Supplementary material; Medline search strategy

Ovid MEDLINE(R) ALL <1946 to April 01, 2022>

1 child/ or child, preschool/ 2062180

2 infant/ or infant, newborn/ 1210034

3 Adolescent/ 2168148

4 Minors/ 2730

5 exp Paediatric s/ 62271

6 (child* or Children*).ab. or (child* or children*).ti. 1519614

7 (infant* or infancy*).ab. or (infant* or infancy*).ti. 472108

8 (baby or baby* or babies).ab. or (baby or baby* or babies).ti. 78754

9 (toddler* or kid or kids).ab. or (toddler* or kid or kids).ti. 21928

10 (boy or boys or boyhood or girl or girls or girlhood).ab. or (boy or boys or boyhood or girl or girls or girlhood).ti. 249187

11 (adolescen* or juvenil* or youth* or teen* or "under age*" or underage* or pubescen*).ab. or (adolescen* or juvenil* or youth* or teen* or "under age*" or underage* or pubescen*).ti. 477151

12 (minor or minors* or schoolchild*).ab. or (minor or minors* or schoolchild*).ti. 258912

13 (paediatric * or paediatric* or peadiatric*).ab. or (paediatric * or paediatric* or peadiatric*).ti. 403032

14 ("young people*" or "young person*").ab. or ("young people*" or "young person*").ti. 36174

15 (newborn* or neonat*).ti. or (newborn* or neonat*).ab. 413797

16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 4833085

17 exp Respiration, Artificial/ 85372

18 exp Ventilators, Mechanical/ 9846

19 ((artificial* or mechanical*) adj3 (respirat* or ventilat*)).tw,kf. 71898

20 artificial airway?.tw,kf. 511

21 (high frequency adj3 ventilat*).tw,kf. 3791

22 ((assist* or support* or wean*) adj3 (respirat* or ventilat*)).tw,kf. 27121

23 ((liquid or fluorocarbon or fluoro carbon) adj3 ventilat*).tw,kf. 729

24 (invasive* adj3 ventilat*).tw,kf. 9997

25 controlled ventilation.tw,kf. 2449

26 (airway pressure release adj3 ventilat*).tw,kf. 303

27 APRV.tw,kf. 188

28 IPPB.tw,kf. 297

29 Airway Extubation/ 2096

30 exp Intubation, Intratracheal/ 41538

31 (intubat* or extubat* or detubat*).tw,kf. 74207

32 Tracheostomy/ 8419

33 tracheo?tom*.tw,kf. 22829

34 (endotrachea* adj3 (tube? or tubat* or ventilat*)).tw,kf. 10709

35 Ventilator Weaning/ 4256

36 (ventilat* adj3 (wean* or liberat*)).tw,kf. 4364

37 (cuff? adj3 deflat*).tw,kf. 654

38 (cuff? adj3 inflat*).tw,kf. 2065

39 Noninvasive Ventilation/ 3170

40 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 234516

41 decision making/ or decision making, shared/ 103192

42 exp choice behavior/ 59762

43 (share$ adj decision adj mak$).ti,ab. 10627

44 ethical decision making.mp. 1465

45 (decision adj analys$).mp. 5860

46 clinical decision-making/ or clinical reasoning/ 14300

47 decision support.mp. 43244

48 Patient-Centered Care/ 21933

49 patient-centered.tw. 19203

50 patient-centred.tw. 6728

51 person-centred.tw. 3390

52 person-centered.tw. 3835

53 patient-oriented.tw. 3452

54 person-oriented.tw. 398

55 patient-focused.tw. 1811

56 person-focused.tw. 144

57 client-focused.tw. 121

58 client-oriented.tw. 158

59 client-centred.tw. 642

60 client-centered.tw. 1035

61 exp professional-patient relations/ 147113

62 professional-family relations/ 15415

63 patient participation/ 28387

64 patient care planning/ 39368

65 exp education, professional/ 319888

66 (patient adj understanding).mp. 1402

67 ((check or clarify) adj3 understanding).mp. 414

68 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 749357

69 16 and 40 and 68 1222

70 qualitative research/ 72618

71 Interview/ 30214

72 Personal Narrative/ 6192

73 Grounded Theory/ 2378

74 Focus Groups/ 34032

75 Hermeneutics/ 473

76 Anthropology, Cultural/ 7116

77 qualitative.af. 302010

78 interview*.af. 445178

79 experiences.ti. or experiences.ab. 237441

80 views.ti. or views.ab. 85129

81 perspectives*.ti. or perspectives*.ab. 148920

82 narrative.ti. or narrative.ab. 48218

83 ethnograph*.ti. or ethnograph*.ab. 12418

84 ("case study" or "case studies").ti. or ("case study" or "case studies").ab. 112604

85 thematic analysis.ti. or "thematic analysis".ab. 29090

86 themes.ti. or themes.ab.90673

87 grounded theory.ti. or grounded theory.ab. 13415

88 field notes.ti. or field notes.ab. 2573

89 audio record*.ti. or audio record*.ab. 8880

90 focus group*.ti. or focus group*.ab. 56247

91 conversation* analys*.ti. or conversation* analys*.ab. 736

92 descriptive stud*.ti. or descriptive stud*.ab. 33100

93 discourse analys*.ti. or discourse analys*.ab. 2079

94 exploratory analys*.ti. or exploratory analys*.ab. 10275

95 exploratory stud*.ti. or exploratory stud*.ab. 18160

96 Hermeneutic*.ti. or Hermeneutic*.ab. 4205

97 naturalistic.ti. or naturalistic.ab. 12965

98 phenomenolog*.ti. or phenomenolog*.ab. 30243

99 participatory.ti. or participatory.ab. 15255

100 semi structured.ti. or semi structured.ab. 57463

101 key informant*.ti. or key informant*.ab. 9355

102 cultural anthropology.ti. or cultural anthropology.ab. 166

103 narrative analysis.ti. or narrative analysis.ab. 1479

104 inductive.af. 23729

105 content analysis.ti. and content analysis.ab. 1784

106 discourse analysis.ti. and discourse analysis.ab. 273

107 narration.ti. and narration.ab. 50

108 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81 or 82 or 83 or 84 or 85 or 86 or 87 or 88 or 89 or 90 or 91 or 92 or 93 or 94 or 95 or 96 or 97 or 98 or 99 or 100 or 101 or 102 or 103 or 104 or 105 or 106 or 107 1253138

109 69 and 108 171

Supplementary material table 1; Key characteristics of included studies

Study	Aim	Year of data collection	Country	Setting	Methodology	Data collection	Data analysis	Sample	Sample characteristics
Bogetz et al, 2022	To explore perspectives of parents of children with severe neurological impairment on clinician counselling regarding home mechanical ventilation	Dec 2018-Oct 2019	US	Academic medical centres providing care for paediatric patients	Qualitative (not specified)	Audio recorded interviews	Thematic content analysis	26 parents, caregivers	22 F 4 M* parents or legal guardians of 24 children with severe neurological impairment
Boss et al, 2021	To understand what considerations drive family decisions for, and against, paediatric home Ventilation	Dec 2018-Oct 2019	US	Academic medical centres providing care for paediatric patients	Qualitative (not specified)	Audio recorded interviews	Thematic content analysis	42 parents, caregivers	35F 7M* parents or legal guardians of 38 children. 8 children had lung disease of prematurity alone, 30 had medical complexity
Study	Aim	Year of	Country	Setting	Methodology	Data	Data analysis	Sample	Sample

		data collection				collection			characteristics
Jabre et al, 2022	To understand parent perspectives about how clinicians can better facilitate decision-making around home ventilation. Our aim was to identify clinician practices that were helpful to parents during decision-making regardless of the eventual choice	Dec 2018-Sept 2019	US	Academic paediatric centers	Qualitative (not specified)	Audio recorded interviews	Inductive thematic analysis	38 parents, caregivers	38 parents of 38 children. 8 children had lung disease with prematurity alone, 30 had medical complexity
Dybwik et al, 2012	To explore the ethical challenges in home mechanical ventilation based on a secondary analysis of qualitative empirical data	Secondary analysis of studies between 2008-2010	Norway	Hospitals and community health services	Qualitative (not specified)	N/A	Secondary content analysis of collected qualitative data from 3 previous studie.	Total across 3 studies. 15 parent, caregivers 68 healthcare professionals	Pulmonologists, anesthesiologists, physiotherapists
Study	Aim	Year of	Country	Setting	Methodology	Data	Data analysis	Sample	Sample

		data collection				collection			characteristics
Edwards et al, 2020	To assess what families with children with chronic respiratory failure and life-limiting conditions need and want for informed decision-making	Dec 2015-Dec 2017	US	Paediatric intensive care units	Qualitative (not specified)	Audio-recorded interviews	Thematic approach based on Framework Analysis	44 parents, caregivers 1 young woman using noninvasive LTV 1 adolescent girl on noninvasive LTV	44 parents, caregivers (34F, 10M*) of 43 children. Primary reasons for LTV included central hypoventilation, ventilatory muscle weakness or chronic pulmonary disease
Edwards et al, 2017	To assess how directors of paediatric home ventilation programs facilitate shared decision-making with families facing decisions of whether to initiate or forgo Long-Term Ventilation for their children with life-limiting conditions. In addition, to assess directors' perspectives on these families' decisional nee	Oct 2015 March 2016	US	Children's hospitals in the US and Canada	Qualitative (not specified)	Audio-recorded interviews	Thematic approach based on Framework Analysis	15 healthcare professionals	15 directors of paediatric home ventilation programs. Median 19 yrs experience caring for children using LTV. 11 were paediatric pulmonologists, 2 paediatric intensivists, 2 specialised in both paediatric pulmonology and critical care
Study	Aim	Year of	Country	Setting	Methodology	Data	Data analysis	Sample	Sample

		data collection				collection			characteristics
Mah et al, 2008	To help physicians and other healthcare professionals become more aware of the perspectives and daily reality of parents' with children on home mechanical ventilation due to neuromuscular disorders by describing the lived experience of these parents	Not specified	Canada	Tertiary care paediatric neuromuscular clinics in Western Canada	Qualitative Phenomenology	Audio-recorded interviews	Phenomenological framework	19 parents, caregivers	15 families (14F, 3M*, 2 adoptive parents) 19 parents of children with a neuromuscular disease on home mechanical ventilation. 15 children, 11 on BiPAP, 4 tracheostomy
Nageswaran et al, 2022	To explore the roles of religion and spirituality of caregivers of children with medical complexity in their decision to pursue tracheostomy for their children	Dec 2013-Nov 2014	US	Children's hospital	Qualitative (not specified)	Audio-recorded interviews	Thematic content analysis	56 parents, caregivers	56 parents, caregivers of 41 children with cmc (38 mother, 13 father, 3 Grandmother, 1 Grandfather, 1 Grandmother figure)
Study	Aim	Year of data collection	Country	Setting	Methodology	Data collection	Data analysis	Sample	Sample characteristics

Nageswaran et al, 2018	To describe caregiver perceptions about their decision to pursue tracheostomy, in particular about satisfaction with their decision, for children with medical complexity living at home.	Dec 2013-Nov 2014	US	Children's hospital	Qualitative (not specified)	Audio-recorded interviews and focus groups	Thematic content analysis	56 parent, caregivers 33 healthcare professionals	56 parents, caregivers of 41 children with cmc (38 mother, 13 father, 3 Grandmother, 1 Grandfather, 1 Grandmother figure) 33 healthcare professionals including physicians, nurses, social care workers, and a care coordinator
Gower et al, 2020	To identify facilitators and barriers to tracheostomy decision-making process for children with medical complexity.	Dec 2013-Nov 2014	US	Children's hospital	Qualitative (not specified)	Audio-recorded interviews and focus groups	Thematic content analysis	56 parent, caregivers 33 healthcare professionals	56 parents, caregivers of 41 children with cmc (38 mother, 13 father, 3 Grandmother, 1 Grandfather, 1 Grandmother figure) 33 healthcare professionals including physicians, nurses, social care workers, and a care coordinator
Study	Aim	Year of data collection	Country	Setting	Methodology	Data collection	Data analysis	Sample	Sample characteristics
October et al, 2020	To determine the incidence	Jan 2015-Dec 2017	US	Three intensive	Prospective, mixed-methods,	Decisional	Directed content analysis	39 parents, caregivers	39 parents, caregivers enrolled,

	of decisional conflict and regret and explore the impact on quality of life among parents considering tracheostomy placement for their child			care units of (PICU, CICU, NICU) at a hospital	longitudinal study	conflict survey at time of tracheostomy Decisional regret and quality of life surveys at two weeks and three months after decision made.			25 parents, caregivers completed surveys at all three time points. 41% children discharged home with tracheostomy
Henderson et al, 2021	To explore the family experience of home ventilation through a comparison of anticipated home life changes with subsequent experiences.	Dec 2018-Oct 2019	US	Hospital to home	Qualitative (not specified)	Audio-recorded interviews	Conventional content analysis	20 parents, caregivers who chose home ventilation	20 parents, caregivers (3M, 19F*) of 20 children requiring home ventilation. 4 for lung disease of prematurity alone, 16 for medical complexity
Ferguson et al, 2011	To determine practices, attitudes and beliefs regarding the timing and content of client/family communication related to ventilatory support decisions for individuals with DMD	Not specified	Canada	Treatment centres for youth with DMD	Not specified	Questionnaire design	Not specified	The lead clinicians for management of Duchenne Muscular Dystrophy from 13 children's treatment centres. 10 parent, caregivers of a child with Duchenne Muscular Dystrophy	The lead clinicians for management of Duchenne Muscular Dystrophy from 13 children's treatment centres. 10 parent, caregivers of a child with Duchenne Muscular Dystrophy

Study	Aim	Year of data collection	Country	Setting	Methodology	Data collection	Data analysis	Sample	Sample characteristics
Smith et al, 2018	To explore if and how decision-making conversations integrated information exchange; deliberation; and plan determination and if they included previously defined shared decision-making elements.	Jan 2011-Jan 2012	US	Paediatric Intensive Care Unit	Mixed methods	Audio and video recorded family conferences After conference, parents and healthcare professionals completed a demographic questionnaire	Qualitative content analysis	14 family conference (FC) transcripts analysed discussing 20 patients.	14 FCs analysed. involving 20 parents (9M, 11F). FC led by PICU fellow or attending physician (36%), pulmonary (43%), cardiology (7%), neurology (7%), hematology/oncology (7%) subspecialist.
Pechmann et al, 2022	To evaluate parents' perspectives on the process of decision-making regarding ventilator support in children with SMA type 1	Dec 2016-June 2017	Germany	Hospital	Qualitative (not specified)	Audio-recorded interviews	Qualitative content analysis	15 parent/caregivers	15 parents of 14 children with SMA. 33.3% (5) used non-invasive ventilator support, 11.1% (2) used invasive ventilator support, 20% had passed away although using non-invasive ventilator support, and 33% (5) children had passed away without using ventilator support.

Study	Aim	Year of data collection	Country	Setting	Methodology	Data collection	Data analysis	Sample	Sample characteristics
Flynn et al, 2020	Longitudinal narrative study to tell the story of parents whose child had a new tracheostomy	Not specified	England	Hospital and home settings	Qualitative (not specified)	Audio-recorded longitudinal. Interviews at 3 timepoints over a 12-month period	Dialogical narrative analysis	12 parents, caregivers	12 (3M, 9F*) parents, caregivers from 9 families
Nurnaningsih et al, 2021	To explore parent's point of view about forgoing life sustaining treatment (LST) in terminal critically ill children and factors affecting their decisions	Feb 2019-Sept 2019	Indonesia	Paediatric intensive care unit	Qualitative Interpretive descriptive method	Audio-recorded interviews	Qualitative content analysis	7 parents, caregivers	7 parents, caregivers of 5 children all who were mechanically ventilated

*M=Male.

*F= Female.

Supplementary material table 2; Quality appraisal table for included studies

Question	Study	Bogetz et al, 2022	Boss et al, 2021	Jabre et al, 2022	Dybwik et al, 2012	Edwards et al, 2020	Edwards et al, 2017	Mah et al, 2008	Nageswaran et al, 2022	Fylnn et al, 2020
	Rating	High	High	High	Medium	Medium	High	High	Medium	High
1. Was there a clear statement of the aims of the research?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is the qualitative methodology appropriate?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Are the studies theoretical underpinnings clear, consistent and conceptually coherent?		No	No	No	No	Somewhat	Somewhat	Somewhat	No	Yes
5. Was the recruitment strategy appropriate to the aims of the research?		Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes
6. Was the data collected in a way that addressed the research issue?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
7. Has the relationship between researcher and participants been adequately considered?		No	Yes	No	Yes	No	No	Somewhat	No	Yes
8. Have ethical issues been taken into consideration?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9. Was the data analysis sufficiently rigorous?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. Is there a clear statement of findings?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
11. How valuable is the research?		a, b, c*	a, b, c*	a, b, c*	a, b*	a, b*	a, b, c*	a, b, c*	a, b, c*	a, b*

*a. Findings considered in relation to existing research, b. Discussion relating to implications of findings upon practice or policy, c. identification of areas in which further research is necessary.

Question	Study	Nageswaran et al, 2018	Gower et al, 2020	October et al, 2020	Henderson et al, 2021	Ferguson et al, 2011	Smith et al, 2018	Pechmann et al, 2022	Nurnaningsih et al, 2021
	Rating	Medium	High	Medium	High	Low	High	High	Medium
1. Was there a clear statement of the aims of the research?		Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
2. Is the qualitative methodology appropriate?		Yes	Yes	Somewhat	Yes	No	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?		Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
4. Are the studies theoretical underpinnings clear, consistent and conceptually coherent?		No	Somewhat	No	No	No	Somewhat	No	No
5. Was the recruitment strategy appropriate to the aims of the research?		Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
6. Was the data collected in a way that addressed the research issue?		Yes	Yes	Somewhat	Yes	Somewhat	Yes	Yes	Yes
7. Has the relationship between researcher and participants been adequately considered?		No	No	No	No	No	No	Somewhat	No
8. Have ethical issues been taken into consideration?		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9. Was the data analysis sufficiently rigorous?		Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
10. Is there a clear statement of findings?		Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
11. How valuable is the research?		a, b*	a, b, c*	a, b, c*	a, b, c*	a, b*	a, b, c*	a, b, c*	a*

*a. Findings considered in relation to existing research, b. Discussion relating to implications of findings upon practice or policy, c. identification of areas in which further research is necessary.