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Parental decision-making for medically complex infants and children: An integrated literature review

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Abstract

Background—Many children with life-threatening conditions who would have died at birth are now surviving months to years longer than previously expected. Understanding how parents make decisions is necessary to prevent parental regret about decision-making, which can lead to psychological distress, decreased physical health, and decreased quality of life for the parents.

Objective—The aim of this integrated literature review was to describe possible factors that affect parental decision-making for medically complex children. The critical decisions included continuation or termination of a high-risk pregnancy, initiation of life-sustaining treatments such as resuscitation, complex cardiothoracic surgery, use of experimental treatments, end-of-life care, and limitation of care or withdrawal of support.

Design—PubMed, Cumulative Index of Nursing and Allied Health Literature, and PsycINFO were searched using the combined key terms ‘parents and decision-making’ to obtain English language publications from 2000 to June 2013.

Results—The findings from each of the 31 articles retained were recorded. The strengths of the empirical research reviewed are that decisions about initiating life support and withdrawing life support have received significant attention. Researchers have explored how many different factors impact decision-making and have used multiple different research designs and data collection methods to explore the decision-making process. These initial studies lay the foundation for future research and have provided insight into parental decision-making during times of crisis.

Conclusions—Studies must begin to include both parents and providers so that researchers can evaluate how decisions are made for individual children with complex chronic conditions to understand the dynamics between parents and parent–provider relationships. The majority of studies focused on one homogenous diagnostic group of premature infants and children with complex congenital heart disease. Thus comparisons across other child illness categories cannot be made. Most studies also used cross-sectional and/or retrospective research designs, which led to researchers and clinicians having limited understanding of how factors change over time for parents.

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Keywords

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1. Introduction

Many children with medically complex conditions who would have died at birth are now surviving months to years longer than previously expected. The initial life-threatening condition (e.g., extreme prematurity, metabolic disease, hypoxic–ischemic encephalopathy, cardiac defect) and the therapies usually lead to a medically complex child (Simon et al., 2010). Medically complex children have chronic complex conditions (e.g., cardiovascular disease, congenital abnormalities), potential dependence on technology (e.g., tracheostomy, cerebral spinal fluid shunts), frequent inpatient admissions, parental administration of multiple medications, multiple specialists involved in care (Srivastava et al., 2005), and potentially an early death (Morris, 2009; Ortenstrand et al., 2010). Decision-making for medically complex children begins at diagnosis and continues throughout the child’s life with each prior decision effecting the next decision (Toebbe et al., 2012).

Decision-making for medically complex children may begin prenatally when fetal diagnostic and imaging studies provide information about a possible life-threatening condition that may elicit making a choice between whether to terminate or continue a pregnancy (Rempel et al., 2004). For others, the decision-making process does not begin until birth or at the time of a later diagnosis when it must be decided whether to once again initiate care that is life-sustaining and curative or opt for therapies that focus on alleviating distressing symptoms that are designated as palliative care (Grobman et al., 2010). Parents and healthcare providers (HCPs) of medically complex children also need to determine how aggressively to pursue potential therapies including both standard and experimental therapies. All decisions are complex and challenging for parents because some of the therapies inflict pain and shorten the duration of the child’s life (Sharman et al., 2005), all of which can profoundly impact parents and health care system resources (Michelson et al., 2009). In essence, the main decisions for medically complex children are often a matter of life or death, depending on which option is chosen.

Regardless of the type of decision, parents work with HCPs to determine the optimal choice for the child. HCPs generally are the first to tell the parents that their child has a life-threatening illness. Parental interactions with HCPs can range from limited information exchange to heavy reliance on HCPs information and advice in the decision-making process. Parents are reluctant for many reasons to accept a diagnosis or complication resulting from a life-threatening illness for their child (Giannini et al., 2008), but when parents and HCPs have an incongruent evaluation of the ‘best treatment’ for the child (usually in the case of neurological injury) (Verhagen et al., 2009), current customs, personal preferences and resources, and legal precedence may become central to decision-making about initiating life-support or withdrawing life-support measures.

Whether parents or HCPs are primarily responsible for initiating life-support or withdrawal of life-support measures in a critical care setting varies significantly. For example in many of the Pacific Rim countries (e.g., Hong Kong, Singapore, Malaysia, Japan, and Australia) the final decision-makers when parents and HCPs do not agree on the appropriate medical interventions for a child, the physicians report they have the final say in treatment decisions (Martinez et al., 2005). In Northern/Western European countries, it is also custom to rely heavily on physicians to be the decision-makers when children are critically ill or have cancer; parents are informed of the decision and generally agreeing with the decision (Devictor and Latour, 2011). In Turkey, physicians often determine the type of treatments, where the treatments are delivered, and the healthcare team for children undergoing cancer treatment (Kilicarslan-Toruner and Akgun-Citak, 2013). For the most part, medical judgment of long-term outcomes impacts these difficult decisions, but physicians in some countries (e.g., Malaysia, Singapore) must also consider the financial burden that will be assumed by the parents because of the medical care (Martinez et al., 2005). In other countries, the medical cost is deferred to government agencies, insurances companies, or other entities. The predominate decision maker and financial constraints can effect the decisions made for critically ill children.

A current legal case in the United States illustrates some of the complexities of decision-making for children. The mother of a child declared brain dead has taken legal action (Winkfield vs. Children’s Hospital Oakland) against the hospital caring for her child prohibiting the physicians from removing the child from the ventilator. The child was originally admitted to the hospital to undergo a complex adenotonsillectomy, uvulopalatopharyngoplasty and submucous resection of bilateral inferior tubinates for treatment of sleep apnea. The medical history of the child is not presented in the court documents available. Following the surgical procedure, the child was transferred to the intensive care unit as planned. The child was alert, but actively bleeding from her mouth. Within an hour, the child went into cardiac arrest. Even though the child was resuscitated, the length of time without oxygen and blood flow led to irreversible brain damage and brain death was declared two days later by two separate physicians in accordance with the standards set forth by the Task Force of Brain Death in Children (2011). The California Health and Safety Code § 7180 states that an individual who has sustained “irreversible cessation of all function of the entire brain, including the brain stem,” is dead. According to this, the child is dead, even if her heart continues to beat. However, the mother refused to accept the child is dead and petitioned the court requesting her child continue to receive treatment and surgical placement of a tracheostomy tube and gastric tube.

The decision being made here is whether or not a child, who has been declared brain dead, should be removed from a ventilator or should the parent be able to request ventilator and nutritional support for a child who is legally dead. The court documents offer insight into the mother’s perspective of the case, but offers little information about the HCPs views. The mother reported that her child appeared to be ‘quietly’ sleeping. Additionally, the mother is Christian and she believes that, as long as, her daughter’s heart is beating her daughter is still alive and should be treated with respect. If the ventilator is removed from the child, the mother views that as killing her daughter. Another reason the mother is reluctant to remove the ventilator is because she has had similar experiences with others who were also declared brain dead who recovered and led a normal life. The factors that influenced this mother’s decision to keep her daughter on a ventilator are potential lack of understanding of neurological injury, religious beliefs, and previous experiences with others. The HCPs and hospital refused to provide additional treatment because the child was legally dead. The court ultimately ruled that it “could not order a physician or a hospital to provide medical treatment that was not authorized by law, and that the decisions whether to insert a gastric feeding tube and to perform a tracheotomy were medical decisions”. The mother was able to find another facility to accept the child. The child was transferred to the facility and news reports indicate the child had a tracheostomy tube and gastric feeding tube placed. This case illustrates several factors that influenced the mother’s decision to continue to provide ventilatory and nutritional support to her child who was declared brain dead, as well as, the extent the mother wanted to be involved in the decision-making process. What is unknown is what other factors influenced her decision, how previous experiences with HCPs influenced her decisions, the type of communication she had with HCPs, her current relationship with the HCPs, and the extent of her knowledge about brain injury.

Within the macro-environment of decision-making, a microenvironment of the parents and HCPs involved in a specific decision for a single child can create conflict. When parents and HCPs have an incongruent evaluation of the long-term outcomes of the child, conflict plagues the communication and relationship between parent and HCPs (Verhagen et al., 2009). The conflict may negatively affect long-term outcomes both physical and psychological health of the parents. Understanding how parents make decisions is necessary to prevent parental regret about decision-making, which can lead to psychological distress, decreased physical health, and decreased quality of life for the parents (Brehaut et al., 2003; Korenromp et al., 2005). A study conducted in the Netherlands, 196 women whose infants were diagnosed prenatally with an abnormality (e.g., chromosomal anomalies) and subsequently opted for termination of the pregnancy continued to regret the decision to terminate and had psychological stress (e.g., pathological grief, post-traumatic stress symptoms) more than 2 years after choosing to termination (Korenromp et al., 2005). Additional evidence suggests that life verse death decision-making can increase parent mortality (Harper et al., 2011; Li et al., 2003), mental illness (Li et al., 2005), and morbidity (Olsen et al., 2005). Therefore, the aim of this integrated literature review was to describe possible factors that affect parental decision-making for medically complex children. The critical decisions included continuation or termination of a high-risk pregnancy, initiation of life-sustaining treatments such as resuscitation, complex cardiothoracic surgery, use of experimental treatments, end-of-life care, and limitation of care or withdrawal of support. For the purposes of this review child refers to infants and children between birth and 12 years of age.

2. Methods

The method of an integrated literature review was chosen because the primary problem identified as decision-making by parents of children with medically complex conditions had the potential for multiple variables to effect the decision. Additionally, researchers used diverse methodologies including: cross-sectional designs, longitudinal designs, retrospective reviews, and prospective designs (Whittemore and Knafl, 2005). The diverse methods required the use of an integrated review methodology. Therefore with a large number of variables expected and multiple types of study designs anticipated to explore the complex process of decision-making, an integrated literature review method of chosen. This method allows for synthesis of many designs and variables to draw conclusions from the empirical literature available. See Table 1 for more details on the integrated literature review method utilized in this review.

PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and PsycINFO were searched using the combined key terms ‘parents and decision-making’ to obtain English language publications from 2000 to June 2013. The search strategy generated 336 articles relevant based on their titles with 305 articles eliminated after review of the abstract. A total of 31 articles retained for this integrated review. The inclusion criteria were English language studies of factors impacting parental decision-making for infants and children with life-threatening illnesses. The decisions had to involve life-sustaining treatments with the intent to cure a significant life-threatening illness (e.g., congenital heart disease, extreme prematurity) or withdrawal and termination of treatments with probable death as the outcome. Infants and children were defined as those <12 years of age. The exclusion criteria were studies of decisions about non-life-threatening illnesses, children with cancer, and decisions about organ donation.

The time frame of 13 years was chosen because the success in treatment for medically complex infants and children has improved substantially in the past decade (Bell, 2007). In addition, the level of involvement of parents in the decision-making process has changed due to the influence of shared decision-making and the endorsement of involving individuals in their health care (Kon, 2010; Malusky, 2005; van den Brink-Muinen et al., 2006).

3. Results

The findings from each of the 31 articles retained were recorded into a matrix extracting themes and definitions of each theme as described by the authors (see Table 2). Disease characteristics of the ill children ranged from extremely premature infants to those with neurological injuries or genetic abnormalities to term infants with metabolic disease. The sample generally included parents or providers. The main study designs were cross-sectional, qualitative descriptive. The definitions from each article were then synthesized to develop themes. Within each theme if the definitions varied across different decisions it was described. The themes included information needs, seriousness of illness, no other treatment options, child’s best interests, religiosity and spirituality, parental characteristics and past experiences, and emotional support.

3.1. Information needs

Parents relied on information to make decisions throughout their child’s life. When the child was initially diagnosed with a life-threatening illness and information about the illness was necessary (Grobman et al., 2010; Moro et al., 2011). However, being in a state of emotional shock after receiving the diagnosis of a life-threatening illness (Boss et al., 2008; Lan et al., 2007; Payot et al., 2007; Vandvik and Forde, 2000) and during other critical changes within the illness course (Snowdon et al., 2006), parents struggled to understand and integrate the illness and treatment options (Boss et al., 2008; Chaplin et al., 2005; Grobman et al., 2010; Partridge et al., 2005; Snowdon et al., 2006). Thus knowing the types of information parents needed and how to effectively communicate this relevant information may aid parents in decision-making.

Information about the illness and treatments was vital to parents. When parents were making decisions to initiate life-sustaining treatment, they needed to know the severity and extent of the illness, specifically the presence of chromosomal abnormalities or structural defects (e.g., hypoplastic left heart syndrome) (Ahmed et al., 2008; Balkan et al., 2010; Chaplin et al., 2005; Lam et al., 2009; Rempel et al., 2004; Zyblewski et al., 2009). Parents also wanted information about how treatments would impact their child’s illness course regarding how the spectrum of the severity of the illness and intensity of the treatments could impact the child’s quality of life including the level of pain and suffering the child may endure (Culbert and Davis, 2005; Sharman et al., 2005; Snowdon et al., 2006).

Parents needed to know the benefits and adverse effects of treatments (Einarsdottir, 2009) with ample time to ask questions (Kavanaugh et al., 2010). Parents sought and/or relied on the HCPs’ knowledge and opinion about which treatment options were best for the child (Bluebond-Langner et al., 2007; Partridge et al., 2005; Rempel et al., 2004; Sharman et al., 2005) and what scientific evidence supported the efficacy of the treatment (Ellinger and Rempel, 2010; Rempel et al., 2004). In cases when the child’s illness did not respond to initial treatments, parents searched for additional treatment options (e.g., Internet, HCPs) and second opinions (Einarsdottir, 2009). If the child deteriorated to the point where withdrawing or withholding support was discussed parents want individualized and unique details of the illness, treatments, and prognosis from HCPs, even if a consensus about the prognosis was not reached (Einarsdottir, 2009; McHaffie et al., 2001). Having this information available in written or electronic form from organizations about the child’s illness and treatment options were also viewed as helpful (Chaplin et al., 2005; Grobman et al., 2010; Redlinger-Grosse et al., 2002).

Parents reported that the way the information was delivered also affected their decision-making. Providers needed to present multiple times in a clear, honest manner with limited jargon to be helpful to parents making initial decisions about life-sustaining treatments (Grobman et al., 2010). Parents needed to feel that HCPs were compassionate and hopeful as these behaviors demonstrated the HCPs respected their child as an individual, instead of a ‘protocol’, specifically during making decisions about initializing treatment or withdrawal/withholding treatment (Boss et al., 2008; Brinchmann et al., 2002; Redlinger-Grosse et al., 2002). Initially objective and neutral communication from HCPs left parents feeling that HCPs had little hope of a positive outcome (Payot et al., 2007; Rempel et al., 2004). The lack of hopeful communication led to a strained relationship between the parents and HCPs because parents were still hoping for their child to be cured of the illness, while they thought providers had ‘given up’ (Kavanaugh et al., 2010). Opposite assessments of hope can create mistrust between parents and HCPs, which leaves parents to advocate for their child by protecting against the perceived negative recommendations of HCPs (Kavanaugh et al., 2010).

The specific types of the information that parents need throughout the child’s illness course have been identified. Multiple types of communication tools (e.g., printed, verbal) are available to help both parents and HCPs; however, how to best communicate the information remains unknown. Future research needs to focus on developing techniques to provide parents with crucial information under stress. How much information parents are able to retain during a critical event with their child remains unknown. Use of multiple types of communication could reinforce content when parents are better able to intake the information. Evaluation of whether parents thought the amount and content of the information to make a decision was adequate also requires additional research.

3.2. Severity of illness

The severity of the illness and predicted long-term outcome of the child influenced parental decisions across the child's illness course. Initially when determining whether to terminate or continue a pregnancy, parents considered the extent of congenital anomalies and the presence of chromosomal abnormalities (Chenni et al., 2012; Menahem and Grimwade, 2003; Rauch et al., 2005; Zyblewski et al., 2009). The severity of the heart defect (Chenni et al., 2012) and the presence of a chromosomal abnormality were associated with proceeding or terminating the pregnancy when a heart defect was identified (Rauch et al., 2005). One study found that the presence of multiple anomalies rather than a single anomaly led parents to terminate a pregnancy because of the more anomalies the increased chance for additional infant morbidity (Rauch et al., 2005). This information was important prenatally for parents making decisions about continuing pregnancy upon identification of abnormal findings. Knowing the infant's life would be shortened (Rauch et al., 2005) or that the infant had no chance of survival influenced parents' decision to terminate pregnancy (Chaplin et al., 2005; Menahem and Grimwade, 2003; Pepper et al., 2012).

Parents also focused on how the severity of the illness and possible treatment decisions would affect the child's quality of life throughout the illness course. Across the illness course, poor quality of life was defined as suffering, limitation of both physical and emotional well-being (McNamara et al., 2009), and not having a 'normal' life (Michelson et al., 2009). Suffering was described as physical and emotional pain (e.g., fear). The physical and emotional pain the child may endure also affected decisions about treatment (Moro et al., 2011). Physical pain could come from the treatments the child endured (Carnevale et al., 2011; McNamara et al., 2009; Meyer et al., 2002; Michelson et al., 2009). The neurological status of the child was used by parents as an indicator of whether the child would be aware of his/her surrounding and if he/she was able to communicate and interact with the world (Ellinger and Rempel, 2010). A normal life was described as the child could be happy and interact with the environment; the child could cope with the condition, and would be able to lead an independent life (Ahmed et al., 2008; Chaplin et al., 2005; Lam et al., 2009). For some parents regardless of the information about survival, suffering and future prognosis (Einarsdottir, 2009), they wanted all treatment options tried to sustain their child's life (Carnevale et al., 2011; Michelson et al., 2009).

The potential severity of a child's illness affects parental decision-making. Parents needed to understand the short and long-term outcomes associated with the child's illness. Many parents based their decisions on whether the child can be 'normal' and not suffer physical and emotional harm. Yet, HCPs cannot predict with certainty how an individual child will respond to the illness and the therapies. Many of the children with life-threatening illnesses will become medically complex children and have multiple episodes that will leave parents potentially making decisions of whether to continue forward with curative therapies or decide to treat the individual symptoms. Ideally, parents and HCPs would have enough information to determine child outcomes. The exchange of information would occur between critical periods so parents could make decisions when they are able to ask questions and discuss what is most appropriate for their child.

3.3. No other option

Parents chose curative or experimental therapy options because they felt they had no other options (Snowdon et al., 2006). Parents described that even when other options were available, they were seen as not acceptable because the other option would result in certain death of their child (Vandvik and Forde, 2000). Parents only proceeded to palliative care when they lost hope in the child surviving (Michelson et al., 2009) or because of a lack of viable treatments with the potential to cure the illness. When all options were exhausted, parents acquiesced to withdrawing or withholding life-sustaining treatments (Michelson et al., 2009). Future research could focus directly on when to approach parents with information on palliative care. Identifying that time point when parents can listen to all the options and think and explore the options. When the child is critically ill with a life-threatening condition is usually a more difficult time to present parents with multiple choices, different opinions, and asking the parents for a time-sensitive decision.

3.4. Religious and spiritual beliefs

Religious and spiritual beliefs were important to parents making decisions about initiating curative treatment or withholding/withdrawing treatments (Ahmed et al., 2006; Meyer et al., 2002; Michelson et al., 2009). Religious beliefs prohibited parents from choosing termination of pregnancy (Ahmed et al., 2006; Chaplin et al., 2005; Ellinger and Rempel, 2010; Redlinger-Grosse et al., 2002), particularly Muslims and Christians. However, parents felt that even if their religion dictated a certain decision, the parent would consider what they felt was best for their child because religious leaders did not understand the illness (Ahmed et al., 2006). Other parents relied on their personal belief system about the sanctity of life and accepting their child diagnosed with a severe congenital defect (Redlinger-Grosse et al., 2002). Religion and spirituality provided a sense of a possible miracle for the child (Boss et al., 2008).

Some parents relied upon God or faith to guide their decision-making (Sharman et al., 2005), others felt that the decision was up to God and not one to be made by humans (Michelson et al., 2009; Pepper et al., 2012; Roy et al., 2004; Sharman et al., 2005). The degree of religiosity a parent reported influenced their decision-making. Very religious parents were less likely to plan the location of their child’s death than parents who were somewhat or not religious at all (Einarsdottir, 2009) possibly because very religious parents continued to pray for miracles and awaited divine intervention (Michelson et al., 2009; Sharman et al., 2005).

Parents also participated in religious and spiritual rituals for guidance in the decision-making process. Einarsdottir (2009) reported that some parents in Iceland relied upon old dreams and interactions with mediums for information about how to proceed with end-of-life decisions and to ask the medium to help/support the HCPs caring for their infant. Some parents chose an emergent baptism when their child was close to death, while others felt that having a baptism in the intensive care unit was an act of surrendering to death (Einarsdottir, 2009). If the child's condition improved, parents interpreted this act as a miracle (Einarsdottir, 2009). Others prayed for miracles or divine intervention (Sharman et al., 2005) but would consider withholding or withdrawing support if 'enough' time had passed and no miraculous recovery occurred (Michelson et al., 2009).

3.5. Parental characteristics

Researchers studied how maternal characteristics (e.g., education level, age) influenced decision-making. Mothers of premature infants who had secondary education levels were more likely than mothers with primary education to attempt save an infant at 'all costs' (Lam et al., 2009). Several other variables were explored in four studies (Chenni et al., 2012; Lam et al., 2009; Rauch et al., 2005; Zyblewski et al., 2009) with mixed results on whether certain demographic characteristics influenced decision-making. Factors that remained inconclusive were maternal age, maternal gravida, maternal parity, race/ethnicity, and gender of the fetus (Chenni et al., 2012; Lam et al., 2009; Rauch et al., 2005; Zyblewski et al., 2009).

Parental race and ethnicity may impact the types of recommendations parents received and whether parents chose to accept the recommendations regarding end-of-life care (Moseley et al., 2004; Roy et al., 2004). In a small study of the impact of race on parental acceptance of HCP recommendations, a non-statistically significant difference was found between African Americans who accepted the recommendation to withhold treatment 62% of the time compared to white parents who accepted the recommendation 80% (Moseley et al., 2004). In another study, Black African and Jewish parents were less likely to agree to withdrawal support for their critically ill children than White, Indian, and Afro-Caribbean parents (Roy et al., 2004). Specifically why ethnicity affected the acceptance of recommendations to withdrawal support was not further explained because data were collected with surveys.

Some parents were concerned about their ability to care for their infant, if he or she survived the hospitalization. Parents were worried about how to financially support the infant and also how to logistically provide the intensive care they would need at home (Sharman et al., 2005). Other parents felt that finances were not at all part of their decision to withdraw support from their infant or child (Meyer et al., 2002).

Parents' previous experiences with death of a family member also affected their decision-making for their child. Parents used previous experiences with deaths of family members to justify and understand how their infant was feeling while being supported by technology (Sharman et al., 2005). Parents also explained that they compared the physical appearance of their family member who died with their infant to determine if they thought the infant was also going to die (Sharman et al., 2005). Parents who experienced a previous loss were more likely to plan the location of death for their infant than parents who did not have a previous experience with loss (Dussel et al., 2009). This previous experience with a death of a family member may provide parents with an understanding of what occurs around the time of death and what decisions are needed during this time.

3.6. Child's best interests

Having the child's best interests in mind was critical to decision-making of parents. Parents relied on HCPs to have their child's best interest in mind and thus valued the opinion of the HCP. Parents determined what was in the child's best interest by parental knowledge of their child and the illness (Boss et al., 2008; Michelson et al., 2009), and their experience with their child (Kavanaugh et al., 2010; Lan et al., 2007). Parents considered what they would want if they were in the same situation (Sharman et al., 2005). Ensuring parents were included as experts in knowing their child was important when including parents in the decision-making process.

3.7. Support

Support was important to all decision for parents. Parents received support other family members and families with similar experiences (Lan et al., 2007) and HCPs (Kavanaugh et al., 2010). Emotional support from HCPs was demonstrated by HCPs listening, being kind and comforting, maintaining hope, providing spiritual support (Kavanaugh et al., 2010), and acknowledging the difficulty and uncertainty associated with making decisions (Redlinger-Grosse et al., 2002). Parents felt the support of HCPs when the provider spent time with them and their child even once the decision was made (Payot et al., 2007).

4. Discussion

Researchers have described how parents, both mothers and fathers, make decisions for children with medically complex conditions. Parental decisions span the trajectory of the child's illness to include continuation of high-risk pregnancies, initiation of life-support, experimental interventions, withdrawing/withholding treatments, and end-of-life decisions. This range of decisions was described in research conducted with children with extreme prematurity, congenital heart disease, neurological injuries and diseases, and chromosomal and genetic abnormalities.

Parental decision-making for children with medically complex conditions is impacted by a range of factors including the type and content of information provided to them as well as the information they sought, the seriousness of the child's illness, whether other treatment options exist, what is best for the child, religiosity and spirituality, parental factors, and support. Parents need information to make decisions, yet they did not always understand or receive enough information to make decisions (Menahem and Grimwade, 2003). Different approaches to explaining complex information could be explored through hypothetical scenarios with parents or comparing what is different between parents who report understanding and those who do not understand.

The development and maintenance of parental trust in the health care team is a critical area that few studies have focused. While communication of hopefulness by HCPs increased parental trust (Boss et al., 2008), it is unclear how much of the information must be hopeful.

Additionally, researchers do not know how a trusting relationship between parents and HCPs develops over time. Further understanding of how a trusting relationship develops and its impact across the child's illness trajectory is needed to understand how to improve parent and HCPs relationships.

The influence of communication and trust on decision-making could be optimized through the use of shared decision-making. The concept of shared decision-making is emerging across many settings and countries including the United States, Canada, and the United Kingdom (Elwyn et al., 2010). The use of shared decision-making in medically complex populations may be a good solution because of the uncertainty that faces both parents and HCPs because often scientific evidence is insufficient and research evidence offers inconclusive results (Legare and Witteman, 2013). Shared decision-making includes parents, HCPs, and extended families in decisions, along with exchanging information and determining a medical treatment plan. The essential elements of shared decision-making include: acknowledging that a decision is required, understanding the risks and benefits of the options available, and ensuring the decision accounts for HCPs' professional guidance and patient's and family's values and needs (Legare and Witteman, 2013). The professional guidance of the HCP includes their expertise in diagnosis, etiology, prognosis, treatment options, and outcome probabilities (Coulter and Collins, 2011). The patient's also bring their own expertise, which includes experience with the illness, social circumstances, attitude to risk, values, and preferences (Coulter and Collins, 2011). If each of these elements is met, the parents should understand the diagnosis, understand the treatment options along with the risks and benefits of each, and also have their wishes and values respected. Shared decision-making should allow for open communication between both the parents and HCPs and hopefully reduce miscommunication that can lead to mistrust.

In the legal case (Winkfield vs. Children's Hospital Oakland) presented above, whether shared decision-making would have helped is unlikely. Legally in the United States the child who is brain dead is pronounced dead upon completion of the brain death studies. The child was pronounced dead, but was not removed from the ventilator due to the court prohibiting the hospital from removing the ventilator. In the view of the hospital, there was no decision to be made. The ventilator was to be removed because medical care is not rendered to a dead person. However, since the child was accepted by another facility and surgical placement of a tracheotomy and gastric feeding tube, the culture surrounding brain death in the United States may change. The public awareness about brain death has increased, which may lead to changes in policies and ultimately laws.

The implementation of shared decision-making is complex and challenging (Elwyn et al., 2010; Stiggelbout et al., 2012). Not all HCPs are willing to shift their practice toward shared decision-making and not all HCPs believe that shared decision-making is the best was to provide for patients (Stiggelbout et al., 2012). Despite the difficulties of implementing shared decision-making, HCPs need to develop ways to collaborate with parents and help parents through difficult and challenging situations they are faced with when their child with a medically complex condition is hospitalized or needs medical treatment. Shared decision-making in end-of-life decisions may also decrease parental grief in parents of infants who died in the intensive care unit compared with decision-making by physicians or having no decision (Caeymaex et al., 2013). Further research about the use of shared decision-making influences communication and trust between parents and HCPs is necessary to understand how to optimize the decision-making process.

Parents described not having any other treatment options as impacting their decision-making for treatments (Michelson et al., 2009; Vandvik and Forde, 2000). Though it is true that many illnesses do not have many options once the disease advances past a certain stage, the option for palliative care generally exist. Why palliative care is not viewed as a treatment option is unclear. However, helping parents understand that palliative care is a treatment that can alleviate pain and discomfort for their child may help reduce the feeling of having no control as a parent and also not having any options. Further examination of how palliative care is presented and overall understanding of palliative care by parents is necessary.

Research is needed to identify and clarify the concept of “the best for the child” across the full illness trajectory. Helping parents explore what is best for their child when making decisions about initiation of life-sustaining treatments and reevaluating how their ideas about what is in the best interest of the child changes throughout the child’s illness may aid parents in making decisions they perceive as ‘good’, thus decreasing conflict and regret.

Religiosity, religious preferences, personal belief systems, and spirituality influenced parental decision-making about initiating life-sustaining treatments (Ahmed et al., 2006; Chaplin et al., 2005) and end-of-life care (Meyer et al., 2002; Michelson et al., 2009). Further exploration about how religiosity and spirituality directly affects parental decision-making is needed. For example, examining how religious preferences guide treatment decisions is necessary including specific descriptions by parents about the reasons religion impacts their decision-making is necessary. By understanding the parents’ specific needs, interventions can be developed to provide parents with the support and guidance needed to make decisions. Further research to identify if parental characteristics influence these types of decisions is needed. Additionally, how and why certain demographic factors influence parental decision-making is needed. By understanding how and why demographic factors influence decision-making, researchers can develop interventions targeted at different groups to better support and meet their needs.

The findings outlined in this integrated review demonstrate that parents use a variety of factors to make medical decisions for their medically complex child. The decisions these parents are making will often determine whether the child lives or dies. Clinicians need to be aware of all the factors that impact decision-making and identify, which factors are pertinent to each parent. Also checking with parents to ensure all their needs are met is critical to helping them make the best decision for their child. Parental decision-making is very difficult, especially in life-and-death decisions, ensuring these parents are supported is paramount.

5. Conclusion

The strengths of the empirical research reviewed are that decisions about initiating life support and with-drawing life support have received significant attention. Researchers have explored how many different factors impact decision-making and have used multiple different research designs and data collection methods to explore the decision-making process. These initial studies lay the foundation for future research and have provided insight into parental decision-making during times of crisis. However, there are still many questions that need to be addressed.

The first gap is that many of the research studies look at parents and HCPs separately without taking into account the individual child and how the parents and HCP interact to make decisions for an individual child. The lack of knowledge about how decisions are made for an individual child is due partly to the research designs employed in most of the studies. Only four studies (Grobman et al., 2010; Kavanaugh et al., 2010; Payot et al., 2007) included the parents and HCPs caring for the same children in the sample. All of the other studies included only parents or included both parent and HCPs but not those caring for the same child. By not examining how parents and HCPs make decisions for a single infant, researchers are unable to understand how differences in perceptions about communication of information and severity of illness impact the decision-making process. Studies must begin to include both parents and HCPs so that researchers can evaluate how decisions are made for individual children with medically complex conditions to understand the dynamics between parents and parent–provider relationships.

The second gap in research to date is related to the diagnostic categories of children included in the research samples. The majority of studies focused on one homogenous diagnostic group of premature infants or children with complex congenital heart disease. Thus comparisons across other child illness categories cannot be made. Also, comparison across studies is difficult. Therefore, researchers do not know if the parents of different groups of children need the same type of information to make decisions or need different information. Parents of children with neurologic conditions may need information explained differently or may use other factors to make decisions for these children, but this remains unknown.

Most studies also used cross-sectional and/or retrospective research designs. Thus the third gap in the empirical knowledge is that researchers have limited understanding of how factors change over time for parents. The weakness of using a cross-sectional or retrospective design in decision-making is there is limited ability to understand how and when parent influences change over the course of the child’s illness. Only four studies (Feudtner et al., 2010; Grobman et al., 2010; Kavanaugh et al., 2010; Payot et al., 2007) examined decision-making using a prospective longitudinal design. When feasible researchers should consider using a prospective, longitudinal design to better understand when and how influences change across the decision-making trajectory for parents.

The purpose of understanding the influences on parent decision-making for children with medically complex conditions is to improve the short-term functioning and long-term outcomes of parents and families who are thrust into these very difficult situations. Multiple influences impact how parents make decisions with no single influence identified as the sole reason for the decision. A combination of these influences leads parents to an eventual decision about treatments. Through identification and evaluation of the different factors that impact parental decision-making, researchers and HCPs can develop interventions to support parents forced to make difficult, challenging, life-changing decisions for children with medically complex conditions.

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Zyblewski SC, Hill EG, Shirali G, Atz A, Forbus G, Gonzalez J, Hlavacek A. Chromosomal anomalies influence parental treatment decisions in relation to prenatally diagnosed congenital heart disease. Pediatric Cardiology. 2009; 30(8):1105–1111. [PubMed: 19705187]

What is already known about the topic?

- The parental role in decision-making has changed over the past decade giving parents more autonomy about how they personally believe their child should be treated.
- Parental participation in medical decisions may lead to additional anxiety and stress, when the parents are already enduring physical and emotional stress watching their child battle a life-threatening condition and complications associated with the disease.
- The importance of understanding how and why parents choose specific treatments is increasingly relevant given the advances in technology and experimental therapies. How making decisions effects parental outcomes in the long-term remains unknown.

What this paper adds

- The results of the integrated review suggest that parental decision-making for children with medically complex conditions is impacted by a range of factors including the type and content of information provided to them as well as the information they sought, the seriousness of the child's illness, whether other treatment options exist, what is best for the child, religiosity and spirituality, parental factors, and support.
- This study identifies gaps within our understanding of factors that effect parental decision-making and suggest the next steps that need to be undertaken by researchers.
- Future research needs to focus on how to understand parental decision-making over the entire course of life, not only at points where parents are choosing between life or death of their child.

Table 1

Integrative literature review method.

Stage of review	Decisions and rationale
Problem identification	Over the past decade, healthcare systems and providers have opted to include parents in making decisions for medically complex children. Parents who participate in decision-making can regret their decisions resulting in psychological stress, increased parental mortality, mental illness, and morbidity. To gain a better understanding of influences effecting parents making decisions and potentially develop interventions to support parents, a literature review was proposed. Therefore, the purpose of this integrative review was to describe possible factors that affect parental decision-making for medically complex children.
Literature search	The overarching focus of this review was parent decision-making for medically complex children. In an effort to identify the maximum number of articles, initial search strategy included the term ‘parent’ combined with ‘decision-making’ in PubMed, Cumulative Index of Nursing and Allied Health Literature, and PsycINFO using English language and dates between 2000 and June 2013. The large number of articles yielded from this strategy was reduced by excluding duplicate articles identified from multiple databases and applying the following criteria first through review of article titles and then through a more comprehensive review of the remaining article abstracts. The inclusion criteria were decisions involving life-sustaining treatments with the intent to ‘cure’ life-threatening illnesses or withdrawal and termination of treatments with probable death as the outcome and empirical data with a sample size greater than 1. For example, life-sustaining treatments could include invasive cardiac surgery for a child with hypoplastic left heart syndrome (HLHS). The children in the studies needed to be less than 12 years of age, as well. *Rationale for life-sustaining treatments with the intent to ‘cure’ life-threatening illnesses or withdrawal and termination of treatments with probably death as the outcome*: • These types of decisions were exclusively chosen because they often involve death as a possible outcome even with treatment. Parents are stressed and can regret their decisions later and have psychological problems years following the decisions. Therefore, providing support through interventions is necessary to possible prevent or lessen the extent of psychological problems these parents face. *Rationale for empirical data only*: • Results from literature will guide future research designed as interventions to help parents make decisions or support them through the process. Using expert opinions when empirical data is available is not advisable when using evidence-based medicine. *Rationale for selecting studies with a sample size greater than one*: • Sample size of one can be powerful, but when designing interventions for parents using studies with greater power is more desirable. Choosing to use studies with a larger sample size did exclude studies exploring legal rulings on single cases because they involved only one subject. It could be argued that these rulings have a broad impact because they change the way the health care system interprets laws and guidelines; however, the author felt that many of the cases are single examples that represent special circumstances that cannot always be understood without studying all the details of the cases which was not the intent of this review. *The exclusion criteria were decisions surrounding the death of a child including organ donation and location of death, child participation in decisions, and samples of children with cancer. Rationale for excluding decisions surrounding the death of a child including organ donation and location of death*: • Organ donation and location of death are both important in the trajectory of a child’s death, but the decisions that occur prior to the donation or the actual death may have more bearing on the psychology effect on the parents. Therefore, these studies were excluded. *Rationale for excluding child participation in decisions*: • When children participate in the decision-making process more variation is added and was excluded at this point because the author was trying produce recommendations for interventions to help parents exclusively make decisions for their children. *Rationale for excluding samples of children with cancer*: • Parents of children with cancer are often faced with multiple different types of decisions about treatment. The decisions do include life-sustaining treatments and also decisions about experimental treatments and sometimes decisions about withdrawal and termination of treatments, but the trajectory of making decisions for these children is often prolonged and is affected by the previous decisions. Therefore samples of children with cancer were excluded because it was not possible to disentangle how previous difficult decisions effected the current decision being examined by the study.

Stage of review	Decisions and rationale
Data evaluation	The final sample for this integrative review included empirical reports. The primary sources included multiple methods to examine factors that effect parental decision-making: retrospective chart reviews, collective case-studies, longitudinal descriptive studies, qualitative descriptive studies, qualitative interpretive studies, prospective cohort studies, phenomenology, retrospective review of state registries, qualitative symbolic interactionism, and ethnography. Since many standard scoring systems are based on the quality of the research design, attempting to assign scores to each of the different types of study designs in this integrative review would have been complex and likely would not have yielded any additional information. Thus quality scores were not assigned.
Data analysis	Data were extracted from the primary source and recorded in a matrix in Table 2. The data included study design, decision type, child diagnosis, sample characteristics, and results. The results from each study were the influences that effected parental decision-making. These influences were defined from each article individually and then synthesized into major themes. If the themes varied across types of decisions these differences were also explained. The following themes were identified: information needs, seriousness of illness, no other treatment options, child's best interests, religiosity and spirituality, parental characteristics and past experiences, and emotional support.

Table 2

Matrix of empirical evidence.

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
Pepper et al. (2012) Canada	To determine perceptions of parental decision-making for extremely premature infants	Qualitative, interpretive description, semi-structured interviews	All NICU decisions	Extreme prematurity	$N = 5$ families (5 mothers and 2 fathers)	Statistics on outcomes Spiritual and religious beliefs
Chenni et al. (2012) France	To determine the effect of different fetal and maternal variables on parental decision making with CHD	Retrospective chart review	Continuation or termination of pregnancy	CHD	$N = 209$ fetus	Severity of structural malformation Ethnicity Gestational age Chromosomal abnormalities
Kavanaugh et al. (2010) USA	To describe behaviors nurses use to assist parents in making decisions about life-support for extremely premature infants	Qualitative, longitudinal, collective case study	Preterm delivery	Extremely premature infants	$N = 40$ cases ($n = 40$ mothers, $n = 14$ fathers, $n = 29$ nurses, and $n = 42$ physicians)	*Parent and nurses' description of nursing behaviors that promoted decision-making*: Providing emotional support Giving information Meeting physical needs of infants and parents *Physician description of nurses behaviors that facilitated decision-making*: Emotional support Giving information
Grobman et al. (2010) USA	To determine approaches that health care providers could use when caring for parents at risk of giving birth to an extremely premature infant	Longitudinal descriptive	Preterm delivery	High risk periviable infants	$N = 40$ mothers $N = 14$ fathers $N = 35$ physicians $N = 17$ nurses	Knowledge of condition Clear communication of information Hope
Balkan et al. (2010) Southeast Turkey	To explore factors that impacted parental decision-making about	Qualitative descriptive	Continuation or termination of pregnancy	Prenatal diagnosis of aneuploidy	$N = 38$ mothers	Severity of abnormality Religiosity Family and social influences Perceptions of mother's health Feeling about having a child with a syndrome Resources to care for child

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
	termination or continuation of pregnancy after diagnosis of chromosomal abnormalities termination or continuation of pregnancy after diagnosis of chromosomal abnormalities termination or continuation of pregnancy after diagnosis of chromosomal abnormalities termination or continuation of pregnancy after diagnosis of chromosomal abnormalities termination or continuation of pregnancy after diagnosis of chromosomal abnormalities termination or continuation of pregnancy after diagnosis of chromosomal abnormalities					
Feudtner et al. (2010) USA	To test the hypothesis that parental hope and parental perception of the child's illness course and their positive and negative affect would be associated with decision to enact limitation of intervention order for patients referred to palliative care	Prospective cohort	Limitation of intervention	Neuromuscular disease Metabolic disease Congenital malformation Cancer Respiratory disease GI disease	*N* = 43 parents of 33 patients	Hope
Dussel et al. (2009) USA	To determine factors associated with planning location of death for a child	Retrospective cross sectional survey	End-of-life	Children who died	*N* = 140 parents	Diagnosis Religiousness Experience with previous loss Communication with physician Home care services *Not significant*: Child age Child gender Parental age Marital status Education level Parental support by psychosocial clinician Distance from hospital Number of other children Income Christianity
Einarsdottir (2009) Iceland	To explore how parental influences on making end-of-life decisions for extremely low birth weight infants	Qualitative descriptive	End-of-life	Extremely low birth weight infants	*N* = 28 mother and *N* = 25 fathers of 29 infants	No meaningful life Information Knowing another person with disabilities Trust Religiosity and Spirituality Dreams and mediums (spiritism) Diagnosis
Michelson et al. (2009) USA	To explore parental willingness to consider hypothetical	Cross sectional descriptive study	Withdrawal of life-support	Chronic illnesses Complications from cancer treatment Post surgical Acute diseases	*N* = 70 parents	Quality of life Suffering Lack of effective treatments available Faith Length of time since diagnosis Finances Inability to consider

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
	withdrawal of life-sustaining therapies and what influences this decision withdrawal of life-sustaining therapies and what influences this decision withdrawal of life-sustaining therapies and what influences this decision withdrawal of life-sustaining therapies and what influences this decision withdrawal of life-sustaining therapies and what influences this decision withdrawal of life-sustaining therapies and what influences this decision					withdrawing life-sustaining therapies Mistrust/doubt toward physicians Reliance on self/intuition Hope
Lam et al. (2009) Hong Kong	To examine the impact of personal characteristics on ‘life or death’ decision-making for infants	Cross sectional descriptive study	Initiation of life-sustaining treatment	Term infants and premature infants	*N* = 34 physicians *N* = 103 nurses *N* = 189 mothers with term infants *N* = 297 parents with preterm infants	*Parents of premature infants*: Secondary education Severity of illness
Verhagen et al. (2009) The Netherlands	To determine the frequency of conflicts about end-of-life decision-making and explore how these conflicts were resolved	Qualitative descriptive	End-of-life	Infants who died in the NICU	*N* = 147 physicians of 150 infants	Sources of conflict related to neurologic prognosis generally Conflict occurred in 6 cases between medical team members *Conflict resolved through*: Meetings Clinical deterioration Conflict occurred in 18 cases between medical team and parents (3 cases involved conflict within medical team and between parents) *Conflict resolved through*: Additional tests Clinical deterioration Meetings Second opinions
Zyblewski et al. (2009) USA	To determine influences of parental treatment decisions for a fetus with prenatally diagnosed with congenital heart disease	Retrospective chart review	Continuation or termination of pregnancy	Congenital heart disease	*N* = 229 children	Presence of chromosomal abnormality Severity of defect Maternal gravida Maternal age *Not significant*: Maternal race Fetus gender Maternal parity Insurance status
Boss et al. (2008) USA	To determine the factors parents use in making decisions about delivery room resuscitation	Cross sectional descriptive	Resuscitation	Extremely premature Major anomaly	*N* = 26 mothers	Intuition about condition Religion and spirituality Hope Relationship with providers

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
Lan et al. (2007) Taiwan	To investigate the experience of mothers during the decision-making process for child undergoing heart surgery due to congenital heart disease	Phenomenology	Cardiac surgery	Congenital heart disease	*N* = 9 mothers	What is best for the child Trust the medical profession
Payot et al. (2007) Canada	To describe how parents and providers engage in the decision to resuscitate an extremely premature infant	Longitudinal interpretive qualitative method (prenatal and 4–6 months post delivery)	Resuscitation	Infants at risk for premature delivery at 23–25 weeks	*N* = 8 couples *N* = 5 physicians	Information Desire to be a parent Desire to make the ‘right’ decision Support
Ahmed et al. (2006) UK	To explore the attitudes of individuals from four ‘faith’ communities and the attitudes of parents with a child with a sickle cell disorder or thalassaemia major for hypothetical pregnancy of infant with sickle cell or thalassaemia major	Cross sectional descriptive	Termination of pregnancy and reproduction choices	Sickle cell disorders and thalassaemia major	*N* = 44 members of faith community groups *N* = 8 mothers of children with sickle cell disorders or thalassaemia major *N* = 3 fathers of children with sickle cell disorders or thalassaemia major	*Termination*: Religion Suffering of child *Reproductive decisions*: Personal moral judgments and beliefs Relationship with God
Snowdon et al. (2006) UK	To explore how parents decide to participate in perinatal randomized controlled trials	Qualitative descriptive	Experimental treatments	Critically ill infants	*N* = 24 mothers only *N* = 27 couples (both parents)	Fear No other options Trust Pace of communication

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
Chaplin et al. (2005) Australia	To explore parents' experience with a prenatal diagnosis of spina bifida and/or hydrocephalus	Qualitative descriptive	Termination or continuation of pregnancy	Spina bifida Hydrocephalus	*N* = parents from 13 families (*n* = 11 mothers and *n* = 4 fathers)	Inability to understand information Severity of illness Religion Provider recommendations
Partridge et al. (2005) Pacific Rim USA	To determine factors that influence parental decision-making about delivery resuscitation of very low birth weight infants	Cross sectional descriptive	Resuscitation	Very low birth weight infants	*N* = 327 parents	Emotional attachment Severity of illness Religion Finances Physician opinion Family opinion
Rauch et al. (2005) USA	To identify factors that predict the decision to terminate pregnancy of fetuses with structural anomalies	Retrospective review of state registry and questionnaires to physicians	Termination of pregnancy	Fetuses with structural abnormalities	*N* = 97 case of fetuses with structural abnormalities	*Significant*: Gestational age at diagnosis Presence of multiple anomalies Anomalies presumed lethal *Not significant*: Maternal age Gravida Parity Race Assisted reproductive technology Genetic counseling
Sharman et al. (2005) USA	To determine factors that influence parental decision-making about end-of-life care	Cross sectional descriptive	Limitation of care or withdrawal of support	Malignancy Respiratory failure Neurologic condition Metabolic condition	*N* = 14 parents of 10 patients	Past experiences with limitation or withdrawal of life support Child's 'will' to survive Do what is best for child Child's condition Child's understanding of condition Family opinions Religion and faith Finances
Moseley et al. (2004) USA	To determine if differences exists between White and AA parents when a physician recommends withholding life-sustaining treatment	Retrospective chart review	Withholding life-sustaining treatment	Infants who died in NICU	*N* = 38 infants	Race not statistically significant between parents of white and AA and those who received recommendation for withholding life sustaining treatment and those who accepted recommendation to withhold life sustaining treatments Descriptively there were differences between whether parents accepted recommendation for withholding life-sustaining treatment.

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
						*Not powered to detect differences statistically *Not powered to detect differences statistically
Rempel et al. (2004) Canada	Describe how parents make decisions following prenatal diagnosis of CHD	Qualitative, symbolic interactionism	Further testing and continuation or termination of pregnancy	Congenital heart disease	*N* = 19 mothers and *N* = 15 fathers of 19 infants	Information about implications for infant and family Chromosomal abnormalities Communication of information
Roy et al. (2004) UK	To determine the frequency and reason for withdrawal or withholding of life sustaining treatments and DNR in infants who died	Retrospective chart review	Withdrawal of life sustaining treatments, withholding life sustaining treatments, and DNR orders	Respiratory failure Congenital anomalies Complications HIE	*N* = 85 infants who died	Religion Culture
Vermeulen (2004) The Netherlands	To determine influences of decision-making for children born extremely premature	Ethnography	Initiation of treatment	Extremely premature infants	*N* = 1 hospital	Severity of illness Quality of life
Menahem and Grimwade (2003) Australia	To determine how parents decide to terminate a pregnancy following a prenatal diagnosis of a complex congenital heart defect	Cross sectional survey	Continuation or termination of pregnancy	Complex congenital heart disease	*N* = 9 couples	No chance for health Suffering Chromosomal anomaly Prognosis Quality of life Fear of loss after surgical intervention Best for family
Redlinger-Grosse et al. (2002) USA	To explore how parents make decisions about prenatally diagnosed infants with HPE	Qualitative descriptive	Continuation or termination of pregnancy	HPE	*N* = 10 couples and *N* = 4 mothers	Revisited the decision throughout the pregnancy Religion Personal belief system Information Communication of information Perceived anticipated grief
Brinchmann et al. (2002) Norway	To understand how parents' participate in life-and-death	Qualitative descriptive	End-of-life	Infection Birth injury Cerebral hemorrhage Chromosomal abnormality	*N* = 35 parents	Survival Varying levels of participation desired Information Communication style

Authors (year) Country	Purpose	Design	Decision type	Child diagnosis	Sample	Influences of decision-making
	decisions about very premature or critically ill infants in the NICU decisions about very premature or critically ill infants in the NICU decisions about very premature or critically ill infants in the NICU decisions about very premature or critically ill infants in the NICU decisions about very premature or critically ill infants in the NICU decisions about very premature or critically ill infants in the NICU			Incorrect diagnosis Complications		
Meyer et al. (2002) USA	To identify influences about end-of-life care	Cross sectional, descriptive	End-of-life care	Children who died	*N* = 56 bereaved parents	Quality of life Chance of meaningful recovery Pain or discomfort Information Religion and spirituality Child appearance or behavior Advice of providers Attitudes of staff
McHaffie et al. (2001) Scotland	To explore parent perceptions of withdrawing or withholding treatments	Retrospective, longitudinal survey	Withdrawing or withholding treatment	Children who died	*N* = 59 families at 3 months N = 50 families at 13 months	Visible deterioration Suffering Information about child's condition Prognosis
Vandvik and Forde (2000) Norway	To understand how parents make autonomous decisions for infants with HLHS	Cross sectional descriptive	Surgical intervention or comfort care	HLHS	*N* = 20 mother (10 chose surgery and 10 chose comfort care)	*Surgical intervention*: Death not an option Felt physicians should decide *Comfort care*: Time Prevention of suffering Parents felt they should decide or collaborative decision with physician

USA, United States of America; UK, United Kingdom; CHD, congenital heart disease; HPE, holoprosencephaly; HIE, hypoxic ischemic encephalopathy; HLHS, hypoplastic left heart syndrome; DNR, do not resuscitate.