Information and Support Needs of Parents with Premature Infants: An Integrative Review

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Abstract

International research, while mostly conducted in high-income countries, repeatedly states that parents of premature infants have increased needs and require additional information and varied support channels after the infant's initial discharge from hospital. However, the perceived self-reported needs of parents concerned with the caregiving of premature infants during the initial time period at home after discharge are not well known. This integrative review explores all extant literature that embodies self-reported or parent-quoted perceptions, experiences and parent testimonials related to post-discharge infant caregiving information and support needs published from January 1990 to April 2019. Generated findings from the review that reveal parents, regardless of country, consistently reported unmet information and support needs, coupled with a lack of adequate community-based and healthcare professional support. Current gaps in literature are identified and recommendations for future research are also addressed.

Keywords: parent, premature infant, caregiving needs, post-discharge, low- and middle-income countries

Introduction

Following the birth of a premature infant, parents go on an unexpected journey through the neonatal intensive care unit (NICU) prior to the discharge to home. Parents of premature infants often need to relinquish their expectations of what constitutes the normal experience of having a healthy infant, and that may lower their self-confidence when identifying themselves as new parents (Aydon, Hauch, Murdoch, & Sharp, 2018; Hutchinson, Spillett, & Cronin, 2012). Although they may be excited and happy at discharge, parents may also feel anxious, insecure and unprepared to care for their premature infants. These feelings can continue long after the premature infants have been discharged from the hospital (Galeano & Carvajal, 2016; Hemati, Namnabati, Taleghani, & Sadeghnia, 2017).

Parents with premature infants experience unique needs related to caring for premature infants upon the initial discharge. These needs play a vital role in aspects such as their ability to cope with their parental roles and the relationship with their infant, their changing emotions, and managing their own personal needs (Boykova, 2016; Hutchinson et al., 2012; Toral-López et al., 2016). A baby's premature birth is often the single most determining factor of adverse outcomes related to the survival, quality of life, psychosocial and emotional impact on the family – regardless of differences in demographic and cultural environments (Boykova, 2008; Smith, Hwang, Dukhovny, Young, & Pursley, 2013).

The World Health Organization (WHO, 2015) states that close to 15 million premature infants are born across the globe every year, with more than 60% of premature births occurring in the lower- and middle-income countries (LMICs) in Africa and South Asia. In many of these countries, population data and medical records are often inaccurate and incomplete (Akhlaq, McKinstry, Muhammad, & Sheikh, 2016). Furthermore, a wide range of challenges such as

discrepancies and inequalities in healthcare, health disparities, human resource incompetencies and a general lack of awareness surrounding premature births has been identified (Mayosi & Benatar, 2014; Shrivastava, Shrivastava, & Ramasamy, 2016). The health and developmental needs of family members often go unmet as a result of limited resources and inadequate social support systems (Ataguba & Alaba, 2012; Ataguba, Day, & McIntyre, 2015).

Although very limited published literature exists about the parenting of premature infants in LMICs, there is global consensus that such countries have an urgent need to implement equitable and sustainable interventions for vulnerable families, such as those associated with the premature birth population (Chola et al., 2015; Galeano & Carvajal, 2016). Hence, the aim of this integrative literature review was to identify, synthesize and present the findings of selected international studies on the perceived information and support needs of parents regarding their caregiving for premature infants when discharged from hospital. These findings served to determine common themes directly connected to parenting and providing care for premature infants at home after the initial discharge. Findings from our review will be utilized as part of a conceptual framework to inform and provide recommendations to healthcare professionals in a LMIC who may seek to develop an early intervention (EI) program to support parents with premature infants.

Method

The integrative literature review is a method of research that explores, critically appraises, synthesizes, and presents the findings in literature to provide a more comprehensive understanding or generate new knowledge and perspectives on the phenomenon being researched (Anthony & Jack, 2009; Torraco, 2016). In this study the integrative review guided the analysis

and synthesis processes to assess what is currently known about the post-discharge period and the support needs of parents with premature infants. We also aimed to identify gaps in current research and suggest future research that targets parents with premature infants and possible associated EI programs (Torraco, 2016; Whittemore & Knafl, 2005).

Procedure

This integrative literature review employed the frameworks of Cooper (1982) (who conceptualized the integrative review) and Whittemore and Knafl (2005) (who revised the integrative review) by expanding on the data analysis and synthesis stage to enhance the systematic nature and rigor of the process. The 5-stage method that was used, incorporated actions to construct the review question, develop a search strategy, critically appraise the literature, analyze and synthesize the data, and present the findings.

The review question

The review question was constructed by utilizing the population, intervention or interest, outcome and time frame (PIOT) format (Davies, 2011). The population (P) refers to all published documents that targeted parents with premature infants, while the intervention or interest (I) is all self-reported or parent-quoted information and support needs that parents stated in relation to caring for premature infants. The outcome (O) refers to studies that reported on different types of parent outcomes (perceptions, experiences, parent testimonies, parent-infant interaction, caregiving information, caregiving support), while the time frame (T) focuses on literature published from January 1990 to April 2019.

Based on the outcomes of the PIOT, the following review question was formulated: "What is stated in published literature regarding the perceived information and support needs as reported by parents relating to the caregiving of premature infants after the initial discharge to home from hospital?"

Search strategy

The second stage in the review process was to develop a search strategy. The inclusion criteria were identified as all published literature relevant to the perceived needs regarding information and support stated by parents with premature infants. The types of literature considered for this review were qualitative (ethnographic, narrative, phenomenological, grounded theory and case study) and quantitative (descriptive, correlational, non-experimental and experimental). This included systematic reviews, documents, reports, interventions, components or strategies such as parent participation, reviews, theses and dissertations. The literature search targeted dates from January 1990 to April 2019, when the concept of the family-centered approach (working with parents to support and strengthen their unique parental abilities) was firmly established (Zigler, 2000).

Exclusion criteria

Only documents published in English were considered for the review. The exclusion of non-English literature was because of language barriers on the side of the reviewers and the high cost associated with translating the documents to English. Books, prefaces, postscripts, letters to editors, editorials, and duplicate studies were excluded. During the search stage of the review, documents or studies that did not mention parent information or parent support needs in the title,

abstract or text were excluded. Titles of each study or article were read to determine relevance to the study topic. Studies or articles were excluded if they were not accessible to the researcher via the university's library or via inter-lending options.

Literature search

Studies were collected using multiple data platforms, while a clear description of inclusion and exclusion criteria guided the search process and ensured a clear audit trail of the search process (Harbour, Lowe, & Twaddle, 2011). The search was conducted from January to April 2019 on five individual data platforms, namely CINAHL, Health Source (Nursing/Academic Edition), MEDLINE, PsycINFO and ProQuest.

The search strategy followed the Boolean/phrase approach of combining any search terms and keywords with operators such as AND, NOT, OR and the wild card symbol (*) to yield more relevant results. The following search strategies were used: parent* AND prem* OR preterm AND infant OR baby AND information needs OR support needs AND care* OR caregiv* AND discharge OR post-discharge. A total of 1230 records were identified on the said five data platforms. Along with the electronic data platform search, a hand search of reference lists of selected records and a Google Scholar general search were conducted to search for additional documents or studies that could be considered for inclusion. Through the additional searches, an extra 31 studies were found that fitted the inclusion criteria for the review. Of the 1261 selected records, 46 were duplicates that were removed (Figure 1).
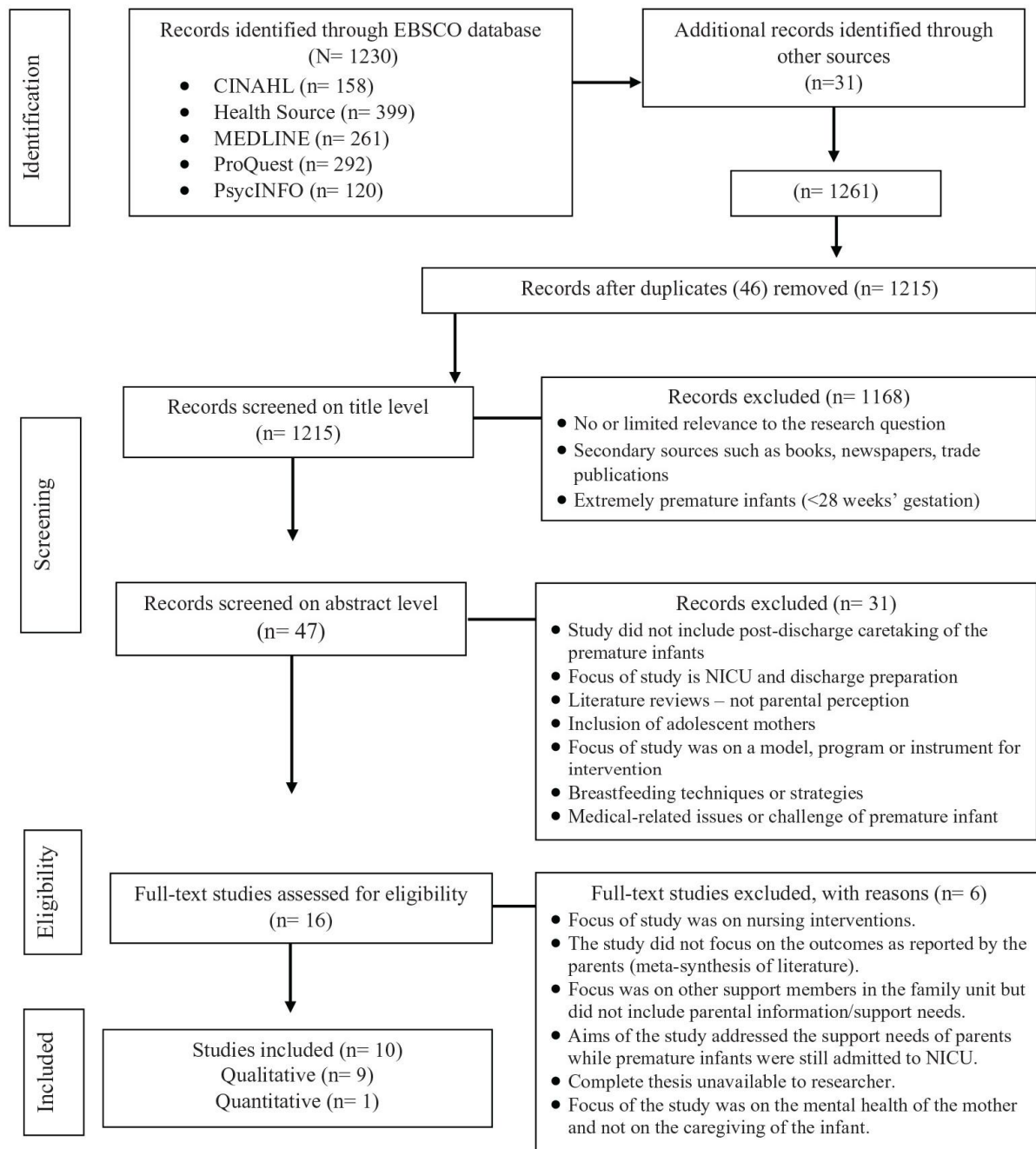
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┌──────────────┐   ┌─────────────────────────────────────┐   ┌─────────────────────────────────┐
│              │   │  Records identified through EBSCO   │   │  Additional records identified  │
│ Identification│   │        database (N= 1230)           │──→│       through other sources     │
│              │   │    • CINAHL (n= 158)                │   │            (n=31)               │
│              │   │    • Health Source (n= 399)         │   └─────────────────────────────────┘
│              │   │    • MEDLINE (n= 261)               │                     │
│              │   │    • ProQuest (n= 292)              │                     ↓
│              │   │    • PsycINFO (n= 120)              │        ┌─────────────────────────┐
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│          │   │ Records screened on title│   │     Records excluded (n= 1168)              │
│          │   │     level (n= 1215)      │──→│  • No or limited relevance to the research  │
│          │   └──────────────────────────┘   │    question                                 │
│          │                                   │  • Secondary sources such as books,         │
│          │                                   │    newspapers, trade publications           │
│          │                                   │  • Extremely premature infants (<28 weeks'  │
│          │                                   │    gestation)                               │
│Screening │                                   └─────────────────────────────────────────────┘
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│          │   │ Records screened on      │   │     Records excluded (n= 31)                │
│          │   │ abstract level (n= 47)   │──→│  • Study did not include post-discharge     │
│          │   └──────────────────────────┘   │    caretaking of the premature infants      │
│          │                                   │  • Focus of study is NICU and discharge     │
│          │                                   │    preparation                              │
│          │                                   │  • Literature reviews – not parental        │
│          │                                   │    perception                               │
│          │                                   │  • Inclusion of adolescent mothers          │
│          │                                   │  • Focus of study was on a model, program   │
│          │                                   │    or instrument for intervention           │
│          │                                   │  • Breastfeeding techniques or strategies   │
│          │                                   │  • Medical-related issues or challenge of   │
│          │                                   │    premature infant                         │
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│Eligibility│  │ Full-text studies        │   │ Full-text studies excluded, with reasons    │
│          │   │ assessed for eligibility │──→│              (n= 6)                         │
│          │   │ (n= 16)                  │   │  • Focus of study was on nursing            │
│          │   └──────────────────────────┘   │    interventions.                           │
│          │                                   │  • The study did not focus on the outcomes  │
└──────────┘                                   │    as reported by the parents (meta-        │
                           │                   │    synthesis of literature).                │
                           │                   │  • Focus was on other support members in    │
┌──────────┐               ↓                   │    the family unit but did not include      │
│          │   ┌──────────────────────────┐   │    parental information/support needs.       │
│ Included │   │ Studies included (n= 10) │   │  • Aims of the study addressed the support  │
│          │   │ Qualitative (n= 9)       │   │    needs of parents while premature infants │
│          │   │ Quantitative (n= 1)      │   │    were still admitted to NICU.             │
│          │   └──────────────────────────┘   │  • Complete thesis unavailable to researcher│
└──────────┘                                   │  • Focus of the study was on the mental     │
                                               │    health of the mother and not on the      │
                                               │    caregiving of the infant.                │
                                               └─────────────────────────────────────────────┘
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Figure 1. PRISMA diagram for retrieval strategies and exclusion criteria (Moher et al., 2009).

Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses; NICU = neonatal intensive care unit.

For the selection process, the remaining 1215 potential records were assessed on the title level and a total of 1168 records were excluded for not meeting the inclusion criteria. A total of 47 potential documents/articles were then screened on the abstract level by the first two authors. Altogether 31 records did not meet the inclusion criteria, which means that, eventually, 16 research articles were suitable for inclusion in the critical appraisal phase of the review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009) set of items was utilized to report on the retrieval process that was followed for the inclusion of studies in the review (see Figure 1).

Critical appraisal of literature

The third stage ensured that the results of the selected studies were credible and useful to inform current healthcare professional practices as well as future research. In the critical appraisal process, the first two authors evaluated all the components of a study, including the introduction, method, findings and discussion. The trustworthiness, credibility, congruency and transferability of the qualitative studies' findings were carefully and systematically determined (Burls, 2014; Porritt, Gomersall, & Lockwood, 2014). Content validity in the quantitative studies were also assessed to ensure the developed self-reported instruments to collect data adequately represented the scope of the study's intended content (Beck & Gable, 2001). The methodologic quality of all 16 selected studies were assessed by means of a checklist, the critical appraisal tool, namely the System for the Unified Management, Assessment and Review of Information (SUMARI) developed by the Joanna Briggs Institute (Munn et al., 2019). The 16 studies selected for critical appraisal of their full text were independently assessed by the first and second authors, who both have experience in the systematic review of studies for methodological rigor.

The procedure required the independent assessors to check responses (yes, no, unclear or NA) against the 10-question checklist to determine inclusion or exclusion of selected studies. After discussion, the two authors were able to reach agreement about the selected studies for inclusion in the review, therefore a third critical reviewer was not necessary. The results of the critical appraisal revealed that 10 studies were suitable for inclusion in the review.

Analysis and synthesis

In stage four of the review, an inductive thematic analysis was conducted by using ATLAS.ti.8, a Computer-Assisted Qualitative Data Analysis software (CAQDAS), to develop a coding system for the findings obtained from the 10 selected studies (Fereday & Muir-Cochrane, 2006; Friese, Soratto, & Pires, 2018). Initial codes were identified on a semantic level with surface-level meanings. The process of initial coding was conducted independently by the first author and yielded 64 codes. The second author also independently coded the studies to increase inter-coder reliability and agreement of the codes (Campbell, Quincy, Osserman, & Pedersen, 2013). Together, the two authors went through the process of re-reading the coded words or phrases to rename, split and merge codes. This resulted in 46 codes.

The grounding (mentioning) of the codes occurred a total of 553 times throughout the 10 studies. A third coder (author 3) was asked to review the final codes to ensure that they accurately represent the literature on hand. The determined codes, the number of times the codes were grounded from the most mentioned to the least mentioned, and examples of direct quotes obtained from parent participants in the 10 selected studies are illustrated in Table 1.

Table 1

Codes, grounded (number of times mentioned), and direct quotes by parent participants in selected studies

Codes	Grounded	Direct quotes by parent participants in selected studies
1. Sources for information and support	37	"So really breastfeeding was my salvation… There is a group run by mums to support you with breastfeeding… it is really good, and it makes all the difference."
2. Feelings associated with fear	37	"I was ecstatic, but terrified at the same time. I remember being confident that I was ready to care for them, but terrified that something would happen, and they would have to be readmitted."
3. Support received/requested from healthcare professionals	33	"I think it would have been helpful to have a nurse visit the home once or twice in the first month after being discharged from the hospital, just to help parents feel like they are on the right track with care."
4. Initial emotions experienced post-discharge	32	"My life turned upside down. I was EXCITED to finally have him home. Couldn't believe he was mine. I was SCARED that I wasn't doing the right things for him. I was very nervous."
5. Infant digestion	21	"I thought he should have at least one or two [bowel movements] a day. He's only had about three in seven days since he's been home...I don't know if that's normal. I'm not really sure you know."
6. Parent-infant interaction	20	"When it came round to just being with him and playing with him we didn't really know what to do."
7. Support and information given by others	20	"I think it was [useful] because there were so many different opinions and it's run by other mums, it was different parents' saying 'yes, my baby did that, or my baby did this' – so reassuring."
8. Feelings of stress or anxiety	19	"I just came home really stressed — jumping out of a sleep to check if he was still breathing…"
9. Exhaustion/fatigue	17	"It was exhausting being alert for signs of distress all the time."

Codes	Grounded	Direct quotes by parent participants in selected studies
10 Types of support wanted from healthcare professionals	16	"I would have liked having someone experienced in working with premature infants so if I had a question, I could ask and not worry."
11 Breastfeeding	16	"Breastfeeding was our biggest challenge. We worked our hardest with breastfeeding using the pump, nipple shields and not being able to latch properly, I had gotten thrush, nipple cracks, and bleeding nipples, blisters, and mastitis."
12 Information received/requested from healthcare professionals	16	"I think if there had been more education about the benefits he could receive with Medicaid, it would have helped. With his feeding issues, we really struggled to buy his food and pay our bills. We didn't find out until much later that he could have gotten WIC."
13 Infant illness or infections	15	"I think I can never quite shake the feeling that something might go wrong. Where she was so ill before ...I'll be adamant about people not coming in with colds and flu or even if they have a bit of a sniffle...You know I'm scared to death about it."
14 Schedules and routines	14	"Life after my son came home was very stressful. We had a strict feeding schedule and a strict medication schedule to keep. We also had many doctors and therapists to juggle. At one point he had five or six specialists, a home nurse and six therapists."
15 Feelings of worry	14	"We were constantly checking to make sure he was breathing, and we were always worried something was wrong."
16 Social disruption	13	"My husband and I were home-ridden and fearful of leaving our child alone with anyone. We never took our child anywhere because we were afraid any little bug would kill him."
17 Sleep deprivation	13	"The first month or so I feel like we slept with one eye open making sure she was still alive and breathing. I guess I felt hyper vigilant, paranoid that anything different might mean something was wrong."
18 G-tube feeding	12	"My husband and I were feared. When he cried and got red, we thought that his tube might be displaced, [therefore], we breastfed him, he cried so much."
19 Infant breathing	12	"Her grunting always seems to confuse me. Instinctively they don't sound right... For some reason she has these scrunchy sounds.... She'll bunch up sometimes looking in pain...I don't know if it's gas or whatever."

Codes	Grounded	Direct quotes by parent participants in selected studies
20 Developmental milestones/adjusted age	12	"There were also the issues of knowing when and what to adjust due to their prematurity."
21 Lack of support from family/friends	12	"I think some sort of support group afterwards would have been helpful. I wasn't given any online groups or information about local help."
22 Infant crying/fussiness	10	"But sometimes she cries and someone gives her the bottle and she refuses it, she doesn't want it. Then, we know that she is suffering from pain."
23 Responding to an emergency	10	"Like, what would I do if she had a bad one. Because I know you have to bag them or something...what would I do at home if it happened to her? Would I be able to make it to the hospital?"
24 Using monitors at home	9	"The inconsistencies in the functioning of the monitor caused additional stress and fear to our days."
25 Supplemental milk feeding	9	"For whatever reason, he just didn't get enough from in [breastfeeding], and we have had to supplement him almost all of the time. Now at 6 months adjusted, we are accepting that he doesn't get enough from it and are moving to formula and using the last of the frozen pumped milk."
26 Difficulties in sharing feelings	8	"I found it extremely hard to share with people. No one understood."
27 Topics difficult to find online by parents	8	"We struggled to find the information we needed on how to care for our premature son and how to understand his developmental milestones."
28 Learning needs of parents	8	"…steep learning curves — learning how to administer all the meds, learning how to use the g-tube, learning how get from place to place with oxygen, monitor, diaper bag, medical records folder, feeding pump, feedings and meds…"
29 Feelings of guilt	7	"I have lingering guilty feelings that I did this to them, but there are worse things than being tired. I just take everything day by day and hope that I'm doing things right!"
30 Social isolation	7	"There is this thing about feeling institutionalized and sometimes a feeling of isolation."

Codes	Grounded	Direct quotes by parent participants in selected studies
31 Spousal/partner relationships	7	"It might not be just as soon as you come home but I remember the first time my husband and I decided to go somewhere after we came home…I think it's important to do something."
32 How much to feed infant	7	"When she came home from the hospital, they said feed her every three hours – two ounces every three hours. And since she's been home, she doesn't want two ounces every three hours. So, it's kind of touch and go."
33 Sleep awake/patterns of infant	7	"I was concerned that she was getting enough rest or if she was sleeping longer than she should between feedings."
34 Expected behaviors of premature infants	6	"I didn't know that premature infants may grunt, groan, sneeze and hiccup or that they may have a slightly irregular breathing pattern than full term infants."
35 Misunderstanding from others	6	"Although people knew that our son was born premature, only we knew what the potential risks involved were when exposing him to the real world and with people who didn't understand why we were asking them to wash their hands and they would look at us funny."
36 Dressing/keeping infant warm	6	"We were like Goldilocks and the three bears because we had him probably too cold the first night. And then the next day it was really hot, it was really humid, and we had the heat on in the house and we had him bundled up. And he was so warm."
37 Taking infant outside of home	6	"I was afraid about him on the first couple of nights."
38 Impaired decision-making abilities	5	"Challenges in the first months after discharge included learning how to care for a baby on our own without nurses or doctors. We were used to having someone to answer our questions on a daily basis and when we were at home, we didn't have that."
39 Giving infant medication	5	"I was also concerned about the strength of the medication and they had shown us how to accurately measure it, so you were always afraid of giving him the tiniest drop extra and being a first-time mother added to it."

Codes	Grounded	Direct quotes by parent participants in selected studies
40 Changing diapers/rashes	4	"Nappies are such a big concern and you're always thinking is this normal? Is there something wrong with her?"
41 Infant weight gain	4	"I remember calculating [feeds], figuring out by their weight how many ounces they should be on; I became totally obsessed with that and recording every single time they fed and how much milk they took; they want them to gain weight so you become obsessed with making sure they do gain weight."
42 Home environment temperatures	4	"…well, if the baby girl is cold, she'll spend more energy and will lose weight, but what is the idea? The idea is that she gains weight, so she is not kept in the hospital…"
43 Well-being of other family members	3	"It was strange getting back to 'normal', because things weren't going to be normal anymore. My husband and I both had three children separately before this one, and the whole NICU experience just turned our lives around completely."
44 When to begin solid foods	2	"I'm still not sure when to start cereal or what kind of cereal to start with because of her adjusted age."
45 Bathing infant/skin care	2	"I wasn't sure when to bathe her or how much to bathe her…daily, every other day? I didn't want her to get cold or sick again."
46 Depression	2	"The first year I found hard because I had postnatal depression and he had very severe reflux, so we had quite a difficult first year."
Total: 553		
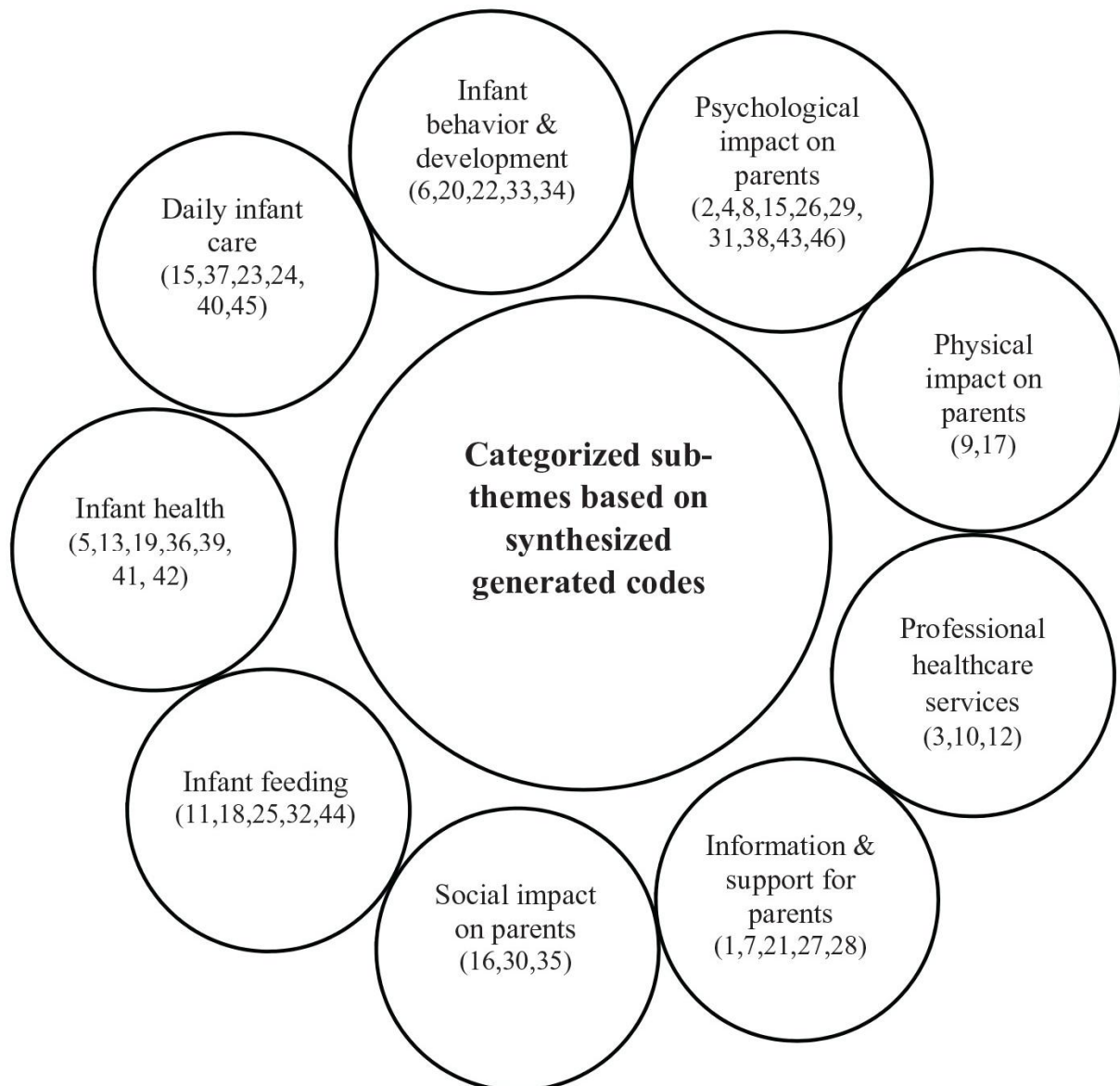
Figure 2. Nine categorized themes with generated initial codes (numbered in parenthesis) from Table 1.

The three authors subsequently analyzed and synthesized the 46 generated codes into nine broad categories that captured and described relevant, similar themes or topics connected to the stated research question (see Figure 2). Through the mutual agreement of the three coders, the nine categorized sub-themes were synthesized into three main themes that provided the outline for the final stage of the integrative review, the presentation of the findings. The main

themes were constructed through interpretation to better depict the categorized themes with broader meanings and concepts (Braun, Clarke, & Terry, 2014).

Presentation of the findings

Throughout the critical appraisal phase that revealed the 10 studies suitable for inclusion in the review, the literature was read and reread several times. The citation details (author(s), year and country of publication) as well as the demographic representations (i.e. parent, age, number of births, sex of infants) and premature infant characteristics (i.e. gestational ages of infants, birthweight of infants, length of infants hospital stay) of the studies participants and the mentioned overall health concerns or needs of their premature infants are summarized in Table 2.

Characteristics of the selected studies including the citation details (author(s), year and country of publication), study title, methodology, aims of the study, and a summarized presentation of the findings are illustrated in Table 3.

The findings from the 10 studies were categorized under the following three main connecting themes:

(1) Parents who are unprepared for discharge require additional post-discharge support services.

(2) Parents lack the necessary information on their infant's developmental outcomes.

(3) Inadequate services and access to support affect the overall well-being of parents.

Some studies produced findings that encompassed more than one of the three main themes and thus they are presented under more than one theme.

Table 2

Characteristics of Participants in Selected Studies

	Alderdice et al. (2018)	Aylward (2002)	Boykova (2008)	Boykova (2016)	Gonzales & Espitia (2014)	Hemati et al. (2017)	Nicolaou et al. (20019)	Nowe (1994)	Petty (2018)	Phillips-Pula (2013)
Country	United Kingdom	USA	Russia	USA	Columbia	Iran	United Kingdom	Canada	United Kingdom	USA
Parents	23 mothers 2 fathers	29 mothers 1 father	32 mothers	48 mothers 4 fathers	10 mothers	23 mothers	20 mothers	14 mothers	13 mothers 2 fathers	8 mothers
Mean age or range	33.8 years	30.4 years	28.8 years	34.2 years	18-37 years	28 years	31 years	31 years	Not mentioned	Not mentioned
Gestational age or range	30.8 weeks	34.7 weeks	30.8 weeks	28 weeks	28-34 weeks	Not mentioned	27 weeks	Not mentioned	20-30 weeks	24-32 weeks
Mean or range infant birthweight	1650 g	2358 g	1580 g	1192 g	670 g-1.495 g	Not mentioned	Not mentioned	Not mentioned	0.615 kg-1.6 kg	0.635 kg-2.722 kg
Mean infant hospital stay	Not mentioned	33.1 days	47.9 days	82 days	34.2 days	Not mentioned	78 days	Not mentioned	Not mentioned	Not mentioned
Infant health concerns or needs post discharge	• Healthy: 10 • Needed additional care or follow-up 11 • Died: 1 • Data missing: 1	• Medically complex: 19 • Prescribed medication: 11 • Surgical diagnoses: 7 • Cardiovascular diagnoses: 4 • Neurologic diagnoses: 5 • Genetic diagnoses: 4	• Periventricular leukomalacia: 6 • Intraventricular hemorrhage: 5 • Retinopathy of prematurity: 2 • Paten ductus arteriosus: 5 • Necrotizing enterocolitis: 1 • Chronic lung disease: 9 • Sepsis: 1	• Transitional or follow-up care programs: 25 • Hospitalized after initial discharge: 23 • Unplanned rehospital-izations: 15	Not mentioned	Not mentioned	Not mentioned	• Con-genital anomaly: 1 • Chronic lung problems: 1	Not mentioned	Not mentioned

Table 3

Overall Characteristics of the Included Studies in Review

Author(s) Year/Country	Study Title	Methodology	Aims	Summary of Generated Findings
Alderdice et al. (2018) United Kingdom	Online information for parents caring for their premature baby at home: A focus group study and systematic web search.	Qualitative focus groups; systematic web search	To explore topics parents deemed important post-discharge with premature infants and evaluate quality of existing websites providing information.	• Adequate information and support for parents were not always readily available. Parents had to explore and find ways to get support within online and community outlets specific to premature infants. • Internet resources were an important source for information although search terms were not solely related to prematurity. • Websites should represent perspectives of both parents and healthcare professionals.
Aylward (2002) USA	The information and support needs of primary caregivers of premature and/or medically complex infants upon discharge from the neonatal intensive care unit.	Non-experimental descriptive design	To determine the perceptions of parents regarding information and support received prior to and four weeks after the discharge home.	• Information needs changed over time from active observers in NICU to the primary caregivers' post-discharge. • More information is needed specific to premature infants and infant temperament (colic, crying and fussy periods). • Information in booklet format was preferred to refer back to on topics such as feeding, infant environment, behavior and development, and recognition of changing health status.
Boykova (2008) Russia	Follow-up care of premature babies in Russia: evaluating parental experiences and associated services.	Descriptive correlational design	To describe what parents perceived of services provided post-discharge.	• Parent concerns are similar between cultures. • More information wanted specific to own needs like every day infant care, behavior, feeding, teeth, safety, and sleeping. • More professional support wanted at home given in a more individual approach.

Author(s) Year/Country	Study Title	Methodology	Aims	Summary of Generated Findings
Boykova (2016) USA	Life after discharge: What parents of preterm infants say about their transition to home.	Descriptive qualitative design	To explore and describe the experiences of parents with premature infants' post-discharge.	• Altered perception of parent role, lowered self-confidence, produced feelings of not being a parent, and decreased decision-making abilities for infant's care and health. • More information needed regarding feeding and breastfeeding problems (lactation issues, latching, spitting and reflux), infant caregiving, behavior and growth and development specific to premature infants.
González & Espitia (2014) Columbia	Caring for a premature child at home: From fear and doubt to trust.	Interpretive phenomenology design	To describe how mothers subjected to separation and limited caregiving participation in NICU, affect caregiving experiences at home.	• Doubts, insecurity and fear experienced by becoming responsible for full-time care of premature infants. • Mothers needed seven weeks to start feeling comfortable and secure to care for premature infants at home. • Positive feedback provided by healthcare professionals post-discharge significant for mothers to feel safe and increased confidence. • Support from spouses, friends, neighbors, and other parents with premature infants valued.
Hemati et al. (2017) Iran	Challenges after infants' discharge from neonatal intensive care unit: A qualitative study.	Qualitative design; purposive sampling	To investigate the challenges of mothers after their premature infant's discharge.	• Challenges occur post-discharge regarding diapering, bathing, cord care, infant feeding, skin-to-skin care, recognition of meanings with different the cries, and specialized care (e.g., medication administration, oxygen therapy, and feeding with a g-tube). • Lack of support, insufficient training about infant's condition, symptoms, and behaviors, and inadequate experiences in feeding with a g-tube intensified mothers' fears and stress in caring for infants causing decreased confidence and competence.
Nicolaou et al. (2009) United Kingdom	Mothers' experiences of interacting with their premature infants.	Qualitative; semi-structured interviews	To explore the thoughts and experiences of mothers in early interactions with premature infants	• Hindered interactions in NICU created feelings of insecurity, anxiety and self-doubt about transition home. • Lack of information given about interacting with infants when discharged home resulted in feeling unprepared to care for infants at home. • More information developmental play, how to play with

Author(s) Year/Country	Study Title	Methodology	Aims	Summary of Generated Findings
			and explore perceived support and information needs.	premature infants, toys, developmental milestones specific to premature infants, and expected infant behaviors that can influence the early interactions like being sleepy and unresponsive. • Healthcare professionals did not know enough about premature infants creating feelings of isolation and uninformed post-discharge.
Nowe (1994) Canada	Concerns of mothers of preterm low birth weight infants during the first week of the infants' discharge from hospital.	Exploratory design	To explore and describe concerns of mothers with premature infants during first week after discharge from the hospital.	• Mothers' concerns about premature infants' health included infections and illness, apnoea, bowel elimination, infant sleep and awake patterns, taking the infant outdoors, keeping the infant warm, fussy periods, giving infant medications and infant feeding (spitting up, amount of milk intake, weight gain, and feeding schedules). • Mothers experienced anxiety about uncertain future outcomes for premature infants while concerns. • Mothers concerned with feeling tired, emotional state and schedules, partners and families.
Petty et al., (2018) United Kingdom	Parents' views on preparation to care for extremely premature infants at home.	Narrative approach; semi-structured interviews	To gain insight into post-discharge experiences of parents and adequacy of preparation for caring for extremely premature infants at home.	• Mixed feelings expressed such as joy, excitement, nervousness and fear about going home with premature infants. • Ongoing health issues of premature infants, rehospitalizations and frequent follow-up appointments placed extra strain on parents' emotional well-being. • Better support wanted from community-based health professionals with knowledge about specific differences and needs of premature infants. • Other parents with premature infants were a source of emotional support during the initial, difficult times after the discharge.
Phillips-Pula (2013) USA	Caring for a preterm infant at home.	Transcendental phenomenology approach	To examine experiences of mothers during the first 6 months after	• Time following NICU discharge reported as most difficult with struggles to manage new roll because of the unexpected challenges. • Exhaustion and lack of sleep impacted spousal

Author(s) Year/Country	Study Title	Methodology	Aims	Summary of Generated Findings
			discharge home.	relationships.
				• Feelings of isolation and misunderstandings from others extended through first year of life.
				• Mothers felt overwhelmed with day-to-day routines and schedules creating barrier in ability to bond with infants.
				• Support and reassurance from other mothers of premature infants, husbands or partners increased optimism about caregiving abilities.

Theme 1: Parents unprepared for discharge require additional post-discharge support services.

Parents of premature infants have increased parental needs after taking their infant home and often require additional information on infant caregiving, social support and professional healthcare services (Aylward, 2002; Petty, Whiting, Green, & Fowler, 2018). Parents who participated in the study with Phillips-Pula (2013) reported that they were not prepared to deal with the unexpected challenges and struggled to manage their roles as primary caregivers after the infant's discharge. Similarly, Aylward's (2002) study revealed that parents needed information specific to premature infants and challenges related to infant feeding, infant behavior and development, colic, crying and fussy periods, and how to recognize their infant's changing health status. They did not receive any of this information in the hospital.

Parents expressed mixed feelings such as joy, excitement, nervousness and fear about going home with their premature infants (Nicolaou, Rosewell, Marlow, & Glazebrook, 2009). The initial mixed feelings experienced by parents were associated with their premature infants' hospitalization. This had altered the parents' perception of their role as a parent, lowered their self-confidence, produced feelings of not being a parent, and decreased their ability to make decisions for their infant's care and health (Boykova, 2016; Nicolaou et al., 2009).

Columbian mothers in the study conducted by González and Espitia (2014) reported that separation from their infants during NICU and their lack of opportunities to experience and develop their maternal role prevented them from taking on this new role with confidence and joy. It also produced doubts, insecurity and fear as they became responsible for the care of their premature infants at home. Similarly, Hemati et al. (2017) investigated the challenges of mothers after their premature infant's discharge to home and found that parents with inadequate experiences or opportunities to care for their infants in NICU had intensified fears and stress

about caring for their infants post-discharge. Yet another study's findings revealed that when mothers' interactions with their premature infants in NICU were hindered, it created feelings of confusion and detachment for the mothers (Aylward, 2002). Mothers in the study experienced anxiety about the transition from NICU to home because they realized they would no longer have the hospital staff to provide care for their infant.

Parental needs change over time as parents transform from active observers in NICU to the primary caregivers at home (Aylward, 2002). González and Espitia (2014) found that on average, mothers needed seven weeks to start feeling comfortable and secure in their care for their premature infants after the discharge to home. This implies that there were several challenges and changes in the mothers' lifestyles, needs and expectations.

Studies conducted in the countries of Russia, USA, Canada, United Kingdom and Iran revealed that parental needs are not really influenced by culture or geographical setting (Boykova, 2008; McKim et al., 1995; Mousavi et al., 2016). Therefore, findings from the current study could be utilized as a reference tool for the post-discharge information and support needs of parents with premature infants for other studies relevant to various cultures and countries, including LMICs.

Theme 2: Parents lack the necessary information on their infant's developmental outcomes.

Relevant studies confirm that premature infants experience greater risks of neurodevelopmental disabilities, cognitive and language delays, behavioral and emotional problems, and learning disabilities (Benzies, Magill-Evans, Hayden, & Ballantyne, 2013; Boykova, & Kenner, 2012). Having to deal with these known risks, parents as the primary caregivers develop feelings of insecurity, anxiety and self-doubt due to the lack of information

given to them prior to the infant's discharge to home (Boykova, 2016; González & Espitia, 2014; Hemati et al., 2017). Uncertainty about the future growth and development of premature infants negatively influences the parents' caregiving abilities and how they respond to and interact with their premature infants (Nicolaou et al., 2009; Petty et al., 2018).

As perceived by mothers, parents need information to help them understand what happens on a day-to-day basis during the first few weeks and months following their discharge from hospital, since they suddenly face unexpected challenges at home (Phillips-Pula, 2013). According to Hemati et al. (2017), mothers need more information on diapering, bathing, cord care, infant feeding, skin-to-skin care, recognition of the newborn's cries, and specialized care (e.g. medication administration, oxygen therapy, and gastrostomy/colostomy care).

The studies indicated that parents often express concerns about how to care for their premature infants after being discharged to home. Nowe (1993) found that mothers had concerns about taking their premature infants outdoors, keeping them warm, handling fussy periods, and administering medications. Infant feeding (spitting up; amount of milk intake; weight gain; feeding schedules), bowel elimination, and sleep and awake patterns were also reported by the mothers to be concerns. Boykova (2016) further found that mothers were anxious about feeding and breastfeeding problems (lactation issues; latching; spitting and reflux; knowing what formula would be best for the infant). Mothers also fretted about how to manage specialized equipment and administer medications, as informational resources were not always available to them.

Similarly, in Alyward's study (2002), parents indicated that they wanted more information specific to premature infants in respect of topics such as feeding, infant environment, behavior and development, and how to recognize a change in their infant's health status. Findings by Nicolaou et al. (2009) added more details about parents' need for more

information on factors that influenced their early interaction with their premature infant. These were developmental play, appropriate toys, developmental milestones specific to premature infants, and expected premature infant behaviors.

The study conducted by Alderdice et al. (2018) revealed that parents often struggled to find appropriate advice and information on different topics specific to premature infant care, infant health, and infant developmental milestones. Internet resources were an important source of information, but parents stated that they often had to use search terms that were not exclusively related to prematurity but dealt more in general with all newborns. The challenges and concerns reported by parents in several studies confirmed that focused information about premature infants was not freely available and accessible to parents.

Theme 3: Inadequate services and access to support affect the overall well-being of parents.

Recent studies by Petty et al. (2018, 2019) aimed to gain insight into what community-based healthcare professionals know and what they need to know in relation to the specific needs of parents with premature infants following the discharge to home. The study also examined parents' experiences in relation to professional community-based healthcare support (Petty et al., 2018, 2019). Findings from these two studies confirmed that parents with premature infants require optimal and ongoing support from healthcare professionals who are familiar with the unique needs of parents and premature infants. These findings correspond with those of one of the selected studies in the current review, which revealed that parents need more professional support and reassurance in their parenting and caregiving skills at home, as well as more information than what was provided in hospital (Boykova, 2016). Parents want community-

based healthcare professionals who are more knowledgeable and consistent in giving information specific to their own premature infant's needs (Boykova, 2008).

Premature infants often have ongoing health issues after being discharged to home, and often these problems result in rehospitalization and frequent follow-up medical appointments. This places an extra strain on the parents' emotional well-being (Petty et al., 2018). The daily infant care routines, combined with parental worries and stress, place high physical demands on the parents and often result in sleep deprivation, exhaustion and fatigue. The parents' social lives are disrupted, which may lead to social isolation, difficulties in sharing feelings, and misunderstanding from others (Phillips-Pula, 2013). Alderdice (2018) found that adequate and professional healthcare services and access to additional support were not always available to parents after discharge. Parents had to explore and find ways of getting more support in communication outlets concerned with prematurity as they felt overwhelmed by and exhausted from being misunderstood by others. A similar study by Nicolaou et al. (2009) revealed that mothers felt that community-based healthcare professionals did not know enough about premature infants to be of help to them, making them feel isolated and uninformed.

Healthcare professionals who provided positive feedback helped parents feel safe and increased their confidence in their caregiving abilities (González & Espitia, 2014). Apart from adequate support from healthcare professionals, mothers in the study by Boykova (2008) valued support from spouses, family members, friends, neighbors, and other parents with premature infants. Nowe (1994) found that mothers who expressed concerns about their premature infants' physical and social development milestones reported that their path to becoming a parent would have been easier if they had had more knowledge about what to expect in their parental role and if they could get the needed support from their partners, family and healthcare professionals.

Discussion

The goal of this integrative literature review was to identify, synthesize and present the findings on the perceived information and support needs of parents regarding the caregiving of their premature infants after discharge. The included studies revealed that, in general, many parents often need additional information and support from different outlets such as family members, friends, other parents with premature infants and community-based healthcare professionals.

The findings of the studies also confirm that parents often feel unprepared for the discharge to home and thus they experienced increased parental stress, worry and anxiety when they have to assume all the responsibilities of caring for their premature infant at home. Permitting the parents to be actively involved in NICU to care for their premature infants while under the supervision of NICU healthcare professionals would be an appropriate place to begin to ensure parents get the optimized support they need. This, in turn, may help to lower parental stress about the anticipated discharge, increase their self-confidence, and further promote the parents' caregiving abilities. Furthermore, providing additional information and support services through community-based healthcare professionals who are trained and experienced in supporting parents and premature infants would be beneficial to fully support parents – particularly in the early months after the discharge to home.

The findings highlighted from this integrative review confirm that parents face challenges and concerns because they lack the necessary information to promote positive future outcomes for their premature infants' growth and development. Interventions that specifically provide parental support, and informational strategies that promote positive future outcomes for the premature infant's growth and development are essential – both prior to and after discharge from

hospital. The studies highlight the need to provide tailored education for community-based healthcare professionals and support services, such as professionals conducting home-visits, to expand their expertise and experiences to support parents practically and emotionally during the initial transition period from the hospital to home environment. Having a tailored community-based program targeting parents and premature infants would further solidify the findings in the studies where parent participants stated wanting more individualized and coordinated care as well as to be reassured by professionals in their parenting and caregiving during the initial transition of assuming full responsibilities of their premature infants once home from the hospital.

Although recommendations or specific types of early intervention support and services were mentioned in each of the studies in the review such as providing optimal opportunities for the infants development, hospital discharge to home plan, therapy treatments for the infants and parent support strategies in community-based programs, parent participants in the studies still felt they needed more information and support related to the caregiving of their infants. Although this review is relatively a small sample, commonalities of themes were reported across the countries represented. The studies provided valuable information on the unmet needs and challenges parents of premature infants face after the initial discharge home.

The most common thread among the studies was that parents wanted healthcare professionals who were more educated in the specific primary care of premature infants. Several of the studies mentioned that premature infants are at risk for re-hospitalization, as well as medical and neurodevelopmental complication. Information in the studies also suggested that the burden of continued health and developmental problems for the premature infants is substantial for the parents. For example, compared with full term healthy infants, premature infants face

greater risks for visual and hearing impairments, speech delays and attention disorders. They may also have poor feeding and growth, respiratory complications, and neurodevelopment challenges. Given these ongoing risks, parents must manage the needs of their premature infants' health and developmental needs above and beyond what is required for a healthy full term infant for months or even years after the hospital discharge.

Each study confirmed that more research is needed on support mechanisms such as specialized health home-visitor intervention, group peer support, in addition to online resources. Despite recent changes in the provision of health care (i.e. family-centered, developmental care in the hospital, rooming in, availability of follow-up clinics, transitional programs, and counselling services, parents continue having challenges in the caregiving of their infants after the discharge home which confirms there continues to be a gap in support for parents when they leave NICU. By identifying the post-discharge information and support needs after the initial discharge home of their premature infants, it becomes relevant to design a community-based EI program where parents are able to access additional support from healthcare professionals to provide the optimal support for the continued growth and development of premature infants as well as support for the overall well-being of parents. This can be achieved more quickly by including the parents' input to ensure their needs are incorporated into the resource's content. There continues to be a need among parents for resources that are readily accessible, easy to understand, trustworthy and parent centered.

Limitations and future research

The current integrative literature review shows the absence of published studies in LMICs in Africa and Asia. Further research – beyond the boundaries of higher-income countries – is

required to determine the most effective and culturally sensitive parent-directed interventions for parents with premature infants who live in LMICs. Moreover, only studies published in the English language were selected for inclusion. Studies published in other languages specific to the LMICs of interest may provide varying or more diverse perspectives on the post-discharge information and the support needs of parents with premature infants. Despite these limitations, the current research provides an in-depth summary based directly on the perceptions of parents. As such, it permits a greater understanding of parents' perceived needs during the important early months at home after their premature infants were discharged from hospital. The current study's findings can serve as a foundation for an EI design or program that specifically targets the information and support needs of parents with premature infants prior to discharge, but that also contains a component of providing continuity of care through expert healthcare professionals within their own communities.

Conclusion

A comprehensive literature search spanning three decades of literature identified ten studies that explored the parents' perceived information and support needs in caring for their premature infants after the initial discharge to home. The integrative review captured the self-reported perceptions, concerns and challenges experienced by parents as they assumed their role as primary caregiver for their premature infant in the home environment.

The findings of this review revealed the importance of including the parents' perceptions, thoughts and opinions when designing intervention strategies or developing EI programs. Parents clearly expressed the need to be equipped with the necessary information and support – if not while their infant is still in hospital, then promptly after their discharge. This review clarifies that

parents of premature infants from different geographical locations share commonalities in their information and support needs. It is therefore hoped that this body of work will help to raise awareness about the vast information and support needs of these parents. If the needs of this vulnerable population were to remain unmet, it can result in short- and long-term negative consequences for the whole family unit.

Authors' note

Declaration of conflicting interests

Funding

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