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Barriers and facilitators to shared decision-making in neonatal medicine: A systematic review and thematic synthesis of parental perceptions

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Abstract

Objectives: Systematically review parental perceptions of shared decision-making (SDM) in neonatology, identifying barriers and facilitators to implementation.

Methods: **Electronic** database (Medline, PsycINFO, CINAHL and Scopus) **and follow-up searches** were conducted to identify qualitative studies. Data were extracted, thematically analysed and synthesised.

Results: Searches yielded 2445 papers, of which 25 were included. Thematic analysis identified six key themes. Key barriers included emotional crises experienced in the NICU setting, lack of medical information provided to parents to inform decision-making, inadequate communication of information, poor relationships with caregivers, lack of continuity in care, and perceived power imbalances between HCPs and parents. **Key facilitators included clear, honest and compassionate communication of medical information, caring and empathetic caregivers, continuity in care, and tailored approaches that reflected parent's desired level of involvement.**

Conclusion: The highly specialised environment, and the emotional crises experienced by parents impact significantly on their perceived capacity to engage in surrogate decision-making.

Practice Implications: **Complex and multi-factorial interventions that address the training needs of HCPs, and the emotional, informational and decision support needs of parents are needed.** SDM skills training, improved information delivery, and integrated emotional and decisional support could help parents to become more involved in SDM for their infant.

Highlights:

- Perceived power imbalances in a highly technical environment and emotional crises experienced by parents are an important barrier to SDM in neonatology
- SDM skills training and interventions could support healthcare professionals to deliver SDM in neonatal settings
- Parents require empowerment, better information, and integrated emotional and decisional support to participate in SDM in the NICU
- SDM in the neonatal settings could be facilitated by an integrated psychologist on the team, providing the emotional support needed to assist involvement in decision-making

1. Introduction

Parents of critically-ill neonates are frequently faced with high risk decisions during periods of significant uncertainty and emotional distress [1], and adequate decision support for parents is critical [2-9]. In 2019, the British Association of Perinatal Medicine published a good practice framework for enhancing shared decision-making (SDM) in neonatal care, which recognises the importance of information sharing and individualised decision-making [3]. Patients' and clinicians' perceived barriers to SDM in healthcare are well-documented. [10, 11] Whilst some studies have explored physicians' perceptions of SDM in neonatal critical care [12], we know less about the barriers and facilitators perceived by parents when making surrogate decisions for their infants in these highly specialised settings. A better understanding of these parental-perceived factors would allow us to develop approaches and interventions that can adequately support SDM in this setting.

SDM is a collaborative approach where healthcare professionals (HCPs) and patients work together to reach decisions about treatment, recognising both the patient's expertise in their own values and wishes, and the clinician's medical knowledge and experience [13]. The benefits of SDM are well-documented [14] and healthcare has witnessed a significant shift away from paternalistic models, but key challenges persist in implementing SDM routinely [10, 15]. Previous research found perceived power imbalance between an individual and their healthcare provider is a key patient-reported barrier to greater involvement in adult healthcare decision-making [10, 16]. Patients may believe it is not their role to be involved in decision-making and value clinical knowledge over their own experience and personal preferences. [10]. Evidence shows that physicians also perceive inequity in power and authority to be a key barrier to SDM in neonatal and paediatric

intensive care settings [12]. Given the specialised and highly skilled environment of the neonatal intensive care unit (NICU), it is likely that this barrier might be more pronounced than in other healthcare settings.

Issues regarding capacity add further complexity to SDM in the NICU. Neonates do not have capacity to make decisions and parents have legal responsibility as surrogate decision-makers. Surrogate decision-making is often more complex, as the clinical team has to balance both the child and the family's interests [12, 17]. Literature concerning surrogate SDM for neonates is sparse, but studies of SDM in older paediatrics and adults lacking capacity (e.g. critically-ill in intensive care units) can shed light on the challenges faced by surrogate decision-makers [17-21]. In these settings, decisions are often made based on the patient's best interests. This can provide a source of conflict between surrogate decision-makers and clinicians because there may be uncertainty about what is best for the patient, and disagreement may arise based on what different parties deem is an acceptable quality of life [18]. In adult medicine, surrogate decision-makers and HCPs can be guided by a patient's known antecedent values or wishes, and older children can engage in discussions to guide decisions, even if they do not legally have capacity [17]. However, in the neonatal setting there is a complete absence of patients' antecedent or current values and wishes [22], thus making surrogate SDM more difficult.

This is further impacted by the complexity of decisions, the invasiveness of interventions, and uncertainty in outcomes for the neonate [23]. NICU decisions can include the withholding or withdrawal of treatment [12], thus parents could be asked to make life and death decisions, with consequences that may result in long-term physical and neurodevelopmental disability for their child [24] and have a substantial impact on the

wider family's future quality of life [25]. Parents face profound emotional challenges as surrogate decision-makers in these settings - not only because they have to make significant and far-reaching decisions for their own child, but also because of uncertainty about the infant's best interests [19, 26-28] and the **parent's overriding wish for their child to survive** [19, 26-28]. The emotional toll of surrogate decision-making can also exacerbate power imbalances and decrease involvement. A review examining parents' perceptions of decision-making in paediatrics found that parents who were emotionally distressed were less active in the decision-making process and more likely to defer to clinicians [29].

Despite the complexities, parents value involvement in decision-making for their child [29]. However, some **clinicians do not always engage parents in discussions about the likely outcomes of available options, for example, regarding resuscitation after extremely preterm birth** [22, 23, 30-33]. Importantly, this **practice may not be intended to paternalistic, but protective; it may be felt inappropriate to directly involve parents in medical decisions where interventions are likely futile, as this places the burden of perceived responsibility on parents when the outcome is inevitable.**

However, where outcomes are uncertain, it is important to include parents in discussions, and we need to better understand how to support parents to be involved in a shared process, **whilst avoiding forcing sole responsibility onto parents at a highly stressful time, and in an area in which they may have limited experience.** Whilst barriers and facilitators of individual-level SDM in adult medicine and general paediatrics have been explored [29, 34], little work has examined the parental perspective of SDM in the neonatal setting and no synthesis of the perceived barriers and facilitators has been conducted. Considering the substantial differences between adult and neonatal medicine, it is important that we

understand parental perceptions to develop training, processes and interventions that better support parents and HCPs to make these difficult decisions together. The aim of this study was to systematically review and thematically synthesise parental-perceived barriers and facilitators to SDM in NICU decision-making.

2. Methods

We applied systematic review methodology, following PRISMA guidelines [35], and thematic synthesis [36] to understand parental-perceived barriers and facilitators to SDM regarding their infants. **A detailed description of methods follows.**

2.1 Eligibility criteria

Studies were included if they reported published empirical research regarding parents' perceptions of SDM in NICUs. SDM was defined broadly as parental involvement in the decision-making process regarding care of their infant [12, 17] e.g. whether or not to initiate resuscitation, maintaining or withdrawing interventions such as ventilatory support, and deciding on different types of treatment for the infant. Studies included decisions made prenatally, as long as they related to postnatal management for the infant e.g. antenatal counselling for imminent preterm delivery to make decisions about whether the baby should be resuscitated at birth. Qualitative studies were included, and quantitative studies were excluded. When eliciting parental perceptions, fixed-survey responses might lack rich data regarding 'why' parents felt that way and can also reflect the researcher's preconceptions [37]. Qualitative methods facilitate exploration of highly emotive and often traumatic experiences, and are more likely to capture the full complexity of parental perceptions of SDM in this context [38]. Studies were also excluded if: they explored

parental involvement in the general care of the infant, rather than involvement in specific decisions; focused solely on healthcare professionals' perceptions of SDM in the NICU, or SDM in older paediatrics / adult medicine. Non-English language and non-primary data (e.g. reviews, letters, editorials) papers were excluded.

2.2 Study identification

Four electronic databases were searched from inception, between April-November 2019 (searches re-run in June 2021): Medline, PsycINFO, CINAHL and SCOPUS. Guided by an information specialist, MeSH headings and key words derived from four broad topic areas informed the search strategies: shared decision-making, neonatal medicine, barriers and facilitators, and perceptions (see Additional File 1 for Medline search strategy). Follow-up searches were conducted, including key author / key word searches on Google Scholar, and references lists of included studies. Titles and abstracts of studies yielded from the electronic and follow-up searches were imported into EndNote and duplicates removed [39]. Title and abstracts of identified studies were screened for relevance against the inclusion / exclusion criteria (OP). Full texts of potentially relevant studies were then assessed by OP (and a sub-set assessed by NJW), and reasons for exclusion were noted.

2.3 Data extraction and synthesis

A data extraction template was developed and piloted. The following data were extracted: study characteristics (study aims, design, country/setting, **sample size, sampling method/recruitment, methods of measurement, conceptual framework used, dates of data collection, outcomes**, analysis), participant characteristics (**e.g. type of parent (mother/father/both), infant condition e.g. parents of extremely preterm infants or**

parents of infants who died) and key findings. Full study results and discussion sections of included studies were extracted verbatim **and entered into Microsoft Excel to support analysis [40]. We were guided by Harden et al's methods for thematic synthesis [36] and used** Braun and Clarke's thematic analysis [41] to inductively code, organise, group and report themes from the data. **OP coded all studies, and a sub-set were independently double coded by NJW.** Our **analysis** was not restricted to the barriers/facilitators identified by the authors of included studies, **but inductively derived from the results/discussion sections. To maximise validity,** all codes were discussed between OP and NJW and grouped into overarching themes, until a final framework of key themes was agreed. Quality of included studies was assessed using the CASP Qualitative Checklist [42]. Due to the small number of studies included in the final review, no studies were excluded based on quality, however, important methodological issues were noted and considered during the data synthesis.

3. Results

3.1 Included Studies

Database and follow-up searches yielded 2445 unique citations; 2253 were excluded based on their title or abstract. The full-text of 192 studies were screened, of which 167 were excluded. Twenty-five articles were included in the final review (see Figure 1 for review process). The earliest studies were published in 1990 [43, 44] and the most recent in 2018 [45-47]. Studies originated from eight countries: USA (n=14), Canada (n=3), UK (n=3), France (n=2), Norway (n=1), Switzerland (n=1), Finland (n=1), Iceland (n=1) (one study was

carried out in both France and the USA). **The total number of participants across all 25 studies was 827.** All studies conducted face-to-face or telephone interviews. Five studies also used ethnographic methods, such as videotaping medical ward rounds [45, 48-51]. Three studies incorporated findings from their interviews to subsequently create and test decision-aid tools for parents [46, 52, 53]. Twelve studies specifically discussed parental involvement in decision-making regarding infants born extremely/very preterm, 12 studies discussed decisions regarding critically-ill infants generally, and one study focused on decisions for infants with a specific condition (bronchopulmonary dysplasia). Study characteristics are reported in Table 1.

3.2 Barriers and facilitators to SDM in neonatal settings – key themes

Six key themes regarding SDM in neonatology were identified, each with several related barriers and facilitators as sub-themes (Table 2): 1) Knowledge, information and communication (five barriers; four facilitators); 2) Paternalism, power and parental autonomy (two barriers; one facilitator); 3) Relationships with staff (one barrier; one facilitator); 4) Emotions (four barriers); 5) Continuity of care and caregivers (one barrier; one facilitator); 6) Tailored decision-making approach (two facilitators). The descriptive themes, including related barriers and facilitators, are presented below with example data.

3.2.1 Knowledge, Information and Communication

Barriers

A lack of medical information was identified by parents as a key barrier to their involvement in decision-making for their infant [44, 47, 48, 52-57]. Many felt they had not been provided

with enough information to participate properly in the decision-making process [49, 58].

Sometimes, there was a feeling that some information was withheld from parents, preventing them from being able to make a fully informed decision [59, 60].

As well as a lack of knowledge, many felt that they were not qualified to decide due to a lack of experience [45, 46, 48, 57]. Some did not want to be involved in the decision-making because they perceived it to be the physician's role, since they held the most knowledge and information to make the most appropriate decision [43-48, 54, 56, 57, 61].

“At that point, I think the doctor (should decide) because they know what’s best for the child. We don’t always know what’s best for him...” (Weiss et al. 2016) [57]

Another barrier was parents' self-perceived difficulty with understanding information communicated to them and translating it into real-world decisions [43, 44, 49, 60-63]. Some parents also recalled unclear or inadequate information-giving by HCPs, and many identified the lack of simple terminology and clear explanations as a major educational barrier [48, 49, 52, 58-61, 63].

“When doctors would explain, the words kept getting bigger and bigger; it would be helpful to have someone to break it down into more simple explanations” (Keenan et al. 2005) [63]

“It was never enough (information) for us to make any decisions, it really wasn’t” (Payot et al. 2007) [64]

Poor communication and one-way information transfer – where HCPs give information without eliciting what parents want to know and allowing them to ask questions - led to isolation and exclusion from the parental role [45, 47, 48, 58]. Many parents felt that doctors communicated information in an overly negative way, adversely affecting the doctor-parent relationship and making parents feel that doctors had “given up” [43, 46, 49, 56, 59, 60, 62, 64].

Facilitators

A key facilitator was parents’ desire to learn more about their child’s medical problems and prognosis [46, 47, 58, 60, 63]. Many parents wanted information, and the more information they received, the more they felt they could be involved in the decision-making [58, 63]. Parents recognised that clear, thorough and honest explanations facilitated their understanding and ability to participate in the decision-making [47, 48, 56, 58-61, 63-67].

“...And I have to say that these doctors didn't go above my head talking to me as if I knew the doctor stuff, but they brought it down where we could understand it... which made the process of making decisions much easier” (Kavanaugh et al. 2005)
[56]

Strong communications skills, including non-verbal actions like eye contact and nodding were important to parents to give the impression of compassion and trust in HCPs [45, 48, 49, 51, 54, 56, 58, 59]. Parents who were offered time to ask questions perceived a better understanding of the situation, facilitating their involvement in SDM [48, 49, 51, 56, 58, 59, 63]. Three studies directly investigated the use of decision-aids for parents of critically-ill

neonates, suggesting that visual decision-aids may facilitate SDM by helping to improve parental knowledge and understanding [46, 52, 53]. Some participants also suggested pamphlets or booklets aided their understanding [60, 63].

3.2.2 Paternalism, Power and Parental Autonomy

Barriers

Some parents felt they were not in control of decisions, or that decisions had been imposed upon them [43-45, 48, 49, 51, 58, 61, 62, 65]. Some parents felt decisions were imposed because they had not been asked for their views, while others described not being given adequate information to make an informed decision (such as alternative treatment options), or being told information in a leading way, particularly when clinicians were pessimistic about outcomes [48, 51, 58]. Doctors were perceived by some to be authoritative figures in positions of greater power, and therefore in control of decisions [64]. This paternalistic environment meant that some parents felt powerless and that they were not offered a choice [48, 49, 58, 61, 62, 65]. Parents sometimes felt that their parental rights to decide were not respected [65].

"They were supposed to call us and they never called. It was almost as if we had to grab them to find out what was going on. We would be visiting and someone would come to do a test and we had no idea what the test was for" (Wocial et al. 2000) [58]

Facilitators

Many parents had strong desires to participate in decisions because they felt they had a right to be involved and to have some parental autonomy [47, 48, 51, 55, 57, 58, 62, 66].

They felt that their opinions mattered, and it was their job as parents to make decisions for their child [47, 51, 57, 58, 66]:

"I, as a parent, want to make the decision after careful consideration and discussion with the specialists" (Einarsdottir 2009)

3.2.3 Relationships with Staff

Barriers

Poor or absent relationships between staff and parents were identified as a barrier to engagement in SDM [46, 47, 58, 61, 67]. Cold, insensitive and emotionally unsupportive staff prevented the formation of a trusting doctor-parent relationship [43-45, 47-49, 51, 58, 60-62, 64, 67]. When parents perceived HCPs to be emotionally unsupportive or unaffected by the situation, they felt abandoned and isolated, hindering their ability to participate in the SDM [45, 48, 60-62, 64].

"In fact, there isn't really a real relationship. The relationship we had with them, it was one of authority. The specialist, he lays out his knowledge, and then leaves"
(Payot et al. 2007) [64]

Facilitators

Conversely, the development of trusting relationships with empathetic HCPs was highly valued by parents and enabled the formation of a collaborative decision-making team [48, 49, 51, 54, 56, 58-62, 64, 66, 67]. Strong relationships with caring and non-judgmental staff

meant parents felt more comfortable with disclosing thoughts and feelings that were important to the decision-making process [47, 48, 51, 54, 60, 61]:

"She is very empathetic, so you have a connection of trust with her" (Daboval et al. 2016) [51]

HCPs had a specific role in providing emotional support to parents, enabling them to process relevant information and come to rational, informed decisions [47, 48, 51, 54, 56, 58, 59, 61, 62, 64]. Parents felt better able to cope with the experience if they had formed strong relationships with caring and compassionate staff [47, 54, 56]. HCPs who showed emotions such as grief during consultations were seen as more caring and empathetic, which encouraged parents to work with them to come to decisions [58, 60].

3.2.4 Emotions

Barriers

Many parents identified being emotionally overwhelmed and in crisis as a major barrier [43-46, 48, 49, 54, 56, 59, 61, 62, 64]. Parents explained that their clouded, shocked or dissociative state of mind hindered their ability to process information and make rational decisions. Parents sometimes described making rushed or intuitive decisions which were not necessarily sensible because of a subconscious desire to flee the stressful situation [43, 48, 54, 61].

“...Because you are so overwhelmed, you are crying, you are upset. A lot of stuff will slip past you what the doctor is saying... and they may have said it or may have informed me what was going on, I didn't hear it” (Kavanaugh et al. 2005) [56]

Many parents also described specific emotions that hindered their desire and ability to be involved in decision-making for their infant [50, 54, 61, 64, 66]. Mostly, parents felt guilty, particularly when making decisions to limit treatment for their infant, which deterred them from participation in the decision-making process [54, 61, 64, 66]. Many parents were also fearful of making the “wrong” decision for their child [50, 54, 61]. A few parents did not want the responsibility of decision-making and felt that doctors had a role to protect parents from the guilt and harsh realities [50, 54, 55, 61, 64, 66]. Some felt that the weight of the decision and the potential consequences were too great to be left in parental hands [54, 64]. Some parents who had not been involved in decision-making described a sense of relief that they did not have to decide [61].

3.2.5 Continuity of Care and Caregivers

Barriers

A lack of continuity of care and caregivers meant parents were sometimes unable to form strong bonds with caregivers [44, 47, 48, 50, 52, 60]. Also, inconsistencies in the information and advice given by HCPs resulted in confusion for some parents [44, 47, 50, 52, 61]. This meant parents were either not actively invited into the decision-making process, or they were not able to participate effectively because of confusion. Some parents described

positive experiences of being involved in decision-making with one doctor, only for the agreed plans to be disregarded by the new doctor [47, 50].

“We spent forty-five minutes, an hour with (consultant) agreeing what the plans going to be, and the following week, the first thing that was done, the first consultant on board threw the plan out the window” (Gallagher et al. 2017) [47]

Facilitators

Having the same caregivers throughout the infant’s experience in the NICU was important for the development of trust and the transfer of information [47, 48, 56, 61]. This helped parents feel satisfied with their child’s care, as well as more “in-the-loop” regarding information and decisions. Parents needed consistent and continuous support and communication of information [48, 56].

3.2.6 Tailored Decision-Making Approach

Facilitators

Many parents strongly suggested that the approach taken by HCPs should be tailored to each family [48, 51, 54, 58, 60, 61, 64]. Taking into consideration a family’s personal situation and their values helped build strong relationships [54, 60, 61, 64]. It also allowed pragmatic and realistic discussions about how the parents will cope with the potential consequences in the context of their specific family situation [61].

"The doctor left me with the choice. He explained to me the risks of these choices. He told me, you already have a three-year-old daughter. He stayed in the context of our little family: for the child, for me, for the family" (Caeymaex et al. 2011) [61]

Crucially, discussions about how much parents wanted to be involved in the decision-making and how much information they wanted to receive were seen as vital by parents [48, 51, 54, 60, 64]. Expectations and desire to be involved in the decision-making varied considerably between families, and therefore it was helpful for HCPs to elicit this in order to fully align parental wishes with their level of involvement [48, 64].

4. Discussion and Conclusion

4.1 Discussion

This review highlights parental-perceived barriers and facilitators to surrogate SDM in NICU settings. Our thematic synthesis of 25 qualitative studies found that key barriers included a lack of medical information provided to parents to inform decision-making, inadequate communication of information, poor relationships with caregivers, lack of continuity in care, and perceived power imbalances between HCPs and parents. **Our study highlights the significant role context plays in the capacity for parents to become more actively involved in SDM. Amplified power-imbalances in the highly specialised NICU, the emotional crises experienced by parents, and the burden of potentially life-limiting decision-making responsibility all impact on decision-making capabilities. This highlights the need for emotional support as an integral part of SDM interventions provided in these settings. Key facilitators included clear, honest and compassionate communication of medical**

information, caring and empathetic caregivers, continuity in care, and tailored approaches that reflected parent's desired level of involvement.

We identified parent's perceived lack of knowledge as a key barrier, often leading parents to defer decision-making to HCPs. **Quantitative neonatal studies have found similar patterns of decision deferral, especially when decisions are seen as 'technical' rather than 'big picture' [28, 68]. The way in which information was communicated was also a barrier; when medical terminology was not clearly explained and understandable, it was hard for parents to engage in the discussion. This has been identified by both parents and HCPs as a barrier to SDM in paediatric settings [69]. Similarly, adult ICU studies have found that clinicians do not routinely check that surrogate decision-makers have fully understood the information provided, resulting in misunderstandings about prognoses [20]. In line with other paediatric-based studies [70], our review also found that parents sometimes receive less information than they need to become involved in decisions.**

Our review found that parents may want to be involved in decisions to varying degrees, and a tailored approach that considers this is a key facilitator. Whilst some parents felt strongly that it was their parental right to be involved in decision-making, others felt uncomfortable with the responsibility, or too emotionally overwhelmed. This is a particular challenge for surrogate decision-makers, where there is a considerable weight of responsibility when making decisions for someone else. This has been highlighted in other paediatric medicine and adult ICU surrogate decision-making studies [20, 28, 29, 71, 72]. Discordance between desired and actual decision-making roles is linked with poorer satisfaction and greater

emotional burden for parents [20, 72]. As such, clear and explicit discussions about desired roles in decision-making should be initiated early on, so that approaches can be tailored.

As found in broader SDM studies [10], knowledge is not the sole determinant of empowerment when it comes to involvement in decision-making. We found that power-imbances perceived by parents in NICU settings impacted on perceived capacity to engage in decision-making. This reflects the findings from a review of **HCP perceptions of SDM in paediatrics [12]**. This balance of power is intricately intertwined with the nature of the relationships between parents and staff. In line with other quantitative and review studies **[29, 73, 74] our findings suggest that** poor communication and insensitivity from staff prevent the development of trusting and emotionally supportive relationships **and exacerbate power-imbances**. This results in parents feeling excluded and unable to cope with the emotional strain, leading to the breakdown of their involvement in decisions.

From an ethical standpoint, communication in these situations is rooted in the principle of best interests. If parents feel well-supported and better informed – especially about longer-term outcomes and quality of life - conflict regarding the best interests of the infant may be less likely. Balancing power relations and developing trusting relationships may further alleviate conflict as it contributes towards an environment where parents feel HCPs are “on their side” [28]. Further, our findings suggest that parents value a tailored approach where HCPs consider their personal family situation. This may help both HCPs and parents to contextualise the infant’s best interests within their specific family scenario [28]. Disagreements may remain because of a parent’s natural tendency to want

their child to survive, which is why SDM here requires a heightened level of emotional and informational support.

A final but crucial barrier to parental involvement in neonatal decision-making is the high level of emotional distress experienced by parents. Many described a sense of shock or feeling overwhelmed by the situation. Willingness to be involved was frequently curtailed by fears that an active role might negatively impact on their longer-term emotional status, possibly due to the associated burden of 'decisional responsibility'. Long-term adverse psychological outcomes (such as post-traumatic stress disorder) have been reported in other adult and neonatal ICU studies, where surrogate decision-making is prevalent [20, 75].

However, emotional crises seem to be more prominent as a barrier in parent-reported studies than in HCP-reported studies [12, 69]. Psychologists have been introduced into some NICUs, and studies show that they provide valuable support to families, as well as staff and infants as they grow up [76]. Hynan et al. provide a series of recommendations for best practice to support the emotional well-being of parents in the NICU, which centre around employing a full-time psychologist and social worker embedded into the NICU staff, and these approaches can be particularly useful for parents with more risk factors or those showing acute emotional distress [75]. Currently, more research is needed to ascertain what type of psychological support parents find most helpful and when this should be delivered [75], but this type of support could be used alongside decisional-support, helping parents to process their emotions and feel more able to participate in decision-making.

This is the first systematic review to synthesise parent-reported barriers to and facilitators of neonatal SDM - without which it is difficult to develop supportive interventions. Much

of the literature on neonatal SDM concentrates on HCPs' perceptions. Parental perceptions are relatively under-represented and have previously not been synthesised. While parental perceptions are subjective and do not account for the full complexity of the situation, they are insightful as they highlight what is important to parents in SDM and can help guide intervention development.

Inclusion of qualitative studies using direct enquiry with parents is a significant strength of this work, allowing us to understand reasons why the barriers exist, rather than solely on what the barriers are. The synthesis of data in this review was consistent with well-documented methods of qualitative analysis and synthesis [36, 41]. The inductive approach ensured themes derived for this study were not dependent on the themes/categories presented by study authors. However, we did not have access to the raw data of each primary study and our synthesis was influenced by what was reported in the results and discussion section. This review included a wide range of research questions and clinical situations which might limit generalisability. Some studies interviewed parents during their time in the NICU, while others retrospectively interviewed participants in the months/years after their experience. These differences in timepoints relative to decision-making events could affect the way parents recall. There was also a tendency for included studies to recruit parents whose child had survived, while parents involved in treatment limitation decisions (whose child subsequently died) were under-represented. As such, key barriers and facilitators to decision involvement could be missed, and further work is needed to explore this.

4.2 Conclusion

The highly specialised and traumatic environment of the NICU appears to amplify key barriers to SDM identified in other paediatric and adult decision-making settings, including perceived power imbalances [17, 19, 29]. Further, the emotional crises experienced by parents and the burden of potentially life-limiting surrogate decision-making impact significantly on parents' perceived capacity to engage in decision-making. Fundamentally, **surrogate** SDM in these settings will require greater “emotional work” from HCPs, in addition to clear communication of likely outcomes and support to consider the child’s best interests and weigh-up the options. However, more work is needed to address outstanding gaps in the literature, which includes the perceptions of parents who report negative experiences and experiences of parents whose infant died.

4.3 Practice Implications

Support for effective SDM is complex and multifactorial, especially for surrogate decision-makers in highly specialised settings. Complex interventions addressing the training needs of HCPs, and the emotional, information and decision support needs of parents are required. **SDM skills training for HCPs should be a core part of any SDM complex intervention, as outlined in the NICE SDM guideline [2].** These sessions should be interprofessional, interactive and use multiple learning strategies (such as roleplay) [77, 78]. ‘SDM checklists’ could be used to prompt discussions between HCPs and parents. These checklists could include essential discussion items for best practice, such as: eliciting parents’ desired decision-making roles; discussing their wishes, preferences and concerns; exchanging a level of evidence-based information that is in line with parents’ desires (using validated patient decision aids or written material where appropriate); and screening for emotional distress that may warrant consultations with the team’s clinical psychologist.

Parental wishes may change over time so regular use of any checklist would be important [12, 79]. If these checklist items are addressed, it may help to target some of the key factors that contribute to the power imbalance that **may be** seen during neonatal SDM. **Our findings highlight the need for emotional support to be integrated as part of SDM interventions provided in these settings. Ultimately, the emotional support needs might need to be addressed before the decision-making support needs.** To be a collaborative partner in decision-making, parents must fully understand the relevant information [80] and should be provided with support to build their knowledge and help them to recognise the value of their contributions to discussions [10]. In adult medicine, patient decision aids have been **shown** to improve knowledge and level of involvement in decision-making [14]. Further research suggests potential benefits of these tools in paediatric [17, 70] and neonatal medicine [46, 52, 53]. These tools could help to balance the power in decision-making by enabling parents to feel competent and confident.

Ultimately, SDM in complex and highly specialised environments like a NICU is resource- and time-intensive, and interventions to promote SDM will reflect this. However, SDM is an important part of high-quality care for infants and their parents, and efforts should be made to introduce these measures.

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Table 1. Description of included articles that identified barriers and facilitators (n=25)

First Author, Year, Country, Citation	Primary Aim	Participants (n=sample size)	Methods and Analysis
Caeymaex, 2011, France, [61]	-To explore parents' experience of the end-of-life decision-making process for their child in the NICU	N=53 families (78 individual parents) -Parents whose child died between 2002 and 2005 in one of 4 NICUs in France	-Qualitative -In-depth face-to-face/telephone interviews -Video/audio-recorded -Discourse analysis
Daboval, 2016, Canada, [51]	-To describe characteristics of communication that parents identify as facilitating their desired participation in decision-making during the antenatal consultations discussing decisions concerning their infant at risk of being born at the limit of viability	N=5 families (16 individual parents) -Parents referred by obstetrician and admitted for threatened premature delivery at 20-26 weeks GA	-Qualitative -In-depth semi-directive face-to-face interviews -Part of wider ethnographical multiple case-study strategy (involved videotaping regular antenatal consultations) -Content analysis
Drago, 2018, US, [46]	-To characterise parental perceptions of antenatal counselling of Latino parents who had experienced extremely preterm birth -To construct and validate a decision aid for antenatal consultations	N=22 parents -Latino parents of infants born before 26 weeks presenting to follow-up clinics	-Mixed -Semi-structured face-to-face/telephone interviews -Simulated antenatal counselling session with before-and-after knowledge test and evaluation survey -Grounded theory
Gallagher, 2017, UK, [47]	-To explore the experiences of parents towards interaction with healthcare professionals during their infant's admission to the NICU	N=14 families (18 individual parents) -Parents of critically ill infants admitted to the NICU	Qualitative -Semi-structured face-to-face interviews at admission to NICU -5 families had a second interview at discharge -Part of wider ethnographical study of interaction between parents and HCPs -Thematic analysis
Guillen, 2012, US, [53]	-To characterise clinicians' experiences with parents of extremely premature infants and the perceptions of parents during antenatal counselling	N= 30 parents N=31 clinicians -Parents of infants born before 26 weeks GA who attended high-risk follow-up clinics	-Mixed -Semi-structured interviews with parents and clinicians (separate) -Thematic analysis -Creation of a decision aid tool -Simulated antenatal counselling session with before-and-after knowledge test and evaluation survey

Payot, 2007, Canada, [64]	-To explore empirically how parents and neonatologists engage in the decision to resuscitate a baby at the threshold of viability	<p>N = 8 parent couples (16 individual parents)</p> <p>-Parents at risk of premature delivery between 23- and 25-weeks gestation</p> <p>N= 4 neonatologists</p> <p>-Neonatologists who conducted the antenatal consultations with these parents</p>	<p>-Qualitative</p> <p>-In-depth semi-directed interviews with parents within hours of antenatal consultation</p> <p>-Second interview with parents 4-6 months after event</p> <p>-Also, semi-directed interviews with neonatologists conducting the consultation</p> <p>-Grounded theory</p>
Skibo, 2017, US, [52]	-To create a decision aid to assist in counselling parents of infants with bronchopulmonary dysplasia to enable a better understanding of this complex disease process and possible treatment options	<p>N = 12 parents</p> <p>-Parents of infants born before 28 weeks GA and diagnosed with moderate/severed bronchopulmonary dysplasia</p> <p>N= 33 clinician interviews</p>	<p>-Mixed</p> <p>-Semi-structured interviews with parents and clinicians (separate)</p> <p>-Thematic analysis</p> <p>-Creation of a decision aid tool</p> <p>-Simulated antenatal counselling session with before-and-after knowledge test and evaluation survey</p>
Brinchmann, 2002, Norway, [54]	-To generate knowledge about parents' participation in life-and-death decisions concerning very premature and/or critically ill infants who are in hospital neonatal units	<p>N=20 families (35 individual parents)</p> <p>-Parents of infants who had been previously admitted to a NICU</p>	<p>Qualitative</p> <p>-In-depth unstructured face-to-face interviews</p> <p>-Grounded theory</p>
Orfali, 2004, US and France [50]	-To examine parents' roles and experiences facing similar problems in two different cultural contexts (US and France)	<p>N=75 mothers</p> <p>-Mothers of critically ill or deceased infants in neonatal units in US and France</p>	<p>-Qualitative</p> <p>-In-depth semi-structured interviews</p> <p>-Part of wider ethnographic study on decision-making concerning life-sustaining treatments in NICUs in France and US2</p>
Boss, 2007, US, [62]	-To characterise the values that parents apply to decision making regarding delivery room resuscitation for high-risk infants	<p>N=26 mothers</p> <p>-Parents of infants who died as a result of extreme prematurity or lethal congenital anomaly</p>	<p>-Qualitative</p> <p>-Semi-structured telephone interviews</p> <p>-Thematic analysis</p>
Pepper, 2012, Canada, [59]	-To investigate parents' perceptions of decision-making involving their extremely premature newborns who received care in a level III neonatal intensive care unit	<p>N=5 families (7 individual parents)</p> <p>-Parents of infants born 24-26 weeks who survived to 6-month follow-up clinic</p>	<p>-Qualitative</p> <p>-Semi-structured face-to-face interviews</p> <p>-Interpretative description analysis</p>

McHaffie, 2001, UK, [55]	-To determine what parents think about involvement in treatment limitation decisions in the NICU	N=59 families (108 individual parents) at 3 months N=50 families (90 individual parents) at 13 months -Parents of critically ill infants who had been involved in any discussions about treatment limitation	-Qualitative -Semi-structured face-to-face interviews 3 and 13 months after infant death
Hendriks, 2017, Switzerland, [48]	-To explore parental attitudes and values in the end-of-life decision-making process of extremely preterm infants	N=13 families (20 individual parents) -Parents of infants born alive before 28 weeks gestation who died in the delivery room	-Qualitative -Semi-structured face-to-face interviews -Hermeneutically-orientated content analysis
Keenan, 2005, US, [63]	-To gain a better understanding of mothers' and counsellors' perception of their roles in the decision-making process about the resuscitation of very premature infants at delivery	N=15 mothers -Mothers of infants born between 22- and 27-weeks' gestation who received at least 1 predelivery counseling session	-Mixed -Standardised interview questionnaire with open-ended questions -Quantitative statistics and qualitative analysis of open-ended questions
Einarsdottir, 2009, Iceland [66]	-To shed light on the experiences and ethical concerns in Iceland of parents to infants with extremely low birth weight with the associated risk for either early death or future disability	N = 53 (28 mothers, 25 fathers) -Parents of children born less than 1000g who survived	-Qualitative -Semi-structured interviews -No information given about analysis
Pinch, 1990, US, [43]	-None given	N = 5 families	Qualitative -Semi-structured interviews -Content analysis
Kavanaugh, 2005, US, [56]	-To describe decision making and the decision support needs of parents, physicians and nurses regarding life support decisions made over time prenatally and postnatally by extremely premature infants	N = 6 cases (6 mothers, 2 fathers, 4 fetal medicine physicians, 2 neonatologists, 2 obstetric nurses) -Cases of threatened premature deliveries where prenatal discussions regarding treatment decisions occurred	-Qualitative -Collective case study; semi-structured interviews -Framework analysis using Ottawa framework
Wocial, 2000, US, [58]	-To understand better parent perceptions of the decision-making process	N = 20 parents	-Qualitative -Semi-structured interviews -Content analysis

		-Parents of infants who died following consideration of withholding and/or withdrawing treatment	
Axelin, 2018, Finland, [45]	-To explore the dynamics of attending neonatologist-parent communication and decision-making during medical rounds and examine how decisions about the infant's care were achieved	N = 22 parents (8 mothers and 7 mother-father couples)	-Qualitative -Individual interviews and ethnographic analysis of video-recorded observation of 15 medical rounds -Thematic analysis
Moro, 2011, US, [67]	-None given	N = 5 cases (5 mothers, 4 physicians, 3 nurses and 1 neonatal nurse practitioner) -Mothers who were hospitalised and counselled about life support decisions for delivery of an infant before 25-weeks gestation	-Qualitative -Semi-structured interviews -Framework analysis using the Ottawa Decision Support Framework
Currie, 2016, US [65]	-To explore and describe parent experiences related to their infant's NICU hospitalisation, end-of-life care and PPC consultation	N = 10 parents -Parents whose infant was hospitalised and subsequently died in a level III NICU	-Qualitative -In-depth semi-structured interviews -Content analysis
Weiss, 2016, US, [57]	-To explore how characteristics of medical decisions influence parents' preferences for control over decisions for their seriously ill infants	N = 30 parents -Parents of extremely or very premature infants	-Qualitative -Semi-structured interviews -Thematic analysis
Alderson, 2006, UK, [49]	-To compare standards of recent guidance with parents' views and experiences of SDM, their first meeting with their baby, making "minor" decisions, the contrasting decision-making contexts in different neonatal units, helpless observers and missed opportunities	N= 80 cases (80 mothers, 16 fathers) -Parents of babies with definite or potential neurodevelopmental problems being treated in a NICU	-Qualitative -Ethnographic observations and semi-structured interviews -No information given on analysis
Pinch, 1990, US, [44]	-To understand the experience from the parents' perspective based on delineation of major themes or concepts that represented the families' viewpoints	N = 32 families (32 mothers, 21 fathers, 2 grandmothers) -Families of neonates in a Level III NICU	-Qualitative -Semi-structured interviews -Phenomenological analysis
Baughcum, 2017, US, [60]	-To examine parent perceptions of their infant's care at the end-of-life in the NICU between 3 months and 5 years of their infant's death	N = 45 parents (29 mothers, 16 fathers) (interviewed) -Parents who were >3 months since their infants death in a Level IV NICU	-Qualitative -Semi-structured interviews and/or quantitative survey -Content analysis

Table 2: Parental perceived barriers and facilitators to SDM: key themes

Barriers and Facilitators	Example from Primary Data
Knowledge, Information and Communication	
Barriers	
Parents' lack of medical knowledge [44, 47, 48, 52-57]	<p><i>"As far as I'm concerned, they updated us on her condition, the situation, because I'm not a doctor, I'm not expecting to treat my daughter, so I just leave in their hands, for all decisions... and I'm happy with that"</i> (Gallagher et al. 2017) [47]</p> <p><i>"Possibly there were other options but when you do not know what other options there are, how should you decide?"</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"At that point, I think the doctor because they know what's best for the child. We don't always know what's best for him. They're the ones looking over him. They can tell if vitals is not stable (sic)"</i> (Weiss et al. 2016) [57]</p> <p><i>"I think it is best that the doctors make the decision... Because like I said again, we don't really know what's going on"</i> (Weiss et al. 2016) [57]</p>
Parental belief that decision-making is the doctor's role because they have knowledge, expertise and experience [43-48, 54, 56, 57, 61]	<p><i>"At that point, I think the doctor because they know what's best for the child. We don't always know what's best for him. They're the ones looking over him. They can tell if vitals is not stable (sic)"</i> (Weiss et al. 2016) [57]</p> <p><i>"To me it was also a medical decision. So, I wasn't asked about it and I don't think I was in a position to say yes or no either way"</i> (Weiss et al. 2016) [57]</p> <p><i>"I think it is best that the doctors make the decision... Because like I said again, we don't really know what's going on"</i> (Weiss et al. 2016) [57]</p> <p><i>"I feel like it should be the doctors because they would know what is best for her survival"</i> (Weiss et al. 2016) [57]</p> <p><i>"As far as I'm concerned, they updated us on her condition, the situation, because I'm not a doctor, I'm not expecting to treat my daughter, so I just leave in their hands, for all decisions... and I'm happy with that"</i> (Gallagher et al. 2017) [47]</p> <p><i>"What was really to decide? But actually... we relied on the staff and their advice. They have more experience, when they say it does not make any sense, then that was the decision. There was not really anything to decide"</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"They [the physicians] want, they want to leave making my decision on what they do. But I'm not a doctor, so it won't be my decision. I'm trusting these guys with, with everything they do"</i> (Kavanaugh et al) [56]</p>
Parental difficulty in understanding and	<p><i>"It was stories of percentages. Therefore in 50% of cases, the children die of side effects and the 50% who remain another 60% die. At the end, there was nothing. But I said, but what is she going to know about life?"</i> (Caeymaex et al. 2011) [61]</p>

<p>processing medical information [43, 44, 49, 60-63]</p>	<p><i>"When doctors would explain, the words kept getting bigger and bigger; it would be helpful to have someone to break it down into more simple explanations"</i> (Keenan et al. 2005) [63]</p> <p><i>"Sometimes healthcare professionals can just come across as this is no big deal, this is nothing or they take for granted the jargon they use. So it's just trying to be respectful that sometimes we have no idea what you're talking about"</i> (Baughcum et al. 2017) [60]</p>
<p>Unclear/inadequate giving of information to parents [48, 49, 52, 58-61, 63]</p>	<p><i>"It was never enough (information) for us to make any decisions, it really wasn't"</i> (Pepper et al. 2012) [59]</p> <p><i>"One (nurse) would inform us well and would start telling us everything on her own; with others you had to drag the information out of them"</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"Sometimes healthcare professionals can just come across as this is no big deal, this is nothing or they take for granted the jargon they use. So it's just trying to be respectful that sometimes we have no idea what you're talking about"</i> (Baughcum et al. 2017) [60]</p> <p><i>"Possibly there were other options but when you do not know what other options there are, how should you decide?"</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"When doctors would explain, the words kept getting bigger and bigger; it would be helpful to have someone to break it down into more simple explanations"</i> (Keenan et al. 2005) [63]</p> <p><i>"They were supposed to call us and they never called. It was almost as if we had to grab them to find out what was going on. We would be visiting and someone would come to do a test and we had no idea what the test was for"</i> (Wocial et al. 2000) [58]</p> <p><i>"It's treating the parent like an idiot, like a sheep you know, if it doesn't know something is coming it won't think about it"</i> (Alderson et al. 2006) [49]</p> <p><i>"We had no idea that we could be doing anything practical. In other words, instead of having a problem that we could perhaps find a solution for, we had this tragedy and the world was black"</i> (Alderson et al. 2006) [49]</p>
<p>Overly negative communication of information [43, 46, 49, 56, 59, 60, 62, 64]</p>	<p><i>"The NICU doctors came in and (said) 'your baby's gonna have cerebral palsy, and your baby's gonna be handicapped, this is your decision to make'"</i> (Pepper et al. 2012) [59]</p> <p><i>"There's no hope... I think the medical people are fearful to tell you anything good, because you'll hold it against them if things go bad"</i> (Pepper et al. 2012) [59]</p> <p><i>"I know doctors have to give and tell you everything regardless if it's bad or good. Don't say the bad stuff and just drop it. Say something like, although this is a big possibility, there is always hope."</i> (Kavanaugh et al. 2005) [56]</p> <p><i>"They should say, these are all the things that could happen but we are going to fight"</i> (Drago et al. 2018) [46]</p> <p><i>"Then, she explained the consequences if I wanted to keep him. If we wanted to keep him, he could be deaf or blind, then mentally disabled and slow."</i> (Payot et al. 2007) [64]</p>

	<p><i>"Cerebral palsy.... She had a risk of being deaf, mute, crippled. Deaf, blind.... Malformations. At 6 months, she could get a blood clot in the brain, because they bleed a lot.... And she'd paralyse"(Payot et al. 2007) [64]</i></p> <p><i>"I felt that they could have had a little more compassion instead of being so negative, especially when a hospital is known for good research and good procedures and stuff. Just be more optimistic. It's really important for a parent to hear some hope, although the rationale says that this is 90% going to happen this way negatively" (Boss et al. 2007) [62]</i></p> <p><i>"I didn't trust the physicians. Every time I talked with them it was always negative. I needed compassion. I would ask the nurse if she agreed with the physician's statements" (Boss et al. 2007) [62]</i></p> <p><i>"She didn't give us any choices. She was real aggressive and she didn't pull any punches. She was pretty blunt about how slim [the baby's] chances were" (Pinch 1990) [43]</i></p> <p><i>"I don't know if there is a way they can be realistic like they need to be, but be more compassionate, I guess. That was kind of tough" (Baughcum et al. 2017) [60]</i></p>
<p>Facilitators</p>	
<p>Parents' desire to learn more [46, 47, 58, 60, 63]</p>	<p><i>"I think the most important thing to us, or the most helpful thing to us is to be frequently updated, to be constantly informed" (Wocial et al. 2000) [58]</i></p> <p><i>"At the end of the day, I'm his mother and I'm supposed to be looking after him, so I need to know everything that's happening with him is correct and I need to keep an eye on everything... at the end of the day, if anything goes wrong, I'm the one who is going to lose everything" (Gallagher et al. 2017) [47]</i></p>
<p>Clear, thorough, honest explanations of information [47, 48, 56, 58-61, 63-67]</p>	<p><i>"The (staff nurse) would spend, you know a couple of hours with me, and just kind of sit and talk, and, and then go over a few things" (Pepper et al. 2012) [59]</i></p> <p><i>"So I would say to any physician, give as much information as needed. Allow the parents to ask. I don't care how silly it may seem to them, but allow them to ask the questions so they can better understand what's taken place. And I have to say that these doctors didn't go above my head talking to me as if I knew the doctor stuff, but they brought it down where we could understand it. And then where there was a time where they didn't, there was like I said a nurse who brought it down further so we could better understand it which made the process of making decisions much easier" (Kavanaugh et al. 2005) [56]</i></p> <p><i>"It was technical for my husband, when it had to be technical for him. When they turned to me, they knew, they must have understood, I suppose, that for me, it wasn't a technical thing... they had to be more human, had to be more emotional, more sensitive. The woman, she spoke more, like a..., like a mother. And that's exactly what I needed. So, she gave us both the same information, but in different terms, in a different tone. She adapted to each of us. It was very... very respectful of our situation, of the kind of information or support we needed. But with my husband, she was more, I would say, professional-technical, using clear, understandable words. I mean, easy to understand. And with me, she spoke with a more... maternal tone" (Payot et al. 2007) [64]</i></p> <p><i>"Explained step-by-step what they would do" (Keenan et al. 2005) [63]</i></p>

	<p><i>"Give us that knowledge you know, educate us so we can have some answers. We had to ask for his CAT scan... Obviously we are not medical students and lot of the stuff may be you know a little tough to understand, but it can be broken down. We will comprehend it if you just lay it out there"</i> (Wocial et al. 2000) [58]</p> <p><i>"You could tell they really wanted to help and they were doing everything they could, you know, to try and help us and give us as much information as they had and try to put it in a form that we could understand"</i> (Currie et al. 2016) [65]</p> <p><i>"I think the best thing is to be really upfront and honest about the medical condition of the child, don't sugar coat anything"</i> (Baughcum et al. 2017) [60]</p>
Strong personal communication skills of HCPs (fac) [45, 48, 49, 51, 54, 56, 58]	<i>"She kept, you know, eye contact with both of us"</i> (Daboval et al 2016) [51]
Decision aids to help communicate information (fac) [46, 52, 53]	No quote available
Paternalism, Power and Parental Autonomy	
Barriers	
Lack of parental control over the decision [43-45, 48, 49, 51, 58, 61, 62, 65]	<p><i>"I did not perceive that I had control of this, because I am not the physician, I am not the one performing the resuscitation, I feel that I don't have control of this"</i> (Daboval et al. 2016) [51]</p> <p><i>"I felt my parental rights was (sic) taken from me because, I knew what the situation was and I was prepared for it"</i> (Currie et al. 2016) [65]</p> <p><i>"They were supposed to call us and they never called. It was almost as if we had to grab them to find out what was going on. We would be visiting and someone would come to do a test and we had no idea what the test was for"</i> (Wocial et al. 2000) [58]</p> <p><i>"Possibly there were other options but when you do not know what other options there are, how should you decide?"</i> (Hendriks and Abraham 2017) [48]</p>
HCP imposing decision on parents [48, 49, 58, 61, 62, 65]	<p><i>"They (the doctors) came to tell us she was going to die, at the same time, it was our choice - but what choice? As if you can talk about a choice. It was surrealistic for me"</i> (Caeymaex et al. 2011) [61]</p> <p><i>"I felt my parental rights was (sic) taken from me because, I knew what the situation was and I was prepared for it"</i> (Currie et al. 2016) [65]</p>
Facilitators	
Belief that parents have a right and responsibility to be	<i>"It's a balance between information, being honest but acknowledging I'm still a parent and you're talking about my child, and yes, your medical opinion is what counts, but my opinion counts too, and we're in a partnership"</i> (Gallagher et al. 2017) [47]

<p>involved [47, 48, 51, 55, 57, 58, 62, 66]</p>	<p><i>"At the end of the day, I'm his mother and I'm supposed to be looking after him, so I need to know everything that's happening with him is correct and I need to keep an eye on everything... at the end of the day, if anything goes wrong, I'm the one who is going to lose everything" (Gallagher et al. 2017) [47]</i></p> <p><i>"Because I should get a say in what I want my baby to have" (Weiss et al. 2016) [57]</i></p> <p><i>"I'm glad that we do have a decision because when it comes down to it, it is our baby" (Daboval et al. 2016) [51]</i></p> <p><i>"I would like to decide... In fact parents should have the last word and the neonatologists should give advice... that is their work" (Einarsdottir 2009) [66]</i></p> <p><i>"I, as a parent, want to make the decision after careful consideration and discussion with the specialists" (Einarsdottir 2009) [66]</i></p> <p><i>"I did not experience this moment as a freedom but rather as a responsibility of course because this baby cannot decide for herself. We are her parents and we should make this decision. And we should decide what is best for our baby. Now in retrospect, I regard that as a great act of love. But in those hours, I thought I would die. But you do not die and you go on and you have to decide" (Hendriks and Abraham 2017) [48]</i></p>
<p>Relationships with Staff</p>	
<p>Barriers</p>	
<p>Cold, insensitive, emotionally unresponsive staff preventing the formation of trusting relationships [43, 45, 47-49, 51, 58, 60-62, 64, 67]</p>	<p><i>"This doctor, I don't ever want to see him again. When he told us that it was no longer legitimate to continue the resuscitation, he said it to us casually without emotion, as if that happened to him everyday. He was not warm. So, was he telling us the truth? That's a question" (Caeymaex et al. 2011) [61]</i></p> <p><i>"She didn't give us any choices. She was real aggressive and she didn't pull any punches. She was pretty blunt about how slim [the baby's] chances were" (Pinch 1990) [43]</i></p> <p><i>"I am not pleased with how they talked with us. We were told in a hall. I was real uncomfortable...you know, the only thing I wanted to do was run. We felt we just had to be so composed. We felt we didn't have the right to cry for our own child" (Pinch 1990) [43]</i></p> <p><i>"They were talking about needing to do a blood transfusion and the question you asked was "oh do you have enough blood" which the nurse then immediately laughed hysterically 'of course we've got enough blood, we're a hospital' which I understand that.... I said 'd'ya want any of mine'... obviously they're doing this job every single day but sometimes it's just nice to think a little more about how they came across... why have you just laughed at us and we're asking the question" (Gallagher et al. 2017) [47]</i></p> <p><i>"They cannot tell if you are upset, not looking at me"(Daboval et al. 2016) [51]</i></p> <p><i>"We don't expect the physician to make the decision for us. But we need to feel that, well that the physician... treats us more humanely ... not like a client (to be able to deal with this intense situation)" (Payot et al. 2007) [64]</i></p>

	<p><i>"I think that what's clearest now is really... the lack of personal follow-up. No guidance. If there had been that, the rest would have been easier to deal with"</i> (Payot et al. 2007) [64]</p> <p><i>"In fact, there isn't really a real relationship. The relationship we had with them, it was one of authority. The specialist, he lays out his knowledge, and then leaves"</i> (Payot et al. 2007) [64]</p> <p><i>"The doctor comes, gives information and leaves, it's like there is no relationship, someone you could rely on"</i> (Payot et al. 2007) [64]</p> <p><i>"It's treating the parent like an idiot, like a sheep you know, if it doesn't know something is coming it won't think about it"</i> (Alderson et al. 2006) [49]</p> <p><i>"I don't know if there is a way they can be realistic like they need to be, but be more compassionate, I guess. That was kind of tough"</i> (Baughcum et al. 2017) [60]</p> <p><i>"I didn't trust the physicians. Every time I talked with them it was always negative. I needed compassion. I would ask the nurse if she agreed with the physician's statements"</i> (Boss et al. 2007) [62]</p>
<p>Facilitators</p>	
<p>Kind, empathetic and emotionally supportive staff facilitating the formation of trusting relationships [48, 49, 51, 54, 56, 58-62, 64, 66, 67]</p>	<p><i>"(The HCP had a) human side; she simply listened to us and was a very sympathetic person"</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"One of the nurses even wrote me an email in the middle of the night to tell me that my baby was sleeping well. That touched me so because... that was my first night at home. I found that amazing."</i> (Hendriks and Abraham 2017) [48]</p> <p><i>"She is very empathetic, so you have a connection of trust with her"</i> (Daboval et al. 2016) [51]</p> <p><i>"Being able to try and put themselves in the situation that they are walking into"</i> (Daboval et al. 2016) [51]</p> <p><i>"He is supportive and he asked me that too. He asked me how I thought he could support me and I said basically tell me the truth and just be there for me"</i> (Daboval et al. 2016) [51]</p> <p><i>"It is not necessarily important to see someone weep over my child, per se, but it is helpful and it is just immensely valuable to have them express genuine emotions... It provides an atmosphere that it makes it easier to make these difficult decisions when you feel like you are in an atmosphere of people who are supportive and caring and sensitive"</i> (Wocial et al. 2000) [58]</p> <p><i>"It was technical for my husband, when it had to be technical for him. When they turned to me, they knew, they must have understood, I suppose, that for me, it wasn't a technical thing... they had to be more human, had to be more emotional, more sensitive. The woman, she spoke more, like a..., like a mother. And that's exactly what I needed. So she gave us both the same information, but in different terms, in a different tone. She adapted to each of us. It was very... very respectful of our situation, of the kind of information or support we needed. But with my husband, she was more, I would say, professional-technical, using clear, understandable words. I mean, easy to understand. And with me, she spoke with a more... maternal tone"</i> (Payot et al. 2007) [64]</p>

	<p><i>"The (staff nurse) would spend, you know a couple of hours with me, and just kind of sit and talk, and, and then go over a few things"</i> (Pepper et al. 2012) [59]</p> <p><i>"They have to let you know every step of the way and be compassionate about it. Because, don't, don't be harsh about it. You've gotta - you've gotta be empathetic with the parents because it's. it's scary laying here and you are carrying a baby all these months and you want the best for it and then one day, it's just up and coming out and you don't know why"</i> (Kavanaugh et al. 2005) [56]</p> <p><i>"So sensitive, he did it really well"</i> (Alderson et al. 2006) [49]</p> <p><i>"The entire staff cared for, not just our son, but our family individually"</i> (Baughcum et al. 2017) [60]</p> <p><i>"There are so many little things you guys have done and really means a lot. We had amazing nurses who really care. I think it was a phenomenal experience from [the] depths of tragedy"</i> (Baughcum et al. 2017) [60]</p>
<p>Emotions</p>	
<p>Barriers</p>	
<p>Emotional overwhelm, shock, dissociative state of mind hindering parents' ability to process information and make rational decisions [43-46, 48, 49, 54, 56, 59, 61, 62, 64]</p>	<p><i>"I was in shock.... The doctor did tell me all the problems but you don't really think about it deeply"</i> (Drago et al. 2018) [46]</p> <p><i>"When it happens, you're all mixed up, you just don't know... Somebody has to help you"</i> (Payot et al. 2007) [64]</p> <p><i>"I mean they were great doctors and nurses but I really can't remember what was discussed because I was scared. I knew she was going to pass away but I still had a glimmer of hope. I'm sure they did discuss genetic things but I was in the mindset where I didn't want to hear that because everything is going to be okay"</i> (Boss et al. 2007) [62]</p> <p><i>"At the time, all the emotions were different. I would have accepted a child with all the handicaps in the world, although I know very well today that that would not have been good for anyone"</i> (Caeymaex et al. 2011) [61]</p> <p><i>"It has a supernatural feeling. You don't really realise anything. Me, I said yes to everything. We were acted on, not actors"</i>(Caeymaex et al. 2011) [61]</p> <p><i>"It might be immoral to push you to make a decision... you were too tired to make. Maybe six months later there is a kind of sobering-up process. Maybe if she were still in [the] situation, critical, being sustained like that, with no hope or little hope, I would start to think differently"</i> (Pinch 1990) [43]</p> <p><i>"I so to speak just watched as if I was not involved... the entire time, I was personally affected but I did not experience it that way. It was like watching a movie. I was not really aware, and I could not really perceive the situation. It was as if in a dream, it could not be true, everything was fine. It took a while before I completely understood that it was my child, my child which was dying"</i> (Hendriks and Abraham 2017) [48]</p>

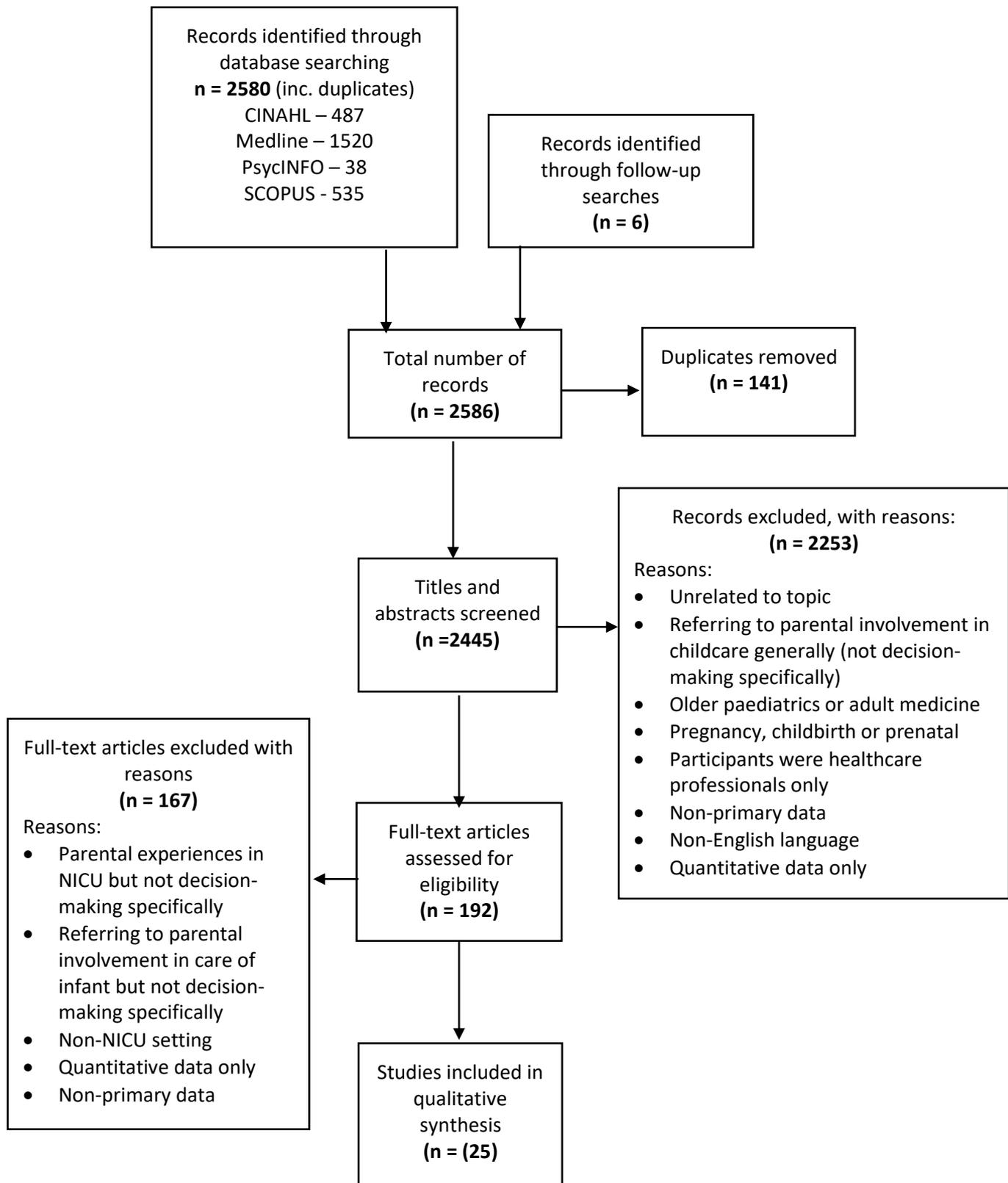
	<p><i>"At that point of time I wanted them to do anything that would save my child. I didn't manage to think about whether or not she would have a good life, that there was perhaps nothing to save her for. I would have saved her at any price.... I don't think that then and there I could decide"</i> (Brinchmann et al. 2002) [54]</p> <p><i>"Honestly when she told me, I really heard nothing that they said...So most of the time I'm crying and I really didn't want to talk about it anymore. I heard the most from the specialist. I heard it again and recognised what I heard"</i> (Kavanaugh et al. 2005) [56]</p> <p><i>"She [the physician] came out and she was telling me that... I was really upset... I didn't understand exactly what she, when I get upset I don't understand what people are saying. I have to stop crying first and then understand. Because you are so overwhelmed, you are crying, you are upset. A lot of stuff will slip past you what the doctor is saying... and they may have said it or may have informed me what was going on, I didn't hear it"</i> (Kavanaugh et al. 2005) [56]</p>
<p>Guilt [54, 61, 64, 66]</p>	<p><i>"It's not something we want. It's like, the final decision we make, it's us that live with it, so we are the ones who are responsible... so of course, we are the ones who live with the responsibility"</i> (Payot et al. 2007) [64]</p>
<p>Fear of making the wrong decision [50, 54, 61]</p>	<p><i>"Sometimes I was very afraid about what to do... With the surgery, I didn't know if it was good. His sister had the same one and she died in surgery"</i> (Orfali and Gordon 2004) [50]</p> <p><i>"The doctor said to me 'your opinion is of course important, and your decision will be equally important, but you should know that the medical team also has an opinion and a decision'. That was good. I said to myself, Thank god, it isn't me who has to decide. Because I had just been thinking what a real, total fright it would be to decide alone"</i> (Caeymaex et al. 2011) [61]</p>
<p>Parents not wanting to be involved in decision-making because of the weight of responsibility [50, 54, 55, 61, 64, 66]</p>	<p><i>"I can't say more than that I think it was a good thing we were spared from making a decision"</i> (Brinchmann et al. 2002) [54]</p> <p><i>"It's not something we want. It's like, the final decision we make, it's us that live with it, so we are the ones who are responsible... so of course, we are the ones who live with the responsibility. So you have to be supported and guided."</i> (Payot et al. 2007) [64]</p> <p><i>"Parents cannot make end-of-life decisions. I do not want that"</i> (Einarsdottir 2009) [66]</p> <p><i>"The doctors say to us: 'It's your choice. We are leaving the decision to you'. And finally, that is very very hard. I don't think it is a good thing"</i> (Caeymaex et al. 2011) [61]</p> <p><i>"The doctor said to me 'your opinion is of course important, and your decision will be equally important, but you should know that the medical team also has an opinion and a decision'. That was good. I said to myself, Thank god, it isn't me who has to decide. Because I had just been thinking what a real, total fright it would be to decide alone"</i> (Caeymaex et al. 2011) [61]</p>
<p>Continuity of Care and Caregivers</p>	
<p>Barriers</p>	

<p>Lack of continuity of care and caregivers [44, 47, 48, 50, 52, 60]</p>	<p><i>"We spent forty-five minutes, an hour with (consultant) agreeing what the plans going to be, and the following week, the first thing that was done, the first consultant on board threw the plan out the window"</i> (Gallagher et al. 2017) [47]</p> <p><i>"The nurses and attendings are all good, but it seems like information isn't passed along like it should be"</i> (Orfali and Gordon 2004) [50]</p> <p><i>"I wish they would stop switching doctors"</i> (Orfali and Gordon 2004) [50]</p>
<p>Facilitators</p>	
<p>Same caregivers throughout [47, 48, 56, 61]</p>	<p><i>"All 10 days, this paediatrician was there. She was really a person with whom we made decisions, choices and she was there for us in the last seconds. She shared everything with us"</i> (Caeymaex et al. 2011) [61]</p>
<p>Tailored Decision-Making Approach</p>	
<p>Facilitators</p>	
<p>HCPs considering parent/family's personal situation, values and wishes [51, 58, 60, 61, 64]</p>	<p><i>"The doctor left me with the choice. He explained to me the risks of these choices. He told me, you already have a three-year-old daughter. He stayed in the context of our little family: for the child, for me, for the family"</i> (Caeymaex et al. 2011) [61]</p> <p><i>"She seemed to know about me. She had read my chart and that meant a lot to me because she made the effort to understand my case"</i> (Daboval et al. 2016) [51]</p> <p><i>"It was technical for my husband, when it had to be technical for him. When they turned to me, they knew, they must have understood, I suppose, that for me, it wasn't a technical thing... they had to be more human, had to be more emotional, more sensitive. The woman, she spoke more, like a..., like a mother. And that's exactly what I needed. So she gave us both the same information, but in different terms, in a different tone. She adapted to each of us. It was very... very respectful of our situation, of the kind of information or support we needed. But with my husband, she was more, I would say, professional-technical, using clear, understandable words. I mean, easy to understand. And with me, she spoke with a more... maternal tone"</i> (Payot et al. 2007) [64]</p> <p><i>"The entire staff cared for, not just our son, but our family individually"</i> (Baughcum et al. 2017) [60]</p> <p><i>"She [the doctor] said 'you know it is your decision. I can [make] you recommendatios. We will do whatever you want to do. We can support him, take him off the ventilator'... I think we felt like we had complete control. So much [is] out of control that, to at least feel like you can carry out your last wishes to the best of your ability for you child is very comforting"</i> (Wocial, et al. 2000) [58]</p>
<p>HCPs eliciting parental expectations and desires regarding their level of involvement in decision-making and what information</p>	<p><i>"He is supportive and he asked me that too. He asked me how I thought he could support me and I said basically tell me the truth and just be there for me"</i> (Daboval et al. 2016) [51]</p> <p><i>"I think that on certain occasions the doctors should perhaps take the initiative to work out an agreement with parents such as 'Shall I bother you with all the details that worry me, or shall I not say anything, or shall we try to find a good middle ground about what I tell you?'"</i> (Brinchmann et al. 2002) [54]</p>

they want to receive [48, 51, 54, 60, 64]

"Tailor your information output to the audience. I know that doctors have their own way of delivering information they think is beneficial to everybody. But not every audience receives it in the same way. Getting to know the parents a little bit and what they can handle might not be a bad idea" (Baughcum et al. 2017) [60]

Figure 1: PRISMA flowchart of selection process



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