014b). Family companion (3 rd edition).	2	3	3	3	3	3
Together for Short Lives (2014c). Medicines management toolkit (2 nd edition).	2	2	2	2	2	2
Together for Short Lives (2014d). Preparing for the future of children's hospice and palliative care: A checklist for Boards and senior management teams.	3	3	3	2	3	3
Together for Short Lives (2014e). Volunteering: vital to our future.	3	3	3	3	3	3
European Association for Palliative Care (2013).Core competencies for education in paediatric palliative care.	3	3	3	3	3	3
Together for Short Lives (2013a). A core care pathway for children with life limiting and life-threatening	3	2	2	3	3	3

conditions (3rd edition).						
Together for Short Lives (2013b). Standards framework for children's palliative care.	2	3	3	3	3	3
Together for Short Lives (2013c) The Future of hospice care report.	2	3	3	3	3	3
Welsh Government (2013). Together for health- delivering end of life care: a delivery plan up to 2016 for NHS Wales and its partners.	3	3	2	2	3	2
Chambers et al. (2012). The big study. A Guide to the Development of Children's Palliative Care Services (3 rd Edition).	3	3	3	3	3	3
Department of Health (2012). Commissioning guidance for specialist palliative care.	1	1	1	1	1	1
NHS Scotland (2012). The children and young people's acute deterioration management plan (CYPADM) policy document. The Scottish Government, Edinburgh.	3	3	3	3	3	3
Royal College of Nursing (RCN) (2012). Palliative care for children and young people	1	1	1	2	1	1
Scottish Children and Young Peoples' Palliative Care Executive	3	3	3	3	3	3

(SCYPPEX) (2012). A Framework for the delivery of palliative care for Children and Young People in Scotland.						
Scottish Government (2012). Cancer plan for children and young people in Scotland.	3	3	3	3	3	3
Together for Short Lives (2012a). Guide to end of life care.	3	3	3	3	3	3
Together for Short Lives (2012b). The verification of expected death in childhood.	2	2	2	1	1	2
Children and Young People's Specialist Services (CYPSS) Wales (2011). National standards for teenagers and young adults with cancer.	2	2	2	1	2	2
Department of Health (2011). NHS at home: community children's nursing services.	1	2	2	2	2	2
Together for Short Lives (2011). A toolkit to support ventilated children and Young People in children's hospices.	2	3	2	3	3	3
Wales Palliative Care Implementation Board (2011). Dying well matters.	1	1	1	1	1	2
British Association of Perinatal Medicine Working Group Report (2010). Palliative care: a framework for clinical practice	2	3	2	3	3	3

in perinatal medicine.						
Department of Health (DH) (2010). National framework for children and young people's continuing care.	2	3	3	3	3	3
Together for Short Lives (2010). The diversity toolkit.	3	2	2	3	3	3
Association for Children with Life Threatening or Terminal Illness and their Families (ACT) (2009). Making life limited children and young people count.	1	3	3	3	3	3
Department of Health and Children (Ireland) (2009). Palliative care for children with life-limiting conditions in Ireland.	3	3	3	3	3	3
Together for Short Lives (2009a). A Guide to the development of children's palliative care services (3rd edition).	3	3	3	3	3	3
Together for Short Lives (2009b). A neonatal pathway for babies with palliative care needs	3	3	3	3	3	3
Department of Health Children Schools and Families (DHCSF) (2007). Aiming high for disabled children.	3	3	3	3	3	3
Welsh Assembly Government (2008). All Wales palliative care standards for children & young	2	2	1	2	2	2

people's specialised health services.						
Association for Children with Terminal Illness (2007). Transition care pathway.	2	2	3	3	2	2
Barnardos (2007). Parenting Positively; coping with death (3 parents, teenagers, child) Access from The Palliative Hub (Ireland).	2	2	2	3	2	3
Craft, A. & Killen, S. (2007). Palliative care services for children and young people in England.	2	2	2	3	3	3
Department of Health (2006) Transition: Getting It Right for Young People. Improving the Transition of Young People with Long Term Conditions from Children's to Adult Health Services.	2	2	2	2	2	2
Department of Health (2005a). National service framework for children, young people and maternity services. Commissioning children's and young people's palliative care services.	2	3	2	2	2	2
Department for Health (2005b). National service framework for children, young people and maternity services; long term ventilation.	2	3	3	3	2	2
National Institute for Clinical Effectiveness (NICE) (2005).	2	2	2	2	1	2

Improving outcomes in children and young people with cancer.						
Noyes & Lewis (2005). From hospital to home; guidance on discharge management and community support for children using long term ventilation.	3	3	3	3	3	3
Specialist Health Commission Wales (2005) All Wales palliative care standards for children and young people's specialised healthcare services	1	2	2	2	2	2
Welsh Assembly Government (WAG) (2005b). National Service Framework for Children, young people and maternity services Acute & chronic illness and injury (Standard 7).	1	1	1	1	1	2
Welsh Assembly Government (WAG) (2005a). National service framework for children, young people and maternity services Disabled children& young people (Standard 5).	2	3	3	3	3	3
Welsh Assembly Government (2005c). National standards for specialist palliative care cancer services.	1	1	1	1	1	1
Department of Health (DH) (2004b). National service framework for children, young	2	3	3	3	3	3

people and maternity services: disabled children and those with complex health needs. Standard 8.						
Welsh Assembly Government (WAG) (2003). A strategic direction for palliative care services in Wales.	2	2	1	1	2	2
Thornes, R. (2001). Palliative care for young people aged 13-24.	1	2	2	2	2	2

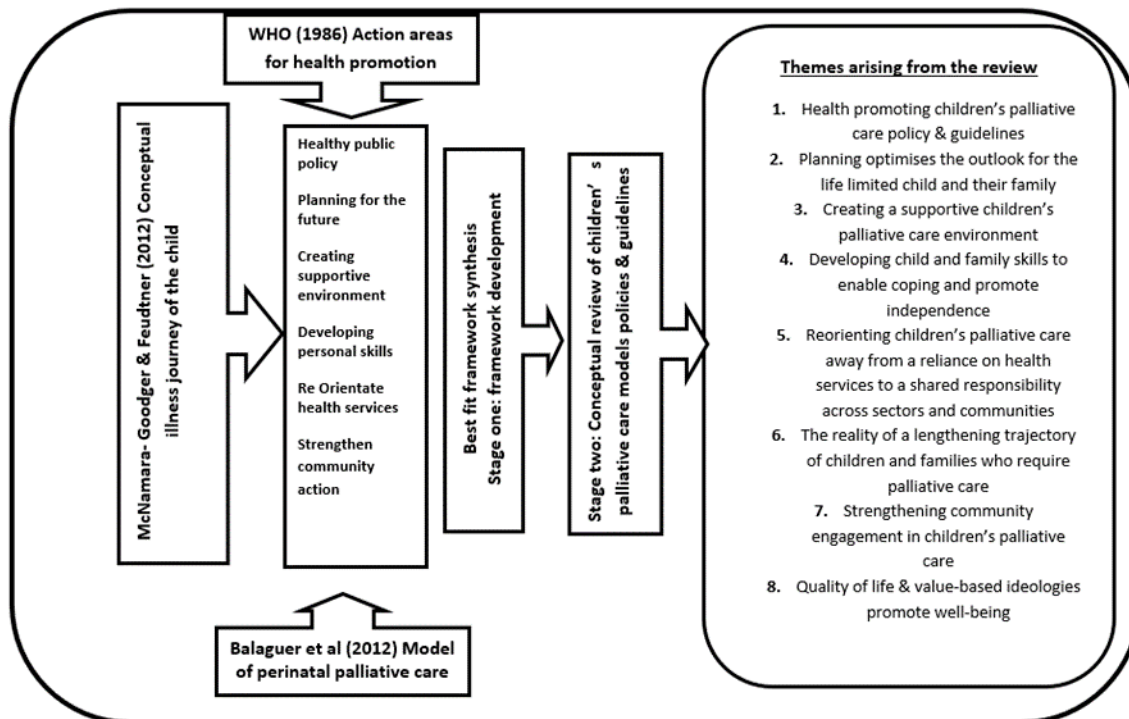
Insert: Table 2 Summary table of reviewed models, policies and guidelines in chronological order illustrating the presence of health promotion concept

Best fit synthesis and development of final framework themes

The final best fit synthesis drew together the two stages of the review process (Carroll, Booth, Leaviss et al., 2013). Relationships between the themes of the a priori framework and the reviewed evidence were expanded iteratively and reconstituted resulting in an extended conceptual framework.

FINDINGS

Data was extracted, reduced and arranged into eight final conceptual framework themes (See Figure 6). The following section reports the eight themes.



Insert: Figure 6. The best fit review process and arising themes

Health promoting children's palliative care policy & guidelines

Early policy aimed at children with disability (Department of Health & Department for Children, Schools and Families (DHCSF), 2007), contemporary guidelines and frameworks (Department of Health , 2010; National Institute for Health and Care Excellence (NICE) , 2016) and Scottish policy (Scottish Government , 2015; Scottish Government, 2016) provided explicit evidence of concepts and functions that promote life limited children's health and wellbeing. Scotland's 2020 vision of 'living and dying well' were all based on participatory frameworks that were traced to a shared philosophy of community and individual health ownership. Basic Symptom Control in Paediatric Palliative Care (Together for Short Lives, 2016a; White, 2015) was an example of guidelines generated within the UK setting and

extending health promoting influence globally as a clinical tool used in children's palliative care.

Planning optimises the outlook for the life limited child and their family

Planning for the future featured as an explicit core conceptual and practical function (DHCSF, 2007; Department of Health, 2010; Department of Health, 2012; National Health Service (NHS) Scotland, 2012; NICE, 2016; Scottish Government, 2015; Scottish Government, 2016; Together for Short Lives, 2016a; Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX), 2012; Together for Short Lives, 2013a; Together for Short Lives, 2013b; Welsh Government, 2013). Although faced with uncertain futures, the importance of anticipating children's fluctuation of need, and the requirement for both human and evidence support to help meet these needs was clearly recognised. Successful planning relied on strong professional and family relationships. This was prominent function promoted in policy for children with disability (Department of Health & Department for Children, 2007) and emerged with greater prominence more latterly in contemporary children's palliative care policy (Department of Health, 2010; NICE, 2016; Scottish Government, 2015; Scottish Government, 2016; SCYPPEX, 2012; Together for Short Lives, 2013; Together for Short Lives, 2016a; Welsh Government, 2013).

Planning for the future, and particularly, planning for death, had strongest explicit evidence in the Children and Young People's Acute Deterioration Management Plan (CYPADM) (NHS Scotland, 2012). The important function of planning ahead also featured in transition policy, one of the major milestones faced by young people who move to adult services for care (Children and Young People's Specialist Services (CYPSS) Wales, 2011; Department of Health, 2012; ; NHS Scotland, 2012; Together for Short Lives, 2015). Most recently, within perinatal care sources, the evidence reviewed described support and resource for planning

ahead from the point of diagnosis to include birth and death (Balaguer, Martin-Ancel, Ortigoza-Escobar, *et al.*, 2012; British Association of Perinatal Medicine, 2010; NHS Scotland, 2012; NICE, 2016; Scottish Government, 2015; Together for Short Lives, 2009; Together for Short Lives, 2013a; Together for Short Lives, 2013b; Together for Short Lives, 2015; Welsh Government, 2013).

Creating a supportive children's palliative care environment

Creating a supportive environment emerged as one of the stronger, more explicit themes (Chambers, Hunt, Coad *et al.*, 2012; Craft & Killen, 2007; Department for Health, 2005a; Department of Health, 2006; Department of Health & Department for Education and Skills, 2007; Thornes, 2001; Together for Short Lives, 2013b). Emphasis on the critical importance of short breaks emerged with benefits attributed to both the child and their family enabling them to cope with the day to day stress by providing a positive experience. Linked to better general health and wellbeing and family coping this is a critical health promoting function of children's palliative care. As parents strive to provide a high level of complex support for children in their homes a more formal supportive network around the family is required (Department of Health & Department for Children, Schools and Families, 2007). Although recognised, (Craft & Killen, 2007), this important function was not consistently explicit despite being identified by families as a characteristic of what better children's palliative care should look like (Chambers, Hunt, Coad *et al.*, 2012).

Developing child and family skills to enable coping and promote independence

Transitional policies and pathways (Chambers, Hunt, Coad *et al.*, 2012; Craft & Killen, 2007; Thornes, 2001; Department of Health, 2005b; Department of Health, 2006; Department of Health, 2008; Department of Health & Department for Education and Skills, 2006; Department of Health, Schools & Families, 2007; Noyes & Lewis, 2005) steered a more

person-centred approach with a step away from family centred care. However, policy poorly attended to the important aspect of social development for the young person with a lack of focus on preparing the young person to cope with their long-term condition independently.

Reorienting children's palliative care away from a reliance on health services to a shared responsibility across sectors and communities

The distinct function of children's palliative care pathways in creating a collaborative working climate was explicit. 'A Core care pathway for children with life-limiting and life-threatening conditions'(Together for Short Lives, 2013a) provided founding structure and suggested processes that have been echoed in most recent policy. This model encourages family and professional collaboration across service and sector boundaries, with less delineation, guiding greater integration across different organisational models of care. This reorientation is important for children and families during periods of transition across services and settings and ensured that models remained responsive to the child's changing needs. In this review the location for provision of children's palliative care delivery was identified as influencing the approach to care and support with home and school-based models of care driving a multiagency approach to support whilst attempting to maintain normality for the child (British Association of perinatal Medicine, 2010; Chambers, Hunt, Coad *et al.*, 2012; Craft & Killen, 2007; Department for Health, 2005; Department of Health, 2006; Department of Health, 2007; Department of Health, 2008; Department of Health, 2010; Noyes & Lewis, 2005; Scottish Government, 2015; Scottish Government, 2016; Together for Short Lives, 2009a; Together for Short Lives , 2014a; Together for Short Lives , 2014b; Together for Short Lives, 2015a; Thornes, 2001; Welsh Government, 2013).

The reality of a lengthening trajectory of children and families who require palliative care

An emerging function within the reviewed evidence was the provision of children's palliative care to groups of children (neonatal and young adults) not traditionally in receipt of this model of care. The drive to extend the children's model of palliative care is linked to the recognised impact it has in improving the health-related quality of life (Children and Young People's Specialist Services (CYPSS) Wales, 2011; Department of Health, 2012; NHS Scotland, 2012; Together for Short Lives, 2009b; Together for Short Lives, 2015a). However (SCYPPEX, 2012) had the greatest emphasis on care and support networks wider than health services, and with emphasis on the young person living well and moving onto independence and person-centred care(Together for Short Lives, 2010).

Strengthening community engagement in children's palliative care

The notion of agency, community support and volunteerism emerged as function to meet projected need and to engage with families (Department of Health, 2004; Department of Health, 2016; Department of Health and Children (Ireland), 2009; Noyes & Lewis, 2005 SCYPPEX, 2012; Together for Short Lives, 2011; Together for Short Lives, 2014a; Together for Short Lives, 2014b; Together for Short Lives, 2014e; Welsh Government, 2013). In an ideal situation this should be woven around the child and family providing a network where a key person, most often a professional who has greatest contact with the family, would provide support (CYPSS, 2011; Department of Health, 2007; Department of Health & Department for Children, Schools and Families, 2018; Together for Short Lives, 2013). The role of key worker was identified in this review as contributing to the function of community engagement.

Quality of life & value-based ideologies promote well-being

Early policy aimed at children with disability (DHCSF, 2007; Department of Health, 2012) contemporary models and guidelines (NICE, 2016; SCYPPEX, 2012;) and Scottish policy

(NHS Scotland, 2012; Scottish Government 2015; Scottish Government, 2016; SCYPPEX, 2012) provided explicit evidence of concepts and functions that promote life limited children's health and wellbeing and this stance was more widely infiltrating most recent reviewed evidence. Scotland's 2020 vision of 'living and dying well' is based on participatory frameworks that can be traced to a shared philosophy of community and individual health ownership.

DISCUSSION

This review provides new insights and preliminary model of the conceptual basis of children's palliative care. It was initially disappointing to find that earlier children's palliative care policy failed to explicitly present the health promoting concepts and functions contained in the framework. This did not imply any failure in relation to the success of care delivery and support for children who required palliative care at that time, rather that concepts shared with health promotion were too deeply embedded and hidden to discern, or were overshadowed by a more medicalised presentation of approach.

It has been acknowledged throughout the evidence reviewed, that families need to be supported to care, and that the need for support continues after the child's death during bereavement. There is, however, a sense of urgency to better support families in this respect. This may in part be attributed to the important epidemiological research conducted that predicts increasing longevity and greater demand for children's palliative care (Fraser, Miller & Hain *et.al.*, 2012).

The models of children's palliative care emerging from this review extended beyond those described by Craig and Baylis (2015) as being; a Community based model, Hospital outreach and shared care model, and a Children's hospice based with outreach home and school-based care. The scope and boundaries of these models extended beyond settings to prenatal

diagnosis and perinatal palliative care, as well as to young people who were undergoing transition to adult palliative care (Together for Short Lives , 2009a; Together for Short Lives , 2014a; Together for Short Lives, 2015a; Together for Short Lives, 2016b). This extension provided a manifestation of the benefits that the palliative care model has in meeting and importantly anticipating the needs of those in receipt of care and support. A common feature appeared to be the ‘blending’ of approaches and the importance of shared concepts across adult and children’s care in the young person’s transition and with obstetric, paediatric and neonatal services in the perinatal model.

Creating a supportive children’s palliative care environment

The increasing complexity of physical and psychosocial care was conceptualised in contemporary guidelines. A function of a more evidence-based approach to palliative care signifying the increasing need by professionals to provide effective care and symptom management (Together for Short Lives, 2016b). This has been enabled by access to growing populations and expanding research into palliative care for children. The growth of guidelines related to sensitive and difficult areas such as sharing bad news, dying and death, symptom management, alongside everyday health considerations for young people such as sexual health, reflect the increased public recognition of the need to deal with the practicalities of living with life-limiting conditions and dealing with child and infant death (Together for short Lives 2012a; Together for short Lives, 2012b; Together for short Lives, 2014a; Together for short Lives, 2014b; Together for Short Lives, 2015a). Although the public health drive is to extend life and avoid preventable deaths, there remains an important need to properly inform and guide the life limited child and young person, parents, professionals and the public about how to deal with these issues pragmatically and socially. This dimension is no different than any other aspect of lifespan guidance.

Equipping children and families with resources to cope and promote independence

Increasing complexity of care needs also requires family carers and professionals to be equipped with the appropriate skills and knowledge and have access to the resources to meet each child's palliative care needs. Recognition of parents as the main care providers of palliative care was unequivocal across reviewed evidence. Where families are upskilled and provided the resources and training required, coping and independence are promoted. The potential for this to feedforward in a positive cycle to build family resilience and functioning was realised.

Knowledge and skills – a shared resource to promote the children's health and well being

A key function of children's palliative care models, policy and guidelines were to shape the delivery and resources for training and skills development, and to create the supportive context to sustain this given the changing trajectory for each child. The intensity and complexity of palliative care needs often require additional specialist input and require the child to move across boundaries and settings to access this care, frequently in intensive care and hospice settings (Carter and Craig, 2012; Longden, 2011). This shifts the focus to the proficiencies of staff and often relies on parents to guide care even when their child is critically ill. Networks of support and integration across health, social and educational systems were identified to support families to care for their child across settings. This clearly aligns to the participatory approaches espoused in the Ottawa Charter action areas (World Health Organisation, 1986) contained in the framework. A model of children's palliative care where the care and resources follow the child across settings is one espoused as gold standard and lobbied for by children and families (WellChild, 2018), however, is yet to be fully realised in practice. From an international perspective The World Health Organisation has recognised that although palliative care provides the best possible health for those children

with life-threatening illness there are widespread misconceptions that prevent it being integrated into universal models of care and that lack of education lies at the root of this conundrum with the education of professionals' key in addressing these issues. The Core competencies for education in paediatric palliative care (European Association for Palliative Care, 2013) are underpinned by principles closely aligned with health promotion with the aim of equipping healthcare providers globally with the skills that ensure the best possible access and optimal responses for children in need.

Person centred models of support

Children with life-limiting conditions and their families face a multitude of stressors. The importance of policy that supports them to draw on critical internal and external resources that contribute to their coping and adaption and in turn promote their health and resilience and wellbeing, is essential (McCubbin and Boss, 1980; Social Care Institute for Excellence, 2019). This approach is relevant across all settings and draws on established ways of working with children and families using a more person centred, social model of support. This review has confirmed that the concepts underpinning children's palliative care models, guidelines and policies share these important concepts with a model of health promotion. The wider determinants that contribute to the life limited child's health and wellbeing are not yet fully understood however this review illuminates the opportunity for the future, building and adapting models of children's palliative care with more explicit reference to the person-centred concepts shared with models of health promotion.

As the synthesis progressed it became clear the most contemporary policies and guidelines had the strongest sense of congruence with health promotion, with a socially driven approach to shaping provision. The impetus and change in model, policy and guideline conceptual emphasis appeared to be towards more integration across health, social and educational

systems, driven by a social model of care. Health services in Scotland have a history of integrated health and social care and a stronger ethos of community centred approaches that have avoided dependence on health care services to meet population needs (Calderwood, 2016; Dayan & Edwards, 2017).

Greater emphasis on functions such as informal networks of support and empowerment were evident, clearly aligning approaches across children's palliative care and the participatory approaches espoused in the Ottawa Charter action areas (World Health Organisation, 1986) Through the conceptual review process, we have uncovered a stance that conceptualises the functions of children's palliative care as optimizing life limited children's health and well-being, helping them to achieve their full potential whatever their norm. This view places greater emphasis on the concepts of health promotion and on empowering children and families to cope and build resilience in areas of healthcare traditionally based on a medical model (Dayan and Edwards, 2017; Social Care Institute for Excellence, 2019; United Nations Convention on the Rights of the Child, 1989). A model of children's palliative care that explicitly identifies how it is informed by health promoting concepts is likely to resonate with children and families and has great potential to develop the conceptual basis of palliative care provision to children.

Extending professional practice to benefit children and families.

This synthesis has revealed that health promoting concepts are embedded in the models, policies and guidelines that shape professional practice. The new conceptual model has made this explicit and has placed emphasis on the need to extend professional practice in a direction that benefits child and family health. This will be increasingly important as the demand for children's palliative care grows and becomes increasingly reliant on families for sustained delivery. The value of an approach that will guide sustainable models of care whilst enabling child and family wellbeing, offers a good starting point for the development of professional practice.

CONCLUSION

This synthesis has produced a new model that sheds light on important relationships between a model of health promotion and the approaches espoused in children's palliative care models, guidelines, and policy. The findings suggest that children's palliative care and health promotion have relationships that may be important in helping to develop understanding about children's palliative care, this emerging relationship has been conceptualised and translated into a preliminary conceptual model for future testing.

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