


A mixed-methods systematic review and meta-analysis of barriers and facilitators to paediatric symptom management at end of life

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Abstract

Background: Symptom management for infants, children and young people at end of life is complex and challenging due to the range of conditions and differing care needs of individuals of different ages. A greater understanding of these challenges could inform the development of effective interventions.

Aim: To investigate the barriers and facilitators experienced by patients, carers and healthcare professionals managing symptoms in infants, children and young people at end of life.

Design: A mixed-methods systematic review and meta-analysis was undertaken (PROSPERO ID: CRD42019124797).

Data sources: The Cochrane Library, PROSPERO, CINAHL, MEDLINE, PsycINFO, Web of Science Core Collection, ProQuest Dissertations & Theses Database, Evidence Search and OpenGrey were electronically searched from the inception of each database for qualitative, quantitative or mixed-methods studies that included data from patients, carers or healthcare professionals referring to barriers or facilitators to paediatric end-of-life symptom management. Studies underwent data extraction, quality appraisal, narrative thematic synthesis and meta-analysis.

Results: A total of 64 studies were included (32 quantitative, 18 qualitative and 14 mixed-methods) of medium-low quality. Themes were generated encompassing barriers/facilitators experienced by carers (treatment efficacy, treatment side effects, healthcare professionals' attitudes, hospice care, home care, families' symptom management strategies) and healthcare professionals (medicine access, treatment efficacy, healthcare professionals' demographics, treatment side effects, specialist support, healthcare professionals' training, health services delivery, home care). Only one study included patients' views.

Conclusion: There is a need for effective communication between healthcare professionals and families, more training for healthcare professionals, improved symptom management planning including anticipatory prescribing, and urgent attention paid to the patients' perspective.

Keywords

Child, paediatrics, palliative care, terminal care, pain management, caregivers, systematic review, meta-analysis

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What is already known about the topic?

- The palliative care needs of infants, children and young people differ to those of adults.
- The broad spectrum of paediatric life-limiting or life-threatening conditions mean that symptoms are varied and complex to manage.
- The UK National Institute for Health and Care Excellence (NICE) has emphasised pain management in paediatric palliative care as a research priority.

What this paper adds?

- This is the first systematic review and meta-analysis to investigate and report on the barriers and facilitators experienced by carers and healthcare professionals when managing paediatric symptoms at end of life.
- Healthcare professionals' attitudes, treatment and its side effects, place of care and families' own symptom management strategies all impact on family caregivers' ability to manage symptoms.
- Barriers and facilitators to symptom management for healthcare professionals include medicine access, treatment efficacy and side effects, specialist support, training and education, health services delivery and home care.

Implications for practice, theory or policy

- This review provides information about ways to improve paediatric symptom management at end of life.
- Effective communication between healthcare professionals and families, increased healthcare professional training and better symptom management planning are needed to improve pain and symptom management.
- There is an urgent need for more research on paediatric patients' views on end-of-life symptom management.

Introduction

It is estimated that nearly 1.2 million children worldwide require palliative care at end of life¹ while nearly 50,000 infants, children and young people in the United Kingdom and 500,000 in the United States live with a life-threatening or life-limiting condition.^{2,3} The broad spectrum of these conditions and the differing palliative care needs of children compared to adults means that symptoms are varied and complex to manage.⁴ Effective symptom management differs significantly in children depending on their age, diagnosis, physiological and cognitive developmental stage and their ability to communicate and understand.⁵

There is a lack of research on family carers' experiences of administering medicines for symptom and pain management in this population. Caregivers may not have the required knowledge and confidence to provide adequate symptom relief while also minimising side effects such as sedation. Fear of errors may lead to insufficient or inappropriate doses of analgesics.⁶ As such, parents will move children away from their preferred place of care if effective symptom relief cannot be provided.⁷ Healthcare professionals also describe home paediatric palliative care as 'difficult, complex and ambiguous'⁸ suggesting that they may lack the skills and training required to support carers.

A clinical practice guideline from the UK National Institute for Health and Care Excellence (NICE) on end-of-life care for children was based on the findings of 20 systematic reviews.⁹ Four of these assessed the effectiveness of interventions for agitation, respiratory distress, seizures and pain management.⁹ Only the latter review found any

studies that met the inclusion criteria and these involved pharmacological interventions only. Although these reviews provided essential guidance, to our knowledge, no systematic review has examined the barriers and facilitators to paediatric symptom management at end of life. NICE emphasised pain management in palliative care as a research priority and recommended further research on the factors influencing preferred place of end-of-life care, hypothesising that symptom management plays a critical role in this decision.⁹ A greater understanding of this could inform the design of evidence-based interventions to support more effective symptom management, thereby improving care for children and their families. The aim of this systematic review was to identify and synthesise the existing literature exploring barriers and facilitators experienced by patients, family carers and healthcare professionals when managing paediatric symptoms at end of life.

Methods

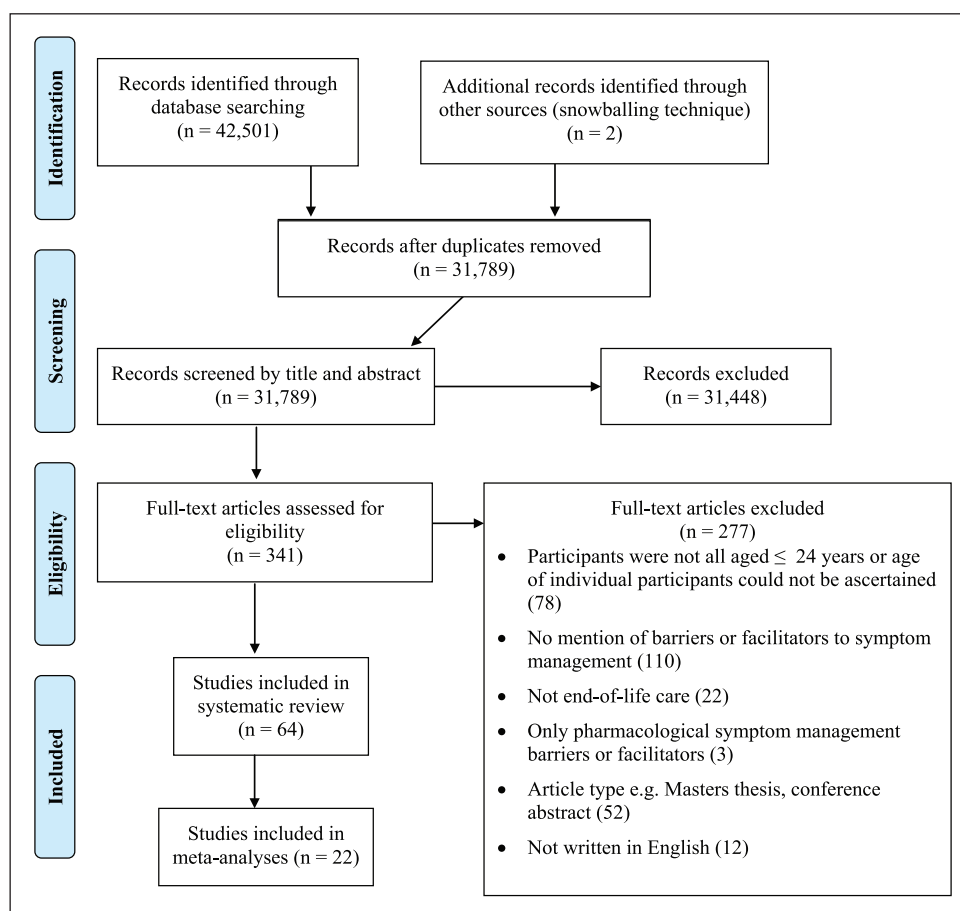
A detailed description of the searches (Supplementary File 1) and quality assessment for this systematic review is included in the published protocol¹⁰ and registered on PROSPERO (ID CRD42019124797).¹¹ Study exclusion and inclusion criteria are shown in Table 1 and the flow diagram of the included studies is shown in Figure 1.

Data synthesis

The majority of included studies were either qualitative, mixed-methods or involved a quantitative survey, as

Table 1. Inclusion and exclusion criteria.

	Inclusion	Exclusion
Population	Views, attitudes, opinions, perceptions, beliefs or feelings of carers, healthcare professionals or patients up to the age of 24 years when managing symptoms in infants, children and young people with terminal illnesses receiving palliative care and/or at end of life. All definitions of 'end of life' will be included	
Location	Worldwide	
Publication type	Qualitative, quantitative and mixed-method studies	Articles written in any language other than English, masters theses, conference abstracts, reviews
Range of years	From the inception of each database until February 2019	

**Figure 1.** Flow of records for inclusion in the systematic review and meta-analyses of barriers and facilitators to paediatric symptom management at end of life.

opposed to an intervention design. A narrative summary approach was taken as this allowed the integration of qualitative and quantitative evidence. Since qualitative data were relatively thin, a thematic synthesis approach to our narrative summary was conducted, enabling the identification and organisation of the data into prominent themes as per our protocol.¹⁰ K.G. and S.H. independently read the

studies and extracted relevant findings into NVivo.¹² After data familiarisation, they generated initial codes with written interpretations of quantitative data coded in the same way as qualitative data, for example, if a study reported that half of the nurses surveyed reported a lack of training in pain relief, this was coded under a theme on healthcare professionals' training.¹³ The two authors discussed and

compared codes and emerging themes, with successive independent re-reading of the studies and data. Over several discussions, K.G. and S.H. developed and refined common themes from the codes for patients, caregivers and healthcare professionals separately. The papers were then re-read by both reviewers to check the data fitted the codes and to check for any relevant uncoded data. There is currently no recommended approach for assessing confidence in combined qualitative and quantitative evidence.¹⁴ However, since we used an integrated design, in which quantitative data were transformed into qualitative data (themes), the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research)¹⁵ was used to summarise confidence in each theme.

Meta-analytic methods

A meta-analysis was chosen to synthesise and summarise the quantitative data and identify any barriers or facilitators arising from these data. The outcome for meta-analysis was the proportion of participants endorsing or reporting each specific facilitator/barrier. Data had to be available from two or more eligible studies reporting similar barriers or facilitators for meta-analyses to be conducted. For each survey item data pertaining to (1) the number of participants endorsing or reporting that barrier or facilitator and (2) the total number of valid survey responses was extracted. If data were only given in percentages, the raw values (i.e. number of participants endorsing each response) were computed. If studies divided participants into subgroups (e.g. by gender or career stage), the data were re-aggregated. The exact question asked, possible responses (where included in the original article) and raw data are provided in Supplementary File 2. Where data were available, we computed the crude unweighted mean proportion of agreement. We then used Comprehensive Meta-Analysis (CMA) version 3¹⁶ to compute a pooled weighted estimate using a random-effects model since this can be used when statistical heterogeneity (I^2) is present. Cochran's Q and the I^2 statistic were used to assess study heterogeneity. With Cochran's Q , a significant result is indicative of heterogeneity. The I^2 statistic describes the percentage of variability in effect estimates due to heterogeneity as opposed to sampling error.¹⁷

Results

Study selection

The titles and abstracts of 31,789 articles were reviewed by one reviewer (K.G.) and a random 20% were checked by a second reviewer (S.H.), with high inter-coder agreement (0.99 Cohen's kappa coefficient). After discussion, 341 full-texts were read and 277 were excluded (see Figure 1 for reasons). The final review included 64 eligible

studies, which included 32 quantitative studies, 18 qualitative studies and 14 mixed-methods studies (see Table 2 for study characteristics).

Study appraisal

The majority of the included studies were of low/moderate quality (see Supplementary File 3). Trustworthiness⁸² of qualitative studies was rated as high in 11, medium in 6 and low in 4 studies. Inter-coder agreement was 0.72, 0.80 and 0.25 Cohen's kappa coefficient for the qualitative, mixed-methods and quantitative studies, respectively. Low inter-rater reliability for the quantitative studies was due to different interpretation of one question (E1) on the Quality Assessment Tool for Quantitative Studies (QATQS)⁸³ regarding the criteria for assessing the validity of questionnaires. Once the interpretation of this item was discussed and agreed, the studies were reassessed on this item giving an overall inter-rater reliability for the QATQS of 0.90 Cohen's kappa coefficient.

Confidence in the evidence (the themes) was assessed using the GRADE-CERQual (Supplementary File 4). For the majority of the evidence, confidence was reduced due to moderate–substantial methodological limitations (insufficient detail on data collection and analysis and validity and reliability of quantitative data collection tools).

Thematic analysis

The thematic analysis produced six key themes relating to family carers' views and eight themes relating to healthcare professionals' views on barriers or facilitators to symptom management. Only one included study involved children's views. A summary is presented in Supplementary File 5.

Barriers and facilitators to symptom management reported by family carers

Giving treatment. Giving adequate medication was, unsurprisingly, seen as beneficial in improving or managing children's symptoms.^{41,45,53,62,63,75,78} One study highlighted the importance of free medication for providing adequate pain control.⁶⁸ In several studies, parents stated that children were not given sufficient medication or treatment therefore leading to poor symptom management (Supplementary File 5, quotation 1 (Q1)),^{29,30} particularly when a child's condition deteriorated;⁶¹ he or she developed complications;^{61,73} or when there was a lack of available drugs licensed for children.⁶¹ Inadequate assistance with administering or managing treatment was a barrier to symptom management in two studies.^{55,57} Some families also felt the assessment of their child's emotional symptoms was not properly met,⁵⁰ suggesting that they were not sufficiently treated either.

Table 2. Characteristics of studies included in the systematic review.

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Amery ¹⁸	Map children's palliative care around the world and survey respondents' learning needs	Varied including healthcare professionals (251), students, managers, social workers, volunteers, academics, counsellors/psychologists, therapists (346)	Closed-question survey	3-month period in 2010	Online questionnaire, UK	Descriptive statistics
Amery and Lapwood ¹⁹	Identify and explore educational needs of children's hospice doctors in England	UK children's hospice doctors (35 for questionnaire, 17 for diary and interview)	Closed-question survey, diary and semi-structured interview	Not stated	Children's hospices in the United Kingdom	Questionnaire and diary: not stated; interview: findings were discussed and crosschecked
Amery et al. ²⁰	Research the children's palliative care educational needs of healthcare professionals in Uganda	Healthcare professionals (48 for survey, 8 for survey interview and focus group)	Closed-question survey, logbook, semi-structured interview, focus group	Not stated	Hospices in Uganda,	Survey: descriptive statistics logbook, interview and focus group: thematic analysis
Bagatell et al. ²¹	Design, implement and evaluate a seminar series for paediatric residents	Paediatric residents (10 pre-test, 8 post-test)	Pre- and post-test closed-question survey	Not stated	University of Arizona, USA	Pre- and post-test comparison, descriptive statistics
Balkin et al. ²²	Create and test a portable reference card to improve paediatric resident education	Year 1 and Year 2 paediatric residents (26)	Pre- and post-intervention closed-question survey	6-month period in 2015	The University of California San Francisco Benioff Children's Hospital, USA	Pre- and post-test comparison, descriptive statistics
Baughcum et al. ²³	Develop and evaluate a paediatric palliative care workshop for oncology fellows	Oncology fellows in a paediatric haematology/oncology fellowship programme (32)	Pre- and post-workshop closed-question survey	1 day in November 2004 and May 2005	Children's Hospital in Columbus, Ohio and at the annual meeting of the American Society of Paediatric Hematology Oncology (ASPHO), Washington DC, USA	Pre- and post-test comparison, descriptive statistics
Bergstraesser et al. ²⁴	Describe perceptions and needs of paediatric healthcare professionals	Paediatric healthcare professionals caring for children with palliative care needs (78)	Qualitative interview	September 2007–January 2008 and February–August 2009	The participants' work environments, Switzerland	Content analysis
Bogetz et al. ²⁵	Examine healthcare professionals' views on barriers to paediatric palliative care	Nurses and other paediatric specialists (275)	Online closed- and open-question survey	2017	Children's hospitals within the University of California, San Francisco Health System, USA	Descriptive statistics and comparison with data from a previous study
Byrne et al. ²⁶	Explore the role of parent self-efficacy related to pain management for seriously ill children and adolescents	Parents/caregivers (50) of children and adolescents expected to survive 3 years or less	Closed-question surveys	Not stated	At home or at a hospital/clinic in the USA	Descriptive statistics

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Chen et al. ²⁷	Evaluate the impact of training on paediatric healthcare professionals' confidence and attitudes related to pain and symptom management for children with life-limiting or life-threatening conditions	Paediatricians and nurses who had completed a 5 hour training programme (71)	Pre- and post-training closed-question survey	Not stated	The Taichung Veterans General Hospital, Taichung City, Taiwan	Pre- and post-training comparison, descriptive statistics
Collins et al. ²⁸	(1) Identify benefits and difficulties encountered by families during their child's palliative care; (2) suggest strategies; (3) assess parents' adjustment after their child's death	Families (18) of children who had died receiving palliative care at home	Semi-structured interviews; closed-question survey	Not stated	Home, hospital or over the telephone, New South Wales, Australia	Not stated
Contro et al. ²⁹	Obtain personal accounts of families' experiences	Parents (68) of deceased children	Face-to-face interviews with closed- and open-questions	September 1998–March 1999	Lucile Salter Packard Children's Hospital (LSPCH), California, USA	Thematic analysis
Contro et al. ³⁰	Conduct a staff survey on paediatric palliative care	Staff members from a children's hospital (446)	Survey with closed-questions and 1 open-question	Not stated	Postal questionnaires, LSPCH, California, USA	Descriptive statistics and thematic analysis
Dangel et al. ³¹	(1) Measure the quality of a paediatric hospice home care programme; (2) assess parents' needs and concerns	Parents/primary caregivers (80) of children who had died under the hospice home care	Open- and closed-question survey	Not stated	Postal questionnaire, the Warsaw Hospice for Children, Poland	Descriptive statistics
Davies et al. ³²	Explore barriers to palliative care experienced by paediatric healthcare professionals caring for seriously ill children	Paediatric healthcare professionals (240)	Closed-question survey	January–March 2002	Postal questionnaire, University of California, San Francisco (UCSF) Children's Hospital, USA	Descriptive statistics
Dickens ³³	Identify and evaluate factors associated with healthcare professionals' confidence in delivering paediatric palliative care	Paediatric healthcare professionals with experience in paediatric palliative care (157)	Closed-question survey	2-month period in 2005	Emailed survey, Helen DeVos Children's Hospital, Michigan, USA	Statistical analysis including descriptives
Ellis et al. ³⁴	Describe pain management practices for children with cancer	Contact person at Canadian hospitals and clinics providing paediatric cancer treatment (26) Nurses (14)	Closed-question survey	Not stated	Email/telephone questionnaire, Canada	Descriptive statistics
Fortney and Steward ³⁵	Explore how nurses observe and manage infant symptoms at the end of life		Face-to-face exploratory qualitative interviews	Not stated	A children's hospital in central Ohio, USA	A framework approach
Fowler et al. ³⁶	Determine Children's Oncology Group (COG) members' comfort level in dealing with end-of-life care	Paediatric oncologist members of the COG in 2003 (623)	Closed-question survey	June 2003	Online survey, USA	Statistics including descriptives

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Friedrichsdorf et al. ³⁷	Elicit parents' perceptions of their children's symptoms and symptom management strategies used during the last week of life	Parents of children who had died under the hospice programme	Semi-structured interview	2004–2006	Telephone interviews, The Barnes-Jewish Hospital Wings Paediatric Hospice Program, Missouri, USA	Categories and labels assigned to data (thematic analysis)
Gilmer et al. ³⁸	Describe parental perceptions of the care of hospitalised, terminally ill children	Parents (15) of children who had died in a children's hospital	Telephone interviews, closed- and open-question survey	Not stated	The Monroe Carell Jr Children's Hospital, Nashville, USA	Descriptive statistics and qualitative content analysis
Grimley ³⁹	Examine the knowledge, barriers and support needs of healthcare professionals providing paediatric palliative care	Healthcare professionals (225)	Survey with closed-questions and one open-question	October 2009–March 2010	Online/paper survey, USA	Statistics including descriptives, content analysis
Groh et al. ⁴⁰	Evaluate involvement of a specialised paediatric palliative healthcare team	Primary caregivers (40) of severely ill children	Pre- and post-intervention survey with closed- and open-questions	April 2011–June 2012	Families' homes, Germany	Statistics including descriptives
Hendricks-Ferguson ⁴¹	Identify symptoms of greatest parental concern and symptom management strategies at end of life	Parents (28) of children who had died under the hospice programme	Telephone interviews with open-ended questions	2004–2006	The Barnes-Jewish Hospital Wings Paediatric Hospice Program, Missouri, USA	Semantic content analysis
Hilden et al. ⁴²	Assess attitudes, practices and challenges associated with end-of-life care of patients with cancer	Paediatric oncologist members of the American Society of Clinical Oncology (ASCO; 228)	Closed-question survey	Not stated	Postal survey to ASCO members in the United States, Canada and the United Kingdom	Statistics including descriptives
Houlihan et al. ⁴³	Establish a standard of care to manage end-of-life symptoms	Inpatient oncology nurses and paediatric oncology fellows (24)	Closed-question survey	Not stated	Emailed survey, The Dana-Farber Cancer Institute/Children's Hospital Cancer Care Program, Missouri, USA	Descriptive statistics
Klepping ⁴⁴	Explore the case of a 16-year old with nasopharyngeal carcinoma	16-year old with nasopharyngeal carcinoma approaching end of life (1)	Case study	Not stated	Hospice (location not stated)	Not stated
Kohler and Radford ⁴⁵	(1) Find out how long children dying of cancer live for when they are taken home to die; (2) find out how these children die; (3) discover the problems faced by these families	Parents (19) of children dying of cancer	Semi-structured interview and a questionnaire (type not specified)	Not stated	Not stated	Not stated
Kolarik et al. ⁴⁶	(1) Determine the extent of paediatric residents' training, knowledge, experience, comfort and competence in paediatric palliative care; (2) learn about their views on palliative care and training	Paediatric residents (49)	Closed-question survey	September–December 2003	The Children's Hospital of Pittsburgh, Pennsylvania, USA	Statistics including descriptives

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Lewis et al. ⁴⁷	Explore the views of healthcare professionals on providing palliative and end-of-life care	Adult and paediatric nurses and doctors (32)	Focus groups, 1 semi-structured interview	Not stated	The Kilimanjaro Christian Medical Centre, Tanzania	Thematic analysis
Malcolm et al. ⁴⁸	(1) Explore which rare life-limiting conditions in children present symptom challenges; (2) explore which symptoms are difficult to manage	Healthcare professionals (43), families (16)	Closed- and open-question survey	3 weeks (not stated when)	Online questionnaire, UK	Thematic analysis
Mariyana et al. ⁴⁹	Explore the experiences of mothers managing their children's pain during palliative care	Mothers (8) of children with cancer receiving palliative care	Semi-structured face-to-face interview	Not stated	The Rachel House Foundation, West Jakarta and Taufan Jakarta Community, India	The Colaizzi method of analysis
Maynard and Lynn ⁵⁰	Evaluate the effectiveness of delivering 24/7 children's palliative care	Healthcare professionals (53), hospice professionals (60), families (26)	Closed- and open-question survey	Not stated	England (setting not stated)	Descriptive statistics, thematic analysis using a framework approach
McCabe et al. ⁵¹	Document the frequency and context of paediatric resident experiences with paediatric end-of-life care and their views on adequacy of training	Paediatric residents (40)	Closed-question survey	February–April 2006	Emailed questionnaire, the Johns Hopkins Children's Center, Maryland, USA	Statistics including descriptives
McCluggage and Elborn ⁵²	Identify the symptoms that cause the most anxiety to healthcare professionals	Healthcare professionals working in UK children's hospices (38)	Open- and closed-question survey	Not stated	Postal questionnaire, UK	Descriptive statistics
Meyer et al. ⁵³	Examine perspectives and priorities of parents of children at end of life in the PICU	Parents of infants at end of life in the PICU (56)	The Parental Perspectives Questionnaire ⁵³ closed- and open-questions	Not stated	Postal questionnaire, 3 paediatric intensive care units in Boston, USA	Descriptive statistics
Michelson et al. ⁵⁴	Determine paediatric residents and fellows' views, training, knowledge, experience, comfort and perceived competence in palliative care	Paediatric residents (52) and fellows (46)	Closed-question survey	Not stated	Emailed questionnaire, USA (study hospital not stated)	Statistics including descriptives
Monterosso et al. ⁵⁵	Elicit parents' and service providers' views of supportive and palliative care	Service providers (n not stated) and families of children with life-threatening conditions (129)	Telephone or face-to-face survey with closed-questions (families), semi-structured interviews (families and service providers)	February 2003 and March 2005	Western Australia (setting not stated)	Descriptive statistics and content analysis

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Monterosso and Kristjansson ⁵⁶	Determine (1) the palliative and supportive care needs of families whose children died from cancer; (2) how well these needs were met; (3) perceived barriers to service provision	Families (24) of children dying of cancer	Telephone or face-to-face semi-structured interviews, survey with closed-questions	February 2003 and March 2005	Western Australia (setting not stated)	Descriptive statistics, thematic analysis, latent content analysis and constant comparison techniques
Monterosso et al. ⁵⁷	Determine (1) the palliative and supportive care needs of families whose children died from cancer; (2) how well these needs were met; (3) perceived barriers to service provision	Families (69) of children who had died from cancer	Phone or face-to-face semi structured-interviews with open and closed questions	Not stated	Western Australia (setting not stated)	Statistics including descriptives
Naicker et al. ⁵⁸	Describe the development of a palliative care package for the home care of young children	Home- and community-based care workers (28)	Photo-elicitation	Not stated	Rural areas in KwaZulu-Natal, South Africa	Thematic analysis
Peng et al. ⁵⁹	Explore (1) neonatal nurses' experiences of caring for dying neonates; (2) their palliative care education; (3) their palliative care needs	Neonatal nurses (115)	Closed-question survey	October 2011–July 2012	3 medical centres in the central area of Taiwan	Descriptive statistics
Price et al. ⁶⁰	Examine healthcare professionals' views on caring for children at end of life	Health and social care professionals (35)	Focus group interviews	November 2008–January 2009	UK (setting not stated)	Thematic content analysis
Price ⁶¹	Explore bereaved parents' experiences of providing children's end-of-life care	Bereaved parents (25)	Face-to-face interview with open-ended questions	November 2007–September 2008	Participants' homes, UK	Thematic analysis followed by narrative analysis
Pritchard ⁶²	Study the symptoms experienced by dying children that were of most concern to parents	Parents of children who had died from cancer (42)	Telephone interviews with open-ended questions, medical record reviews	Not stated	A paediatric cancer centre, USA	Statistics including descriptive statistics
Pritchard et al. ⁶³	Identify (1) cancer-related symptoms that most concerned parents of children at end of life; (2) the care strategies that parents found helpful from healthcare professionals	Parents of children who had died from cancer (65)	Telephone interview, review of medical records	Not stated	A paediatric cancer centre, USA	Content analysis and consensus coding, descriptive statistics
Rapoport et al. ⁶⁴	Examine the attitudes of palliative care physicians towards paediatric patients	Palliative care physicians (44)	Open- and closed-question survey	4-month duration	The University of Toronto, Ontario, USA	Descriptive statistics, content analysis
Saad et al. ⁶⁵	Evaluate the quality of paediatric palliative care as perceived by bereaved parents	Parents (29) of children who had died of cancer	Face-to-face interview with open- and closed-questions	September–December 2008	Parents' home, Lebanon	Descriptive statistics, analysis for open-ended questions not stated

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Stein et al. ⁶⁶	Assess the impact of chronic life-threatening illness on families and their perception of hospice care	Families (25) of children with chronic life-threatening illnesses	Face-to-face interview consisting of a semi-structured questionnaire and survey	Not stated	Oxfordshire, UK	Descriptive statistics; analysis of open-ended data not described
Szymczak et al. ⁶⁷	Explore paediatric oncology providers' views on the paediatric palliative care service	Paediatric oncology providers (16)	Semi-structured interviews with open-ended questions	Not stated	A place of the participants' choosing the United States (state not stated)	Modified grounded theory approach
Tamannai et al. ⁶⁸	(1) Gain a better understanding of the needs of Burkitt-Lymphoma patients and families in rural Cameroon; (2) assess their perception of the palliative care outreach programme; (3) identify issues	Children with Burkitt-Lymphoma (3), their caregivers (7) and nurses (2)	Semi-structured interviews with open-ended questions	Not stated	Interviews conducted during home visits in a rural area of Cameroon	Thematic analysis
Theunissen et al. ⁶⁹	Examine symptoms in children with cancer and their parents during palliative care	Parents (59) of children with cancer receiving palliative care	Postal questionnaire with closed-questions, review of medical records	Not stated	The Radboud University Nijmegen Medical Centre (RUNMC), The Netherlands	Descriptive statistics
Thienprayoon et al. ⁷⁰	Explore parental perspectives on the hospice experience	Parents (34) of children who had died of cancer	Qualitative interview with open-ended questions	Not stated	Interviews conducted at a location chosen by the parent, Children's Medical Center Dallas, Texas, USA	Thematic content analysis
Ullrich et al. ⁷¹	(1) Describe fatigue as experienced by children with advanced cancer; (2) evaluate factors hypothesised to be associated with fatigue and its treatment	Parents (141) of children who had died of cancer	Telephone or face-to-face semi-structured survey – all closed-questions	1997–2001	The Dana-Farber Cancer Institute/Children's Hospital Boston and the Children's Hospitals and Clinics, St Paul and Minneapolis, USA	Statistics including descriptives
Van der Geest et al. ⁷²	Explore the perspective of GPs caring for children with advanced cancer at home	GPs (91)	Open- and closed-written survey	2013	The Netherlands (setting not stated)	Statistics including descriptives
Verberne et al. ⁷³	Provide an overview of parental caregiving	Parents (42) caring for children with life-limiting diseases	Interview with open-questions	August 2013–November 2015	Interviews conducted at parents' homes, Amsterdam, The Netherlands	Inductive thematic analysis

(Continued)

Table 2. (Continued)

Study (in alphabetical order)	Aims	Participants (sample size)	Design and data collection	Date and duration	Setting and location	Data analysis methods
Vickers et al. ⁷⁴	Gain understanding into parents' experience of caring for a terminally ill child	Parents (10) of children who had died	Interview with open-questions	Not stated	Interviews conducted at parents' homes, UK	Thematic content analysis
Vollenbroich et al. ⁷⁵	Evaluate the perception of symptoms, treatment and their influence on palliative care as perceived by parents	Parents of children who had died due to a life-limiting disease (38)	Closed-question postal survey	June–December 2007	The Coordination Center for Paediatric Palliative Care (CPPC) of the University of Munich, Germany	Statistics including descriptives
Vollenbroich et al. ⁷⁶	Evaluate whether paediatric palliative home care can be improved with a paediatric palliative home care team	Parents (38) of children who had died, healthcare professionals involved in the children's care (87)	Closed-question postal survey	June–December 2007	The Coordination Center for Paediatric Palliative Care (CPPC) of the University of Munich, Germany	Statistics including descriptives
Wheeler ⁷⁷	(1) Establish survey properties; (2) describe attitudes and practices of paediatric nurses regarding the care of infants and children with life-threatening conditions; (3) assess barriers to care; (4) examine differences in attitudes, practices and barriers	Paediatric nurses (343)	Closed-question survey	Not stated	A large children's hospital, USA	Statistics including descriptives
Wolfe et al. ⁷⁸	Determine (1) the patterns of care among children who die of cancer; (2) the symptoms, effectiveness of treatment and factors related to suffering from pain at end of life	Parents (103) of children who had died from cancer	Telephone or face-to-face interview with closed-questions, review of medical records	September 1997–1998	Boston Children's Hospital and the Dana-Farber Cancer Institute in Boston, USA	Statistics including descriptives
Yorke ⁷⁹	Explore experiences of families whose child died in the paediatric intensive care unit (PICU)	Parents (23) of children who died in PICU	Semi-structured interview and closed-question survey	Not stated	PICU at the UNC Children's Hospital, USA	Constant comparison content analysis
Zaal-Schuller et al. ⁸⁰	Investigate (1) what parents and physicians consider important for quality of life in children with profound intellectual and multiple disabilities (PIMD); (2) how parents and physicians discuss and incorporate quality of life in end-of-life decision-making	Parents (17) of children with PIMD and physicians (11)	Semi-structured interviews with open-ended questions	Not stated	The Netherlands	Qualitative data analysis using coding
Zelcer et al. ⁸¹	Explore the end-of-life experience of children with brain tumours and their families	Parents (25) of deceased children with brain tumours	Focus group interview	Not stated	Interview conducted outside of hospital, the Children's Hospital, London Health Sciences Center, Canada	Thematic analysis

Treatment side effects. Parents made decisions not to use medication aimed at treating symptoms, due to the drugs' side effects. In one study, for example, parents turned down a doctor's suggestion for chemotherapy as they did not want their child to be sick and miserable (Q7).⁶² The only study involving patient interviews included a 14 years old who had decided to stop taking oral morphine due to nausea, despite the 'burning pain' she experienced.⁶⁸

When new symptoms appeared, parents had to decide between leaving these untreated or risking new or worsened side effects.⁷³ One study also reported a parent's view that healthcare professionals did not treat their child's pain due to fear of symptoms from the medication (Q8).⁷⁹ Some parents chose perceived quality of life (QoL) over pain relief, delayed the start of pain medication so their child could play, assuming that they would only sleep if treatment was given.⁷³ However, our review also suggests that parents will expose their child to side effects if they feel this is beneficial overall. In one study, for example, a minority of parents mentioned very low QoL with little chance for improvement as a reason for starting pain relief medication that could lead to or hasten death.⁸⁰

Healthcare professionals' attitudes. Parents' perception of symptom management is influenced by healthcare professional's attitudes towards them and their children.^{29,30,41,48,61,62,66,75,78} Parents felt healthcare professionals were dismissive of symptoms such as constipation⁴⁸ or did not take their concerns about inadequate pain relief seriously (Q10).²⁹ They discuss having to convince healthcare professionals to give pain medication or other treatment.⁶² Lack of involvement in the child's care (as reported by parents) by an oncologist was associated with more suffering from pain.⁷⁸

Inadequate communication from healthcare professionals was also a barrier to symptom management. One study described how parents wished hospital staff had communicated sooner that pain doctors were available (Q11).³⁰ In another, children's pain was associated with parents' perception of receiving conflicting information from healthcare professionals.⁷⁸

In contrast, when healthcare professionals were seen as vigilant and attentive, this was perceived to have a beneficial impact on symptom management. This included anticipating the child's needs,^{41,61} treating parents as active members of the child's care team, being honest with them (Q12),²⁹ listening to parents²⁹ and the child (Q14),⁶² and placing a high priority on symptom relief.⁶⁶ Several studies^{38,57,75} reported that advice or information from healthcare professionals facilitated symptom management. For example, a father in one study discussed how he was initially concerned that his baby would only be treated for pain; however, the paediatric palliative care team explained that other potential symptoms could be managed (Q15).⁷⁵

Influence of hospice care. In several studies, families described how the hospice environment was helpful for controlling children's pain and other symptoms.^{31,66,70} Families valued the emphasis on symptom relief at the hospice (as opposed to a focus on interventions to manage the child's condition) and the staff's experience with rare conditions and complex symptom clusters.⁶⁶

However, one study conducted in the United States found that Spanish-speaking families viewed the hospice as a facilitator to symptom management (Q16); yet English-speaking families returned to hospital care due to poor symptom control.⁷⁰ The authors suggest this could be due to Spanish-speaking families prioritising place of care (at home or at the hospice as opposed to the hospital) over pain control, while the English-speaking families' main priority was pain and symptom relief. In another study, parents noted that the hospice did not know how to control the pain, but they were unable to access a hospital pain team because the child was not an inpatient.²⁹

Care and support at home. A number of studies highlighted barriers to symptom management for children being looked after at home.^{28,31,65} Parents feared that their child might not receive medical treatment,³¹ and that symptoms would not be controlled.^{45,81} One study noted a parent's fear that they would make their child worse if they accidentally gave too much medication (Q17).⁷⁴ Several studies noted that parents reported a lack of information, knowledge and support around pain control and symptom management (Q20, Q21).^{48,55,57,68}

When parents did receive information, advice or education from healthcare professionals or disease-specific organisations, this was seen to facilitate symptom management.^{41,48,62} In one study, the child's suffering was not worse in children being cared for at home and receiving specialised paediatric palliative care compared to those being cared for in hospital.³⁷ However, parents in another study emphasised that they had learnt to control their child's symptoms 'on their own'; yet some still struggled when their child's disease progressed or when complications occurred.⁷³

Other barriers to symptom management at home included a lack of access to support in the form of home visits from healthcare professionals^{38,49} or 24-hour support.^{50,56} Community nurses were viewed as facilitating symptom management by providing complex care at home such as the preparation of pain relief (Q22).⁵⁶ One parent noted the importance of having a regular nurse to help with home care, who had knowledge of their child's specific symptoms (Q23).⁵⁶

Availability of resources at home also affected symptom management. Parents reported having to wait for, or locate, prescribed medication after leaving hospital or having to coordinate care from different agencies.⁶² In one study, children were admitted to hospital due to limited availability of equipment at home.⁶⁵ In other studies,

healthcare professionals supported parents by arranging the necessary equipment (Q24).^{56,61} In a study conducted in India, some parents noted they were not able to administer enough medication to control pain at home and they also had difficulties in using or accessing hospital services due to cost and transportation barriers.⁴⁹

Caregiver mental wellbeing may also influence symptom management at home. Byrne and colleagues found that self-efficacy to manage children's pain was negatively associated with higher parental strain and negative mood and positively associated with higher parental vigour.²⁶ While this suggests that parental mood and strain could impact on pain management, this study cannot demonstrate causality.

Families' symptom management strategies. Several studies reported that families carried out a number of non-pharmacological symptom management strategies. One study described how parents worked constantly to reduce, relieve or prevent symptoms.⁷³ In another study, mothers assessed their child's pain by asking them using a pain level tool (0–10) to determine the extent of their pain before deciding on suitable symptom management.⁴⁹

Placing the child in different positions to avoid issues such as skin breakdown and pain was noted as a symptom prevention strategy (Q27)⁴¹ as were distraction techniques such as reading, singing and talking to the child^{41,49} and encouraging and motivating children to fight their pain.⁴⁹ In India, parents used non-pharmacological treatments such as kencur (i.e., *Kaempferia galanga*, also known as aramotic ginger) or eucalyptus oil or massages to help eliminate their child's pain.⁴⁹ Parents felt they helped relieve their child's symptoms by staying close to them and providing physical comfort.^{41,49,62} Healthcare professionals staying close to the child was also viewed as helpful by parents.⁶² In addition, some parents chose to keep their child out of day care to minimise the risk of infection.⁷³ Parents described feeling overwhelmed by the decisions they had to make around preventing or reducing symptoms and balancing this with the need for the child to have 'a life worth living'.⁷³

Barriers and facilitators to symptom management reported by healthcare professionals

Access to medicines. A lack of access to medicines and resources was noted as a barrier to providing care in four studies (Q28).^{20,47,58,60} Three of these were conducted in low-income countries where medical care access is limited for economic reasons; however, one study was based in the United Kingdom.⁶⁰ It was not clear whether the lack of access in this instance was financial or logistical.

Treatment efficacy. Healthcare professionals in several studies reported children experiencing pain and other

symptoms.³⁷ In some cases, this was linked to inadequate pain control⁵⁹ or not addressing emotional symptoms,⁵⁰ although the reasons for this were not identified. In a case review, Klepping⁴⁴ describes a teenage boy whose pain was worsened by events around him (such as the presence of certain family members), which appeared to impede the effectiveness of medication.

Age and gender of healthcare professionals. Two studies found that male healthcare professionals had greater confidence or comfort in managing symptoms compared to female healthcare professionals.^{33,36} The authors in these studies suggested this could be due to differing perceptions of comfort³⁶ or differences in self-reporting confidence.³³ Older healthcare professionals were also more confident in managing symptoms,³³ which could be linked to greater experience, self-report differences or accumulating life experiences.³³ Physicians and nurses reported greater expertise in managing symptoms compared to psychosocial staff.³⁹ The reasons for this were not described.

Treatment side effects. Healthcare professionals' concerns about side effects of treatment can be a barrier to symptom management when decisions are made not to administer medication. In several studies, fears of addiction, sedation, respiratory depression or hastening death were identified as potential barriers to treatment (Q30).^{34,43,47} Balancing the need for symptom relief with the risk of these side effects was a difficult decision for some healthcare professionals.⁸⁰ However, side effects were not always barriers but rather acted as facilitators to seeking alternative symptom management – one study reported a patient's preference for the side effect (drowsiness) as opposed to being in pain.^{44,80}

Specialist advice and support. In a number of studies, healthcare professionals stated that access to specialist support, for example, from a paediatric palliative care team, would be favourable for paediatric symptom management.^{24,35,54,77} In three studies, healthcare professionals had access to either a specialist paediatric palliative care team or support from other colleagues, and this was viewed as beneficial for effective symptom management.^{52,67,76} In one study, the involvement of a palliative care team was delayed by physicians, who were concerned about families readiness for palliative care, the association of 'palliative' with 'death' and the fear of negatively impacting the physician–family relationship.⁶⁷

Healthcare professional education, training, knowledge and experience. In a number of studies, healthcare professional's education, training, knowledge and/or experience were seen as barriers or facilitators to symptom management. Only one study appeared to indicate that

the majority of healthcare professionals felt they had sufficient knowledge to manage symptoms at end of life.³⁴ Healthcare professionals reported having inadequate training, education or support to manage symptoms in children at end of life, and that they would value further training.^{19–21,25,32,43,46,51,54,58,59,64,76} In one study, the barriers to obtaining the necessary education or training included a lack of opportunities, time and costs.³⁴ Fowler et al.³⁶ found that healthcare professionals with formal training were more likely to feel comfortable treating pain and psychological issues.

Healthcare professionals described feeling inexperienced to manage symptoms.^{30,39} In two studies, healthcare professionals felt this resulted from the 'low volume' of patients they encountered with complicated pain problems.^{34,39} In line with this, healthcare professionals with more experience reported greater confidence in treating pain³³ and this was associated with less fatigue in children.⁷¹

A lack of experience or exposure to certain conditions meant that healthcare professionals voiced difficulties in managing rare and/or progressive conditions⁴⁸ and in recognising and treating symptoms^{35,52} sometimes due to a lack of guidance or evidence (Q34, Q35).⁴⁸ Studies found improvements in healthcare professionals' comfort, confidence or knowledge following training or education aimed at improving end-of-life symptom management.^{21–23,27} In one study in Uganda, a healthcare professional noted that a myth had existed that children do not experience pain. Training had enabled the healthcare professional to appreciate that this was untrue and therefore that pain can be assessed and managed (Q36).²⁰ Another study found that paediatric residents' self-reported knowledge and comfort in end-of-life symptom management increased after the introduction of a Paediatric End-of-Life Care Management Reference Card.²²

Delivery of health services. This theme encompasses the working practices utilised by healthcare professionals, how decisions are made and how care is planned. It includes how healthcare professionals collaborate within teams and with families. The benefits of well-planned, interdisciplinary decision-making and symptom management were reported in one study,⁵⁰ whereas another identified these as areas that needed attention, along with the lack of standardisation of care and symptom control.²⁴ In another study, general practitioners (GPs) providing home-based palliative care reported receiving insufficient information from the hospital about symptoms and difficulties during the palliative phase.⁷² Similarly, after a review of patient cases, Houlahan and colleagues⁴³ identified barriers including a lack of available physicians as reported by nurses, difficulty in obtaining orders for medication and delays in obtaining medication from pharmacy.

Disagreement and conflict about treatment decisions and goals were identified as other symptom management barriers. Conflict (about treatment) between healthcare professionals and families was noted in three studies,^{32,35,60,77} as well as disagreement among healthcare professionals (Q37)^{19,35} and among families.⁷⁷

Factors relating to care at home. One study conducted a survey on pain management in Canadian paediatric cancer centres.³⁴ The authors note the difficulties encountered by healthcare professionals in these areas including a lack of infrastructure for effective and timely links between the cancer centre, community and the family. The need for parent and home care nurse education around pain assessment and management was also highlighted. In a study conducted in Tanzania,⁴⁷ the hospital was reported by healthcare professionals as the best place for care due to the lack of equipment at home (Q39). In another study, adequate pain control and symptom management were noted as difficult due to lack of communication between hospital and community staff.⁷²

Meta-analysis

Meta-analyses were run on six barriers/facilitators, four of which corresponded to the themes developed through the thematic analysis. Forest plots are shown in Supplementary File 6, and overall effect sizes are shown in Figure 2.

Barriers and facilitators to symptom management reported by family carers. Three studies^{53,75,78} that asked families about pain management facilitators found that giving treatment (usually pharmacological though this was not always specified) was helpful. This was reported by between 27% and 84% of participants (crude unweighted mean: 0.645, 95% confidence interval (CI): 0.278–1.011). Meta-analysis (Analysis 1) yielded a pooled weighted mean of 0.672 ($k=3$, $n=197$, 95% CI=0.231–0.933), with significant heterogeneity (Cochran's $Q=53.06$, $df=2$, $p<0.001$, $I^2=96.23$). A further meta-analysis (Analysis 2) on studies that surveyed families about symptom management in general (not just pain)^{53,62,63,75,78} found that treatment was again reported as a facilitator (crude unweighted mean = 0.541, 95% CI = 0.342–0.739). The pooled weighted estimate was 0.545 ($k=5$, $n=295$, 95% CI: 0.328–0.746), with significant heterogeneity (Cochran's $Q=47.77$, $df=4$, $p<0.001$, $I^2=91.63$).

Three studies included survey items about the effect of caring for a child at home on symptom management.^{28,31,65} This was reported as a barrier by between 22% and 24% of participants (crude unweighted mean: 0.238, 95% CI: 0.077–0.399). Meta-analysis (Analysis 3) yielded a pooled weighted mean of 0.244 ($k=3$, $n=197$, 95% CI=0.177–0.326), without

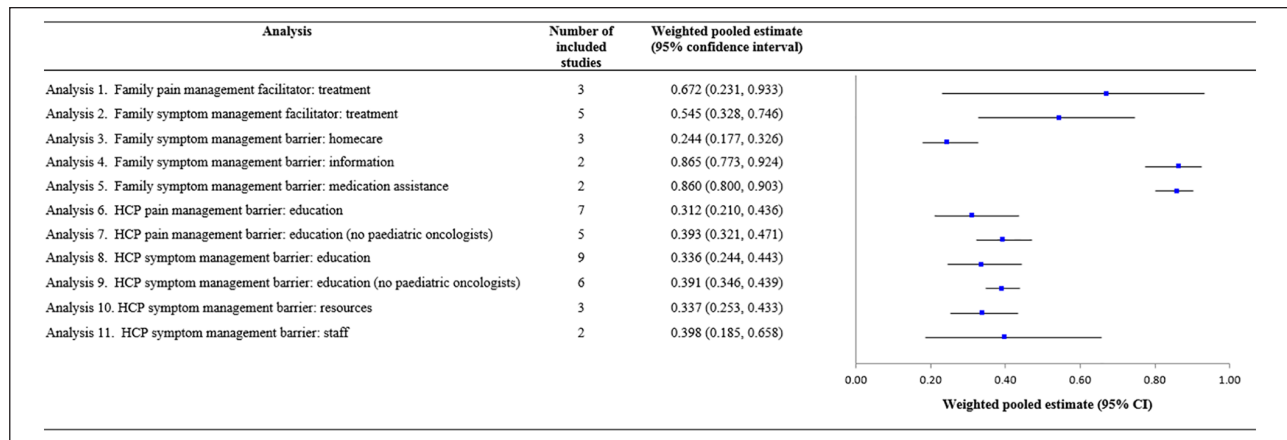


Figure 2. Overall weighted pooled estimates and 95% confidence intervals (CIs) for each analysis of barriers and facilitators to paediatric symptom management at end of life.

Squares represent the barrier/facilitator weighting with horizontal lines representing the corresponding 95% CIs.

significant heterogeneity (Cochran's $Q=0.06$, $df=2$, $p=0.969$, $I^2=0.00$).

Two studies^{38,57} reported that advice or information facilitated symptom management for between 86% and 93% of participants (crude unweighted mean: 0.894, 95% CI: 0.818–0.971). Meta-analysis (Analysis 4) yielded a pooled weighted mean of 0.865 ($k=2$, $n=84$, 95% CI=0.773–0.924), without significant heterogeneity (Cochran's $Q=0.63$, $df=1$, $p=0.428$, $I^2=0.00$).

A lack of assistance with administering or managing treatment was reported as a barrier to symptom management in two studies^{55,57} by between 84% and 87% of participants (crude unweighted mean: 0.857, 95% CI: 0.825–0.888). Meta-analysis (Analysis 5) yielded a pooled weighted mean of 0.860 ($k=2$, $n=179$, 95% CI=0.800–0.903), without significant heterogeneity (Cochran's $Q=0.36$, $df=1$, $p=0.547$, $I^2=0.00$).

Barriers and facilitators to symptom management reported by healthcare professionals. Inadequate training, education or support to manage symptoms in children at end of life was a barrier to pain management reported by between 0% and 61.9% of participants in seven studies^{25,30,32,36,39,42,64} (crude unweighted mean: 0.316, 95% CI: 0.131–0.450). Meta-analysis (Analysis 6) yielded a pooled weighted mean of 0.312 ($k=7$, $n=2317$, 95% CI=0.210–0.436), with significant heterogeneity (Cochran's $Q=147.410$, $df=6$, $p<0.0001$, $I^2=95.93$). Perceived lack of confidence or support was considerably lower in studies that only surveyed paediatric oncologists^{36,42,43} as opposed to nurses or other physicians. A further analysis was run after excluding these studies. The crude unweighted mean was 0.414 (95% CI: 0.258–0.570) and the pooled weighted estimate (Analysis 7) was 0.393 ($k=5$, $n=1474$, 95% CI: 0.321–0.471), with significant heterogeneity (Cochran's $Q=30.693$, $df=5$, $p<0.001$, $I^2=83.71$).

Nine studies surveyed healthcare professionals on the extent that they lacked education, training, knowledge or experience in paediatric symptom management in general (including, but not limited to, pain) at end of life.^{25,30,32,36,39,42,43,64,76} Again, this was reported by between 0% and 61.9% of participants (crude unweighted mean: 0.346, 95% CI: 0.206–0.486). Meta-analysis (Analysis 8) yielded a pooled weighted mean of 0.336 ($k=9$, $n=2412$, 95% CI: 0.244–0.443), with significant heterogeneity (Cochran's $Q=142.56$, $df=8$, $p<0.001$, $I^2=94.39$). After excluding studies that only surveyed paediatric oncologists,^{36,42,43} the crude unweighted mean was 0.411 (95% CI: 0.299–0.523) and the pooled weighted estimate (Analysis 9) was 0.391 ($k=6$, $n=1561$, 95% CI: 0.346–0.439), with significant heterogeneity (Cochran's $Q=15.10$, $df=5$, $p=0.01$, $I^2=66.89$).

Three studies reported that a lack of resources (information or staff) was a barrier to symptom management^{43,72,77} for between 30% and 56% of participants (crude unweighted mean: 0.393, 95% CI: 0.269–0.759). Meta-analysis (Analysis 10) yielded a pooled weighted mean of 0.337 ($k=3$, $n=450$, 95% CI=0.253–0.433), without significant heterogeneity (Cochran's $Q=4.64$, $df=2$, $p=0.098$, $I^2=56.86$). A follow-up analysis (Analysis 11) on studies that included items regarding a lack of staff specifically^{43,77} found a crude unweighted mean of 0.430 (95% CI: 0.170–0.690) and a pooled weighted estimate of 0.398 ($k=2$, $n=359$, 95% CI: 0.185–0.658) with significant heterogeneity (Cochran's $Q=4.608$, $df=1$, $p=0.032$, $I^2=78.30$).

Discussion

Main findings

This narrative synthesis and meta-analysis has uniquely identified the barriers and facilitators to paediatric symptom

management at end of life. Both family carers and healthcare professionals described barriers and facilitators related to treatment efficiency and side effects, and factors relating to care at home, particularly issues around a lack of education and information. In addition, family carers described aspects of hospice care; the attentiveness of healthcare professionals; their own symptom management strategies; ease of access to medicines, assistance with medication and provision of information as affecting symptom management. Healthcare professionals emphasised support from palliative teams as a facilitator and issues relating to health service delivery as a barrier to managing symptoms. These factors link to the recent NICE guidelines,⁹ which recommend that healthcare professionals consider the importance of good communication with families, providing information, care planning, practical and social support, support for caregivers and appropriate service delivery.

Our review has highlighted the importance of symptom management planning in paediatric end-of-life care especially since caregivers and healthcare professionals believe that children suffer at end of life due to inadequate symptom treatment. This could be due to fear of treatment side effects, which may be based on inaccurate or outdated beliefs. In keeping with this, aside from paediatric oncologists, healthcare professionals in several studies reported that a lack of training and education prevented effective symptom management. Paediatric palliative care was only recognised as a speciality in the United Kingdom in 2009;⁸⁴ yet the studies in our review date back to 1985; as such, misunderstandings related to treatments may be less prevalent today. Nonetheless, widespread implementation of paediatric palliative care is far from being attained in many countries, including the United States;⁸⁵ thus, misconceptions about side effects may still hinder symptom management in many areas of the world. We recommend that clear and comprehensive symptom management plans are implemented to avoid children suffering at end of life, and that healthcare professionals involved in paediatric palliative care are given adequate training to recognise, treat and prevent symptoms including pain.

Issues around care at home were linked to poor symptom management and further indicate the need for good care planning. Caring for a child at end of life is challenging for parents,⁸⁶ and our study highlights the need for more practical and social support and information to enable children to be looked after in their chosen place of care.⁹ Without effective pain relief, they may face unnecessary hospital admissions.⁷ We recommend that families are provided with information about symptom management so that they are equipped to effectively manage symptoms, including pain, when providing care for children at home. Future research could investigate what specific support or information is required to manage symptoms at home.

Our review highlights the need for good communication between healthcare professionals and families and within care teams. Some family carers felt that healthcare professionals did not respond to their concerns about symptoms, or that they received conflicting advice. Healthcare professionals also reported conflict within care teams. Delivery of palliative care services should be organised to ensure continuous care and prevent delays in access to treatment, with guidelines that enable healthcare professionals to make safe and effective decisions that put children and their families at the forefront of care. Communication training for healthcare professionals is a key component of the recommendations made by NICE⁹ to ensure that children and their caregivers are involved in care planning and decision-making.

Access to treatment was identified as a further potential barrier. Several studies were conducted in low-middle income countries where supply chains and prescriber difficulties may inhibit symptom management. In the United Kingdom, access to medicines for patients at home can sometimes be challenging, and we recommend that families are supported to ensure they have access to essential equipment and to the medications they require, including the provision of anticipatory prescribing.

Strengths and limitations

Our review was fairly broad in its approach and inclusive to ensure we identified as many sources of data as possible. However, due to the lack of studies specifically and properly designed to identify barriers and facilitators to paediatric symptoms management at end of life, our review has incorporated a number of studies of low quality. Some aimed to identify barriers yet did not give participants the opportunity to freely discuss these and instead presented pre-defined concepts. Other studies included decisions about treatments aimed at disease modification and/or prolonging life, rather than purely symptom management. In addition, the majority were not informed by a theoretical framework or model. Further research is required in this area, particularly regarding the views of children themselves, since only one study included patients' perspectives.

The majority of the surveys used in the quantitative studies were devised by the researchers. This limited their comparability and the number of meta-analyses that could be performed. Differences in individual study effect sizes in the meta-analyses could be due to the varying ways in which questions were asked, especially as the exact questions and possible responses were not always listed. These findings suggest the need for a reliable, valid questionnaire assessing barriers and facilitators to paediatric symptom management at end of life.

What this study adds

Our findings are limited by the quality of studies on which this review is based; however, they highlight the importance of clear communication between clinical teams and between healthcare professionals and families. Healthcare professionals and families would benefit from increased education and training, while delivery of services needs to include social and practical support for families, anticipatory care planning and symptom management planning.

Author contributions

E.H., R.F.H., M.J. and I.W. conceived the idea and reviewed the protocol and manuscript. C.L. conceived the idea, planned, designed, reviewed and revised the protocol, reviewed and revised the search strategy, search findings and manuscript. D.E.S. planned the searches, data extraction and statistical analysis, conducted data synthesis and reviewed and revised the protocol and manuscript. K.G. and S.H. planned and carried out the searches, data extraction, quality assessment and data synthesis and drafted and revised the protocol and manuscript. J.B., S.S.J. and L.B. provided critical insights and reviewed the study protocol and manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Supplemental material

Supplemental material for this article is available online.

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