

## SUPPLEMENTARY MATERIAL

### Medline Search Sample:

#### **Concept 1: technology dependence**

**Keywords:** “technology depend\*” OR “technology-depend\*” OR “technological depend\*” OR “technological-depend\*” OR “screen depend\*” OR “mobile depend\*” OR “device depend\*” OR “screen-depend\*” OR “mobile-depend\*” OR “device-depend\*” OR “medical technol\*” OR “dependen\* on medical technol\*” “technology relian\*” OR “technolog\*-relian\*” OR “technological relian\*” OR “screen relian\*” OR “mobile relian\*” OR “device relian\*” OR “screen-relian\*” OR “mobile-relian\*” OR “device-relian\*” OR “medical relian\*” OR “relian\* on medical technol\*” OR “over\*reliance in technolog\*” OR “over\*dependence on technolog\*”

#### **Concept 2: Physical disability OR chronic illness OR complex care OR complex medical care OR complex needs**

**Medline:** (MH “Complex Care”) OR (MH “Chronic Disease”) OR (MH “Critical Illness”) OR (MH “Disabled Persons+”)

**Keywords:** “Physically Handicapped” OR “physical handicap\*” OR “Physically Disab\*” OR “Physical disability\*” OR “Physically Challenged” OR “chronically ill” OR “chronic illness\*” OR “chronic disease\*” OR end-of-life OR “end of life” OR “life-limiting condition\*” OR “life limiting condition\*” OR life-threatening OR “life threatening“ OR “terminal illness\*” OR “life-limited” OR “life limited” OR life-sustaining OR “life sustaining” OR “sustaining life” OR “Life Limiting Illness\*” OR “Life-Limiting Illness\*” OR “Genetic Disease\*” OR “Genetic Disorder\*” OR “Genetic condition” OR “Inborn Genetic Disease\*” OR “Single-Gene Defect\*” OR “Single Gene Defect\*” OR “Critical Illness\*” OR “critically ill” OR “Catastrophic Illness\*” OR “Multiple Chronic Conditions” OR “Multiple Chronic illnesses” OR “complex care” OR “complex caring” OR “complex nursing” OR “complex need\*” OR “multifaceted need\*” OR “multifaceted care” OR “complex medical need\*” OR “complex medical care” OR “multiple needs” OR “multiple care” OR “medically fragile” OR “medically frail\*” OR blind\* OR “visual impair\*” OR deaf\* OR “hearing impair\*” OR “mobility impair\*” OR “physical deficiency” OR “physical incapacity” OR “physically limited”

Technology	Medline
Technology	6,061
Phys Disab /Complex/Chronic	865,087
Combined	498
Peer Review	n/a
Total	498

#	Query	Limiters/Expanders	Last Run Via	Results
S6	S4 AND S5	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	498
S5	AB ( "technology depend*" OR "technology-depend*" OR "technological depend*" OR "technological-depend*" OR "screen depend*" OR "mobile depend*" OR "device depend*" OR "screen-depend*" OR "mobile-depend*" OR "device-depend*" OR "medical technol*" OR "dependen* on medical technol*" "technology relian*" OR "technolog*-relian*" OR "technological relian*" OR "*" OR "screen relian*" OR "mobile relian*" OR "device relian*" OR "screen-relian*" OR "mobile-relian*" OR "device-relian*" OR "medical relian*" OR "relian* on medical technol*" OR "over*reliance in technolog*" OR "over*dependence on technolog*" ) OR TI ( "technology depend*" OR "technology-depend*" OR "technological depend*" OR "technological-depend*" OR "screen depend*" OR "mobile depend*" OR "device depend*" OR "screen-depend*" OR "mobile-depend*" OR "device-depend*" OR "medical technol*" OR "dependen* on medical technol*" "technology relian*" OR "technolog*-relian*" OR "technological relian*" OR "*" OR "screen relian*" OR "mobile relian*" OR "device relian*" OR "screen-relian*" OR "mobile-relian*" OR "device-relian*" OR "medical relian*" OR "relian* on medical technol*" OR	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	6,061

	"over*reliance in technolog*" OR "over*dependence on technolog*" )			
S 4	S1 OR S2 OR S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	865,08 7
S 3	AB ( "Physically Handicapped" OR "physical handicap*" OR "Physically Disab*" OR "Physical disability*" OR "Physically Challenged" OR "chronically ill" OR "chronic illness*" OR "chronic disease*" OR end-of-life OR "end of life" OR "life-limiting condition*" OR "life limiting condition*" OR life-threatening OR "life threatening" OR "terminal illness*" OR "life-limited" OR "life limited" OR life-sustaining OR "life sustaining" OR "sustaining life" OR "Life Limiting Illness*" OR "Life-Limiting Illness*" OR "Genetic Disease*" OR "Genetic Disorder*" OR "Genetic condition" OR "Inborn Genetic Disease*" OR "Single-Gene Defect*" OR "Single Gene Defect*" OR "Critical Illness*" OR "critically ill" OR "Catastrophic Illness*" OR "Multiple Chronic Conditions" OR "Multiple Chronic illnesses" OR "complex care" OR "complex caring" OR "complex nursing" OR "complex need*" OR "multifaceted need*" OR "multifaceted care" OR "complex medical need*" OR "complex medical care" OR "multiple needs" OR "multiple care" OR "medically fragile" OR "medically frail*" OR blind* OR "visual impair*" OR deaf* OR "hearing impair*" OR "mobility impair*" OR "physical deficiency" OR "physical incapacity" OR "physically limited" ) OR TI ( "Physically Handicapped" OR "physical	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	579,51 4

	handicap*" OR "Physically Disab*" OR "Physical disability*" OR "Physically Challenged" OR "chronically ill" OR "chronic illness*" OR "chronic disease*" OR end-of-life OR "end of life" OR "life-limiting condition*" OR "life limiting condition*" OR life-threatening OR "life threatening" OR "terminal illness*" OR "life-limited" OR "life limited" OR life-sustaining OR "life sustaining" OR "sustaining life" OR "Life Limiting Illness*" OR "Life-Limiting Illness*" OR "Genetic Disease*" OR "Genetic Disorder*" OR "Genetic condition" OR "Inborn Genetic Disease*" OR "Single-Gene Defect*" OR "Single Gene Defect*" OR "Critical Illness*" OR "critically ill" OR "Catastrophic Illness*" OR "Multiple Chronic Conditions" OR "Multiple Chronic illnesses" OR "complex care" OR "complex caring" OR "complex nursing" OR "complex need*" OR "multifaceted need*" OR "multifaceted care" OR "complex medical need*" OR "complex medical care" OR "multiple needs" OR "multiple care" OR "medically fragile" OR "medically frail*" OR blind* OR "visual impair*" OR deaf* OR "hearing impair*" OR "mobility impair*" OR "physical deficiency" OR "physical incapacity" OR "physically limited" )			
S 2	(MH "Complex Care") OR (MH "Chronic Disease") OR (MH "Critical Illness")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	279,255
S 1	(MH "Disabled Persons+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	61,659

			Search Screen - Advanced Search Database - MEDLINE	
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**Narrow reason types identified by the review**

<b>Narrow reasoning categories for initiation</b>	<b>Narrow reasoning categories against initiation</b>	<b>Narrow reasoning categories - unclear if for or against initiation</b>
<p><i>Actively positive reasons</i></p> <p>Action to reduce pressure on the brain[28]</p> <p>Acute situations[25]</p> <p>Acute treatment to avoid death[32]</p> <p>Benefit to patient[38]</p> <p>Child unable to meet nutritional needs orally[28]</p> <p>Doctor-centred[27]</p> <p>Emergency situation [26, 28]</p> <p>Established diagnosis and treatment[17]</p> <p>Feeding tube for survival[23]</p> <p>Hope for a miraculous or unexpected good outcome[16]</p> <p>Hope/ expectation of good quality of life[33]</p> <p>Improve or ensure respiration[28]</p> <p>Improved child health[29]</p> <p>Life prolonging attitude[21]</p> <p>Long term outcome[27]</p> <p>Medical stability of the child[18]</p> <p>Need for respiratory support[23]</p> <p>Perceived as safe and expected treatment[37]</p> <p>Preserving hope[21]</p> <p>Recovery or bridge to transplantation[34]</p>	<p><i>Positive reasons not to initiate</i></p> <p>Alleviate moral dilemmas[22]</p> <p>Avoiding distress for the child[11]</p> <p>Avoiding prolongation of suffering[13]</p> <p>Acute deterioration of respiratory condition[15]</p> <p>Best interest and open discussion[25]</p> <p>Best interests of the child[29]</p> <p>Best interests, avoiding intensive futile care[47]</p> <p>Caring responsibility[27]</p> <p>Cultural factors supporting child death at home[34]</p> <p>Due consideration to value of continuing life sustaining support[24]</p> <p>Family, caring responsibility[29]</p> <p>Future quality of life, life expectancy[30]</p> <p>Improve quality of life, preserving remaining life[15]</p> <p>Parental insight into child's prognosis[34]</p> <p>Poor quality of life on technology[38]</p> <p>Providing supportive comfort care[8]</p> <p>Quality of life would be compromised by treatment[8]</p> <p>Respect patient or parent's wishes[51]</p> <p>Responsibility to prevent needless pain[25]</p>	<p><i>Altruistic reasoning</i></p> <p>Accurate information and wellbeing[29]</p> <p>Alleviate burden of guilt[25, 29, 61]</p> <p>Alleviate burden on parents[34]</p> <p>Authority to make decisions[56]</p> <p>Best interest of the child[11, 27, 29, 42]</p> <p>Burdens on family, family context[33]</p> <p>Burden on parents[55]</p> <p>Burden of treatment at home[37]</p> <p>Capacity of services and resources[19]</p> <p>Carer well-being[29]</p> <p>Child well being[29]</p> <p>Child and family under stress[39]</p> <p>Control family's uncertainty through selective communication[14]</p> <p>Decisions based on rang of conditions, experience and prognosis[19]</p> <p>Doubt about parent understanding of consequences[21]</p> <p>Empathy[27]</p> <p>Empathy from professionals[27]</p> <p>Evaluating patient future quality of life[33]</p>

<p>Role of healing[14]</p> <p>Technology to improve survival[39]</p> <p><i>Least worst option</i></p> <p>Acquiescence to parent views[31]</p> <p>Active euthanasia (attitude negative)[40]</p> <p>Avoid raising expectations that create a moral dilemma[22]</p> <p>Buy time to make a reasonable diagnosis[22]</p> <p>Child well-being[29]</p> <p>Choice of treatment reflects resources[37]</p> <p>Choosing the least detrimental alternative (slight negative tone)[14]</p> <p>Complex decision making[32]</p> <p>Continue short-term invasive therapy[43]</p> <p>Disagreement with relatives (attitude negative)[40]</p> <p>Fear of charges of homicide, abuse or neglect[14]</p> <p>Keeping alive for benefit of others (author against this reason)[24]</p> <p>Legal consequences (attitude negative)[40]</p> <p>Legal consequences influencing action [13]</p> <p>Legal obligation[14, 40, 44]</p> <p>Maximum therapeutic care despite physician opinion[34]</p> <p>Neonatal resuscitation unclear prognosis[17]</p> <p>Not withdrawing care without prognosis[17]</p> <p>Ongoing dependence[41]</p>	<p>Sensitive communication and respect[47]</p> <p>Withdrawal of care as ethical in futile cases[17]</p> <p>Withdrawal of technology dependence[32]</p> <p><i>Confidence and experience</i></p> <p>Acceptability[31]</p> <p>Confidence to resist pressure[21]</p> <p>Causing the death of the child[21]</p> <p>Closeness to patient prevents objectivity[21]</p> <p>Distinction between acts and omissions[51]</p> <p>Duty to preserve life and health[51]</p> <p>Duty to the dying and to the sick is different[12]</p> <p>Easier to limit LST in young children[33]</p> <p>Experience of outcomes[46]</p> <p>Favouring the status quo[51]</p> <p>Length of professional experience[40]</p> <p>Moral duty to uphold ethics despite the consequences[51]</p> <p>Moral obligation to relieve suffering[14]</p> <p>Morbidity, device malfunction and poor quality of life[38]</p> <p>No confidence to withdraw treatment if survival possible[46]</p> <p>No parental support[30]</p> <p>Non-acquiescence to parent views[31]</p> <p>Not required to provide futile care[52]</p>	<p>Evaluating what family can bear[33]</p> <p>Family well-being[29]</p> <p>Fear of frightening the parents[21]</p> <p>Greater prospects of survival but living with substantial disability[37]</p> <p>Lack of home care nurses to provide home support[54]</p> <p>Life-sustaining and prevention of suffering - holistic outcomes[11]</p> <p>Morbidity post-technology dependence[38]</p> <p>Outcome likely to be poor[32]</p> <p>Overriding parental decisions based on child welfare[47]</p> <p>Perceived inability to provide good quality of life[32]</p> <p>Poor outcome[32]</p> <p>Quality of life[34]</p> <p>Responsiveness to patient needs[61]</p> <p>Risk to child and family health[39]</p> <p>Taking burden from parents[31]</p> <p>Tensions between sanctity of life and quality of life[19]</p> <p>Uncertain prognosis and what is best interests of child[42]</p> <p>Uncertainty of future improvement[41]</p> <p>Unclear prognosis[46]</p> <p>Understanding complexity of case[14]</p> <p>Understanding future consequences[29]</p> <p>Values of physician - best interests of the child[33]</p>
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<p>Over optimism and appearing not to give up[19]  Parental hope of miracle recovery[34]  Treatment[27]  Treatment prone medicine[21]  Treatment to allow clear assessment[42]  Uncertain prognosis[21]</p> <p><i>Wider concerns (wellbeing)</i>  Family well being[29]  Future quality of life, future consciousness[33]  Influence of personal beliefs[17]  Minimise risk of long term morbidity[19]  Outcome for the child[21]  Post investigation[26]  Postponing or passing on responsibility[21]  Pressurized by parents to initiate[46]  Prolonging treatment opposed to active euthanasia[24]  Survival but increased morbidity[35]  Treatment covered by health insurance[37]</p> <p><i>Obligations</i>  Experience of physician to make decisions[8]  Obligation to preserve life[14]  Obligation to use the technology if it is there[16]  Others will benefit from testing the technology in this case[16]</p>	<p>Physicians not to provide services that are futile[49]  Poor prognosis and no benefit of treatment[32]  Responsibility to minimise harm and maximise benefits in a clinical and wider sense[51]  Risks to home caring abilities[29]  Taking action (withdrawing care)[21]  Taking burden from parents[31]  Technology only prolongs death[22]  Technology dependence not beneficial[50]</p> <p><i>Knowledge and judgement</i>  Awareness of home mechanical ventilation in adults influencing paediatricians[15]  Child receive no benefit from CPR[25]  Correcting nocturnal or proven (diurnal) ventilatory failure[15]  Cultural differences as influences on ethical differences[48]  Cultural variation in 'position statements' of viability[48]  Disability future quality of life[49]  Fatal or terminal illness – prognosis[40]  Futile care[49]  Futile treatment withdrawn[25]  Futility of care[33]  Futility of further treatment[12]  Future consequences for patient views / views of</p>	<p><i>Working in a team</i>  Act to steer patient views[14]  Appropriate language used to describe unclear options[56]  Aware of parent or patient perspective[53]  Burdensome to talk about death[44]  Child's ability to communicate views[8]  Consensus decision making[58]  Consideration of advance directives[60]  Consultation with family but clinical team make final decision[25]  Counselling families of all possibilities[32]  Difference in perception of well being[38]  Difficult treatment decisions[32]  Effective communication[29]  Effective communication[11]  Effective communication for the child and parent[57]  Empathy and appreciation for parental decision making[59]  Ensure full understanding of options[56]  Family assessment of child's condition[33]  Family caring responsibility[29]  Family understanding of clinical need[39]  Future family wellbeing[45]  Indirect involvement of parents[31]</p>
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<p>Parental desire for treatment[8]          Pressure of public expectation of technology's capabilities[11]          Sole decision making[21]</p>	<p>patient[42]          Individual unit approach to decision making[48]          Ineffective treatment[29]          Lack of confidence in ethics[21]          Lack of community resources leads to intensive treatment at end of life[50]          Legal and moral considerations[33]          Legal support[47]          Miserable and unhappy[21]          Moral distress[27]          National differences in determining futility[31]          Need for agreement[21]          Need to relieve life-threatening symptom[29]          No chances of survival[30]          Non elective ventilation[15]          Non-curative treatment[29]          Obstacles to transition home[45]          Over-pessimistic[23]          Poor future quality of life[11]          Poor neurological prognosis[11, 22, 25, 40]          Providing nutrition and hydration only[24]          Regret reported by parents who opted for tracheostomy[36]          Severity of prognosis[8]          Socio-economic and cultural differences of parents[48]          Treatment risks [29]</p>	<p>Information about diagnosis and prognosis[54]          Information for parents for options at end of life[34]          Lack of evidence as guidance for parents[54]          Lessons learned from family[29]          Long-term caring requirements for the child[39]          Mutual trust and shared knowledge[25]          No opportunity for parental involvement[34]          Opinions of other professionals[21]          Parents as information receivers[34]          Parents as significant decision makers[34]          Parental decision based on medical advice[47]          Parental involvement[31]          Parents may prefer a form of paternalism[36]          Patient autonomy[29]          Patient's future ability to interact with others[7]          Presence of hospital ethics committee[40]          Physicians as information providers[34]          Potential for conflict[32]          Psychological support to parents[38]          Reassurance from colleagues, experts, ethical committee[57]          Receptive to parental / family needs and views[29]          Repeated opportunities for imparting information[36]          Respect for other members of clinical team[25]          Risk of catastrophic event at home[54]          Risk of social isolation in the long term[39]</p>
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	<p>Updated guidelines support Withholding or withdrawing care [40]</p> <p><i>Dispute</i></p> <p>Being distrusted, treatment as abuse [13]</p> <p>Courts discussing values of respect for life [49]</p> <p>Discrimination against disability [49]</p> <p>Facilitating parental change of mind once accepting of terminal diagnosis [34]</p> <p>Families reluctant to consent [39]</p> <p>Futility as a means of reclaiming lost decision-making power [12]</p> <p>Loyalty conflicts [46]</p> <p>Parental refusal of consent [11]</p> <p>Parents' wishes are legally classed as euthanasia [44]</p> <p>Persistent vegetative state legal possibility to discontinue treatment [44]</p> <p>Reducing fear of legal consequences [17]</p> <p>Resisting parental request [30]</p> <p>Secrecy of acts/ euthanasia [14]</p>	<p>Risk of unilateral decision making[32]</p> <p>Sharing decisions to empower families[28]</p> <p>Shared discussions leading to decisions[32]</p> <p>Sharing the decision[8]</p> <p>Supportive and empathetic information provision[29]</p> <p>Support to make decisions slowly[39]</p> <p>Time to make best decisions[29]</p> <p>Timely discussion before a child requires technology dependence[32]</p> <p>Timing of information to inform decisions[50]</p> <p>Understanding how to communicate information[59]</p> <p>Willingness to involve parents in decisions[17]</p> <p><i>Impartiality</i></p> <p>Aiming to act fairly[53]</p> <p>Assessment of quality of life[23]</p> <p>Assumptions based on quality of life[41]</p> <p>Availability of resources[33]</p> <p>Avoid value-based or unfounded assumptions on quality of life[42]</p> <p>Avoiding close relationships with parents[46]</p> <p>Certainty of outcome[24]</p> <p>Changing prognosis/child's situation[25]</p> <p>Complex evaluation of burden and risk[42]</p> <p>Confidence in decision[21]</p> <p>Cost and complexity of care[54]</p>
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		<p>Criteria for withholding or withdrawing treatment[34]</p> <p>Culturally appropriate communication[53]</p> <p>Death expected or survival unacceptable quality of life[24]</p> <p>Decision based on diagnosis, prognosis and quality of life [24]</p> <p>Delegating effective care[61]</p> <p>Differences between neonates and older children[8]</p> <p>Economic resource costs[33]</p> <p>Economic and labour costs[45]</p> <p>Estimation of quality of life[23]</p> <p>Excluding information believed to be irrelevant[43]</p> <p>Financial or economic impact[29]</p> <p>Future challenges in diagnosis[28]</p> <p>Future morbidity[28]</p> <p>Future outcomes[57]</p> <p>Future quality of life[57]</p> <p>Global fair allocation of resources[53]</p> <p>Guidelines influence decision making[17]</p> <p>Importance of quality of life on decision making[24]</p> <p>Increased survival but also morbidity[55]</p> <p>Information reflecting linguistic and cultural needs[50]</p> <p>Institutional treatment and caring[29]</p> <p>Judgement of benefit or risk of treatment[25]</p> <p>Legal obligation[14, 29, 40]</p> <p>Longitudinal outcome[27]</p>
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		<p>Non curative treatment[29]</p> <p>No difference in mortality between those who do and don't rely on technology[36]</p> <p>Objectivity hiding parts of the truth[21]</p> <p>Obligation to be responsible for care at home[61]</p> <p>Outcomes[27, 53]</p> <p>Overtreatment[21]</p> <p>Physician responsible for final decision[25]</p> <p>Potential for consciousness[24]</p> <p>Power/trust in technology[29]</p> <p>Prolong life[61]</p> <p>Rationing of resources[58]</p> <p>Realistic assessment of problem[14]</p> <p>Responsibility[27]</p> <p>Responsibility for outcomes[61]</p> <p>Responsibility to avoid bias or judgement about quality of life[42]</p> <p>Responsibility to do the least harm[53]</p> <p>Right to determine how skills are used[57]</p> <p>Role is to preserve life[22]</p> <p>Technology potentially incompatible with child growth and development[38]</p> <p>Treatment associated with benefits and burdens[36]</p> <p>Treatment related factors - invasiveness, complications, reversibility, life expectance, functioning, quality of life, psychology[33]</p> <p>Uncertain or inaccurate prognosis[21, 43]</p>
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		<p>Uncertain outcomes[27]</p> <p>Uncertain prognosis[8]</p> <p>Using facts to determine moral decision[43]</p> <p>Wider concept of best interest of the child[25]</p> <p>Worth the economic costs[27]</p> <p><i>Disputes</i></p> <p>Answers to disputes are empirically based[7]</p> <p>Complex ethical and legal challenges[8]</p> <p>Conflict between child rights and parent rights[46]</p> <p>Conflict between hospital and community care[45]</p> <p>Conflict in decision making[36]</p> <p>Conflict with media/ journalists[46]</p> <p>Conflict with nurses[46]</p> <p>Difficult to communicate because of health care requirement to treat[44]</p> <p>Dull the need to reappraise actions[43]</p> <p>Fear of tracheostomy[39]</p> <p>Inadequacy of outcome measures to inform prognosis[19]</p> <p>Increased conflict in adults[8]</p> <p>Inconsistent legal requirements international[52]</p> <p>Information is understood differently by both parties (parents and clinicians)[55]</p> <p>Intensive treatment at end of life[50]</p> <p>Lack of availability of skilled home nursing care[37]</p>
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		<p>Lack of consensus between physicians[8]</p> <p>Loyalty conflicts[46]</p> <p>Media spotlight[58]</p> <p>Not using information in decision[54]</p> <p>Obstacles to transition home[45]</p> <p>Parents sidelined due to complex clinical situation[35]</p> <p>Paternalism of information provision[24]</p> <p>Physician / family disagreement[29]</p> <p>Physician doubt about parent motivation[21]</p> <p>Potential litigation[11]</p> <p>Potential for racial bias in care provision[50]</p> <p>Pressure from parents[21]</p> <p>Public nature of discussion dictates action[14]</p> <p>Recommending a treatment they would not want for themselves[27]</p> <p>Risk of paternalism[56]</p> <p>Socioeconomic disparity at the end of life[50]</p> <p>Undisclosed fears of prosecution[14]</p> <p><i>Feelings and emotions</i></p> <p>Anxiety influencing clinical judgement[42]</p> <p>Anxiety and fear of the entire process (family)[39]</p> <p>Assessing feelings[61]</p> <p>Assuming responsibility for risk of the decision[57]</p> <p>Attitudes influenced by personal and psychological factors[8]</p>
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		<p>Awareness / consciousness[24]</p> <p>Compassion for life 'slippery concept'[58]</p> <p>Considerations of quality of life and values[8]</p> <p>Decisional regret after tracheostomy[36]</p> <p>Emotions and discomfort[33]</p> <p>Experience, optimism, patient subjective experience[33]</p> <p>Fear and anxiety, loneliness[21]</p> <p>Fear of media criticism[21]</p> <p>Fear of mistakes[21]</p> <p>Fear of prolonging suffering[46]</p> <p>Good and bad[61]</p> <p>Hesitation in withholding and withdrawing[33]</p> <p>Hope[27]</p> <p>Increased emotional input - humour, anger, animation[7]</p> <p>Lack of importance of prognosis to experienced parents[35]</p> <p>Less regret because technology was better than expected[36]</p> <p>Moral distress[27]</p> <p>More experience greater fear of negative media attention[21]</p> <p>Narratives of being 'good parents' with no regrets[19]</p> <p>Need to do something[36]</p> <p>Not allowing anxiety to influence clinical decision[42]</p> <p>Overwhelming power of technology[22]</p>
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		Personal agony[14] Personal convictions and values[8] Personal factors and experiences influencing decisions[8] Presence of hope[29] Relieve suffering (ambivalent)[61] Relieve suffering[58] Regret[36] Stigmatisation[29] Suffering at end of life[35] Transparent and honest[29]
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