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Parental Roles in Early Detection and Long-Term Care of Necrotizing Enterocolitis

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ABSTRACT

Necrotizing Enterocolitis is a devastating disease of the gastrointestinal tract, where full-thickness necrosis develops through processes that remain uncertain, and with early diagnosis, a patient's prognosis can be improved. However, parents are the primary caregivers of neonates; they may be best positioned to identify early signs of necrotizing enterocolitis, and their involvement is fundamental. **Objectives:** To evaluate the role defined by parents in the early recognition of necrotizing enterocolitis symptoms in the relevant neonates, as well as the potential suggestions from parents on how their involvement could impact early recognition, management, and outcomes of the disease. **Methods:** The literature used in this review paper is selected from PubMed, Scopus, CINAHL, and Google Scholar. The search method included using terms such as "Necrotizing Enterocolitis," "parental involvement," "early detection," "educational programs," and "premature neonates". Studies from qualitative and quantitative were selected and published within five years. A total of 1200 articles were selected, and after removing duplicate studies, 850 articles were sought. Consequently, 50 articles were introduced in the final review. **Results:** The results indicated that parents play an important role in identifying the early signs of Necrotizing Enterocolitis in premature neonates. Research emphasizes educating parents on recognizing these warning signs and encouraging prompt communication with healthcare services. **Conclusions:** It was concluded that the crucial role of parental enlightenment and education about symptoms of Necrotizing Enterocolitis, as well as liaison with the healthcare providers, would ensure that early diagnosis and treatment for an increase in newborn survival chances take place.

INTRODUCTION

Necrotizing enterocolitis (NEC) is a disorder of the intestines that typically affects preterm, very-low-birth-weight infants and is characterized by rapid onset, progression, and potential dead-end complications, including intestinal perforation, septicemia, and high mortality rate The precocious diagnosis becomes then quite necessary because the early treatment can change the course of a so simple and fragile patient. This review demonstrates the crucial part parents play in early identification of NEC by describing how vigilant observation, even on minor changes from parents, could lead to early diagnosis and subsequent outcome. Severe NEC results in large numbers of infants being taken for surgery because of intestinal perforation and often leads to a lethal outcome, but it can be treated immediately if diagnosed at an early stage. General NEC symptoms are abdominal discomfort, vomiting, feeding difficulties, and tiredness [1]. This post examines the presentation, scoring, and management of neonates with necrotizing enterocolitis. It also states that it would be a demand to treat the patients with Crohn's Disease (CD) as an inter-professional team [2]. NEC greatly increased neonatal morbidity and mortality. Reported mortality rates range from 20 to 40%, and long-term sequela can be poor with significant developmental delays, including short bowel syndrome [3]. Longer hospitalizations, repeat surgeries, and ongoing feeding problems are common among NEC survivors. Therefore, early recognition and treatment are necessary to minimize morbidity and maximize survival in the neonate [4]. The exploration research study looks to

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measure the feasibility of involving parents in early identification and whether parental perspectives can contribute to the early initiation of nonverbal cognitive impairment[5].

This study aims to identify and synthesize the published evidence on how parents can help in the early detection of NEC in premature infants, up-to-date the literature specifically related. The literature on this subject specifically addresses whether parents can act concerning NEC and its early diagnosis. The paper also highlights the gaps in the available literature explains the importance of such an issue for the practice, and proposes further research efforts[6].

METHODS

The research was conducted using the sourced articles from various databases including Pub Med, Science Direct, CINAHL, and Google Scholar. The search parameters included the words 'NEC', 'parental involvement', 'early detection', 'educational programs', and 'premature neonates'. All the studies have been conducted over the last five years and included both qualitative and quantitative approaches. Out of the initial 1200 articles identified through database searches, some of the duplicates were removed, leaving about 850 studies. Out of these, 338 articles were selected for full-text eligibility deserving full review. Ultimately, 22 studies were selected where the topic of parental involvement in the early detection of NEC in premature infants was addressed. Both qualitative and quantitative studies were combined to help further understand how parents were involved in noticing the signs of NEC. This approach is not only beneficial to the data but also aids in the development of evidence-based practices in the field. The Prisma chart is drawn for this study(Figure 1).

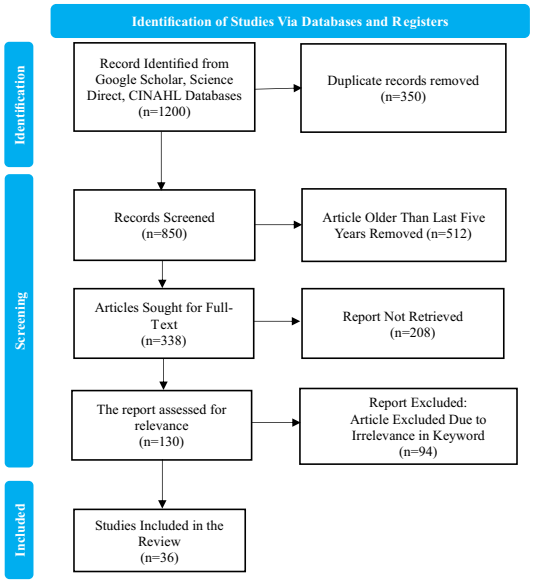

Figure 1: Studies Involved in This Research

RESULTS

The analysis of the reviewed literature revealed that the roles of parents in the identification of early signs of NEC. showed feeding problems, unusual irritability, disruption of sleep patterns, and abdominal distension are some of those early warning signs of NEC [11]. Therefore, the parents were the first persons to observe these warning signs frequently. Results show the studies that have been reviewed cover a wide range of methodologies such as surveys, cross-sectional studies, qualitative research, and review papers. Examining the range of methodologies may help understand the perceptions of populations such as parents of infants with NEC and health professionals on the condition. Additionally, knowing the geographical location helps in understanding cultural and systemic influences on parental involvement and healthcare delivery(Table 1).

Table 1: The Methodological characteristics of the reviewed studies

Author	Year of Study	Study Design	Study Population	Country
[2]	2017	International Survey	Parents	USA
[4]	2022	Qualitative Study	Parents	USA
[6]	2019	Interventional Study	Infants	Canada
[7]	2019	Review	Unknown	-
[8]	2020	Cross-sectional study	Parents	Italy
[9]	2022	Review Paper	-	China
[10]	2023	Commentary	-	-
[11]	2019	Review	-	USA
[12]	2023	Review	-	UK
[13]	2023	Reference Work	-	-
[14]	2023	Review paper	Unknown	-
[15]	2023	Survey	Survivors and parents of NEC	USA
[16]	2020	Review	Infants And Risk At NEC	USA

Parenting an at-risk newborn for developing NEC is emotionally and psychologically stressful [7]. Research studies have already pointed out that parents repeatedly worry and feel anxiety, primarily because they do not know when to detect and deal with a potential health issue involving their child [8]. According to the study conducted in Thailand, Parents experience more anxiety and confusion during the transition phase after the discharge from the hospital[17]. The parents are generally unaware of the NEC early warning signals and cannot request medical attention in time. Therefore, the infants are delayed in proper treatment, which causes a very high morbidity and mortality rate [9]. The reviewed studies highlight several key aspects related to parental roles and challenges in recognizing and responding to early warning signs of NEC. These studies underscore the need for enhanced educational initiatives targeting parents to equip them with the skills necessary to identify symptoms promptly

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and advocate for their child's health effectively. The summary of the literature is presented (Table 2).

Table 2: The Summary of the Key Findings of the Reviewed Studies

Key Aspects	Findings
Early Warning Signs	Early warning indicators of NEC, including irregular sleep patterns,unusual irritability, feeding issues, and stomach distension, are commonly noticed by parents.
Emotional impact on Parents	Anxiety over identifying health problems arises from the emotional and psychological strain of raising a baby who is at risk of getting NEC.
Challenges in the diagnosis	Despite improvements in medical technology, NEC symptoms remain ambiguous, making early identification more difficult. Early warning indicators are frequently missed by parents, which delays treatment and raises rates of morbidity and mortality.
Need for Education	There are very few parent education programs available about NEC. Formal curricula that teach parents how to recognize warning indicators are scarce in research, even though they potentially increase the rates of early diagnosis.
Clinical diagnosis challenges	NEC's clinical diagnosis is made more difficult by its comorbidity with other intestinal diseases. Although there are numerou scoring systems that can achieve sensitivity and specificity of up to 96%, their therapeutic potential is not fully realized.
Prognosis of NEC	Total mortality rates range from 10% to 50%, and the prognosis is contingent upon the severity of the disease at diagnosis and the start of treatment.] Because of the significant intestine damage, advanced instances might result in 100% fatality. The improvement of results depends on early detection.
Parental involvement initiatives	To raise parental involvement in care standards and educate them about probiotics, educational activities have been put into place. Parents are in a good position to identify early symptoms that medical experts may overlook.

Although prevention programs are highly promising, parents often lack the training and support necessary to effectively manage the complications [7]. Only a few studies report formalized curricula of instruction-teaching parents on identifying warning signs for NEC. Such education significantly enhanced early detection rates and the duration of intervention by health professionals [10]. Many studies have revealed that the etiology of NEC is unknown. There are no specific treatments, and regulatory science is an essential step in advancing drug development [11]. The clinical diagnosis of NEC is still problematic because of overlap with other intestinal pathologies, such as septic ileus and localized intestinal perforation. The sensitivities and specificities of these models are now up to 96%. The therapeutic value of these models has not been optimally used [12]. The prognosis of NEC is dependent upon the severity of the disease at the time of diagnosis and the start of therapy. Total mortality is within the range of 10% to 50% [13]. Therefore, early detection plays an important role in early treatment and improves its prognosis and the parent is an important key in early identification. The lives of survivors and their families are, however, impacted years after the survivors have been discharged from the NICU, causing a reduction in their general quality of life and affecting their emotional, physical, and social health [14]. Resources and tools endowment by health care providers to families will help them cope with the long-term effects of the condition and ensure appropriate follow-up treatment from infancy up to adulthood. Better family support and all-rounded, quality care should be offered to patients of NEC by being aware of the long-term implications of the condition [15]. Moreover, studies also revealed that survivors of severe NEC often lack severe neurodevelopmental disabilities, allowing them to go to school. Thus, ongoing follow-up care and developmental assessments of children who are victims of NEC become paramount. The role of parents is significant in this aspect as they make sure their child goes to scheduled check-ups, attends developmental screenings, and undergoes any necessary therapies. The long-term effects of NEC on the patient may be made more comprehensible to parents if they are informed about such long-term consequences [18, 19].

DISCUSSION

The role of parents in early NEC diagnosis is considered an important component of neonatal care as a primary caregiver. Parents, especially mothers can play a critical role in the early identification of NEC and its long-term management [20]. Based on the literature review, there should be structured educational programs for parents, as it is important to raise the parent's awareness of the symptoms of NEC, such as feeding intolerance, abdominal distention, and change in stool pattern, so that the condition can be recognized with early intervention [1]. The result findings also indicate the significant gap in educational initiatives for parents of neonates diagnosed with NEC. Parents and caregivers lack sufficient information regarding NEC's symptoms, treatments, and potential long-term consequences. This lack can lead to challenges in identifying the condition promptly, which is important to delay the diagnosis, which results in severe complications. deficiency in understanding can lead to challenges in recognizing the condition promptly, which is crucial given that delayed diagnosis can result in severe complications [21]. However, parents are unaware of how NEC will affect their child's physical, emotional, and social lives. The scarcity of educational resources makes it more

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difficult for parents to cope with the challenges of caring for an infant affected by NEC. Therefore, creating thorough educational reform programs for parents is essential, which includes follow-up care instructions, ways to monitor symptoms, and emotional support options for parents [3]. Also, a collaborative approach should be between parents and caregivers, as it can enhance the outcomes, which will emphasize early detection by the parents. Multiple studies define that parents take part in the early identification of NEC among infants, and their close observation of changes in their behaviour and physical state is the reason they hold a crucial position as the first responders in this respect [16]. According to the studies NICU bedside reading by parent's work is a significant factor that impacts mother-infant bonding and maternal stress. This implies with less stressful environment and enables parents to early indicators for the NEC through direct medical intervention. This will support the Healthcare systems in detecting early signs and symptoms and immediate medical intervention for NEC-diagnosed infants [22]. Well-supported and informed parents are most likely to understand early signs of complications and provide care according to the protocols recommended. Understanding the impact of stress on their parenting role will enable healthcare providers to design interventions to empower parents to take up more responsibility in caring for their children. The conclusions reached from this research indicate that the involvement of the parent is paramount for early recognition and long-term management of such illnesses in children like NEC [18, 23]. Moreover, a requirement for an international consensus in definitions of NEC, to further improve research and outcomes for patients in the setting of parental roles in early NEC detection, since accurate and standardized language will better help parents detect the signs of this disease [24 16]. Comparing the findings with previous studies reveals a consistent theme that parental involvement plays a vital role in the early identification of NEC. Research indicates that the healthcare professional has the ultimate responsibility in the diagnosing of NEC and parents play a pivotal role in identifying their infant's behaviour and health [25]. This aligns with the NEC-Zero Project and the Gut Check NEC toolkit emerging as an important tool in bridging communication gaps between healthcare professionals and patient families [4]. In addition, the NEC Passport helps the parents in addressing the substantial information gap [5]. Both these approaches will empower parents to act as early responders for early diagnosis of NEC, and also, it will support the families to understand and minimize the long-term challenges and complications. The initiatives should be introduced worldwide especially in developing countries to reduce the incidences of NEC. Also, Initiatives such as kangaroo care are beneficial for pre-term and low birth-weight infants who are at a higher risk for developing NEC. This initiative requires continuous educational program sustainability from healthcare providers for better outcomes to reduce the mortality rate for infants due to NEC [26]. Similarly, many infants experience an average fasting period of 24 days after the onset of NEC. Parents must remain cautious during this time, looking for symptoms of discomfort or feeding complications. Prompt recognition of signs like as intolerance to feeding or stomach distention may encourage parents to seek the advice of healthcare professionals earlier, resulting in quick evaluations and actions [24, 27]. Moreover, another study brings attention to the fact that the Mother's own milk (MOM) can reduce multiple premature morbidities, including NEC [26]. Support from partners and family is crucial in helping the mother sustain exclusive pumping and foster better outcomes for neonates [16]. This education can be disseminated among the parents. The psychological toll of caring for an infant with NEC extends well beyond hospitalization. Parents experienced a heightened level of stress and anxiety due to prolonged hospital stays surgical interventions, and ongoing follow-up care requirements [13]. Accordingly, when parents suspect problems, they should be entitled to seek the right diagnostic tests and act as an advocate for their child's health thus demonstration is important to ensure that the children receive immediate and effective treatment [16]. The impact on mental health can persist into childhood and remains beyond not only the survivors but also the families and the effect on their quality of life (QOL). Families frequently encounter inadequate support systems and barriers to specialized care, which attributed continued health problems to unrelated causes due to the time elapsed since the initial NEC diagnosis. Therefore, healthcare systems must provide adequate support for families navigating these challenges [16]. Integrating the principles of Family-Integrated Care (FICare) offers a helpful approach to addressing the parent's involvement while caring for an infant with NEC [28]. According to the FICare Plus model elements such as performing organized educational programs for parents, the provision of emotional support, and the inclusion of parents in active caregiving will enhance parental competencies regarding NEC care through constant mentoring sessions and emotional support programs [23]. These family-integrated care approaches will prioritize parental involvement to improve the long-term implications of NEC in neonates [29]. Educating parents about the possible long-term implications of NEC and the importance of early intervention may help reduce the emotional and financial burden that families may have to bear in the future [2]. It is essential to implement comprehensive educational reform by emphasizing symptom monitoring, continuous assessment, directions for follow-up care, and ways of

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emotional support [22]. Through the assessment, parents, being the primary caregivers, are in the best place to notice anything. Educating parents on early warning signs of NEC may bring in timely intervention that can help limit morbidity and mortality due to this disease [30]. However, parents should be educated on the nutritional management of NEC and feeding techniques once diagnosed. Parents would be able to actively participate in the care of their children, ensuring that all nutritional needs were met [31]. The coordination of these educational initiatives with the principles of palliative care can help healthcare systems better assist families in navigating the complexities of NEC. A palliative care framework would provide families with emotional and decision-making support to address the many challenges of cases with complex NEC. Initiatives that adopt a collaborative approach between parents and healthcare providers can empower parents to become active participants in early detection and long-term management. Such integration enhances parental confidence and fosters better clinical outcomes, including early diagnosis, reduced complications, and improved developmental trajectories for neonates affected by NEC [21]. Literature also suggests that along with the educational reforms financial assistance programs should be offered to the parents by the government and the community agencies to reduce the parent's burden and encourage them to participate in educational initiatives [16]. However, significant gaps exist in the literature regarding the long-term impact of parental involvement in NEC outcomes. There is no standardized course training for parents on these signs of NEC, which might still be a promising area for future research in enhancing parental engagement and safe neonatal care practices [32, 33]. Ultimately, a collaborative approach between health service providers and families may most likely improve health outcomes for vulnerable neonates [34, 35].

CONCLUSIONS

It was concluded that improving health outcomes for vulnerable newborns impacted by NEC requires a cooperative approach between families and healthcare professionals. We can promote earlier detection and intervention, which will ultimately lower the morbidity and mortality linked to this critical condition, by filling in educational gaps and increasing parental engagement through organized programs. In order to further empower families, future research should concentrate on creating standardized training procedures for parents and investigating efficient communication techniques within neonatal care systems.

Authors Contribution

Conceptualization: AAA[1]
Methodology: AAA[1], SS
Formal analysis: AAA[1], SS
Writing review and editing: AAA[1], AAA[2]

All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

All the authors declare no conflict of interest.

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