



Transition From Hospital to Home in Parents of Preterm Infants

A Literature Review

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ABSTRACT

Transition from hospital to home is a complex and multidimensional phenomenon for parents of prematurely born infants (<37 weeks of gestation). The absence of a clear conceptualization of this particular transition coupled with the challenges parents have when they return home and higher costs of healthcare service usage postdischarge dictates the need for a better understanding of this phenomenon. A literature review was undertaken using Whittemore and Knafli's theoretical framework for integrative review as a guide. A systematic search of the electronic databases (PsycINFO, PubMed, Medline, Cumulative Index of Nursing and Allied Health Literature, EMBASE, Cochrane Database for Systematic Reviews, and EBSCO) was performed. Fifty selected reports of research conducted on parents of preterm infants during 1980–2014 are included in this article. Five themes emerged from the review—disruption of parental role development, distorted development of parent-infant relationships, psychological consequences of a preterm birth and infant hospitalization, learning caregiving and parenting, and need for social and professional supports—which appear to reflect parental challenges during transition from hospital to home after

discharge. Several inconsistencies in results of the studies dictate the need for further research in this vulnerable population; the better conceptualization and measurement of transitional challenges are warranted.

Key Words: parent, preterm infant, transition to home

Transition from hospital to home is a complex and multidimensional phenomenon for patients of all ages.^{1–4} This transition can be especially challenging for parents of prematurely born infants (<37 weeks of gestation). Preterm delivery and hospitalization after birth are stressful events to parents for which they are seldom prepared. Discharge home, a joyful moment, can also be a stressful event because parents have to accept full responsibility for the health and care of their infant at home and without help from hospital health professionals. Research has documented that parenting and caregiving of medically fragile and prematurely born infants are difficult and demanding tasks for parents.^{5–7} Research has also shown that emergency department use, readmissions, and rehospitalization rates are higher in the population of preterm infants than in term infants.^{8–10} Most readmissions, rehospitalizations, and the higher use of healthcare services occur in the first weeks and months after the initial discharge.^{11–16} Moreover, researchers have reported a higher withdrawal from neonatal follow-up clinics occurs after the first visit; reasons for withdrawal included limited resources and fear of bad news.^{17,18} There is evidence of inadequate referrals of preterm infants to early intervention services as well^{19–21} and low adherence of parents of preterm infants to the health visit schedule.²² Researchers also found the need for better preparation of early intervention specialists and neonatal nurse practitioners in primary settings to meet the needs of the preterm infant and family postdischarge.^{23,24}

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It is not completely clear what influences the inappropriate use of healthcare services in the population of parents of preterm infants postdischarge. One of the reasons could be the parental perception of the child's vulnerability that was associated with higher use of services.²⁵ Other possible factors could be (a) the infant's health status at discharge and complications of prematurity, (b) parenting and caregiving difficulties parents face at home, and (c) inadequate provision of care in primary healthcare settings when parents of preterm infants transition from hospital to home. Although studies on parenting and hospital readmissions of preterm infants are rich in qualitative and epidemiological information, a theoretically solid summary of the postdischarge transitional experiences of parents of preterm infants is lacking. Transition to home in this population is not well understood and not conceptually defined. Therefore, purpose of this article is to summarize and synthesize the available literature (1980–2014) related to the experiences and needs of parents who had their preterm infants hospitalized and discharged home.

METHODS

This review used Whittemore and Knaf's framework for integrative reviews as a guide.²⁶ Integrative review, the broadest type of literature reviews, allows inclusion of studies with different methodologies and the combination of findings from experimental and nonexperimental research. This is done to more fully understand a phenomenon under investigation, to define concepts and clarify healthcare problems that are of importance to nursing.²⁶ The problem formulated for this integrative review was: "What are the challenges and needs parents of preterm infants face in the first 12 months after discharge from a hospital?" For this review, transition from hospital to home in parents of preterm infants is defined as a nonlinear, time, and situation-bound process of accepting parenting role and caregiving responsibilities when moved from the safety of the hospital environment to independent caregiving and parenting at home.

Search strategy

A systematic search of the electronic databases (PsycINFO, PubMed, Medline, Cumulative Index of Nursing and Allied Health Literature, EMBASE, Cochrane Database for Systematic Reviews, and EBSCO) was performed. The defined search strategy used the keywords *transition*, *parent*, *parenting*, *preterm infant*, *hospital discharge*, *transition from hospital to home*, *mother*, *father*, *follow up care*, and *transitional care*. These terms and combinations of them

were used to search titles and abstracts of published reports. Bibliographies of the reports were examined for additional sources and references; hand searching of journals was performed as well.

For a report to be included, the study should have concerned (1) caregiving and/or parenting of preterm infants after discharge from a hospital or neonatal intensive care unit (NICU); and (2) postdischarge healthcare issues faced by parents of preterm infants when transitioning to home and to primary healthcare settings. Only studies conducted in the 12-month period after hospital discharge were included. Studies involving any parent (mother or father, or both parents) were included. No limits for gestational age of preterm infants were set. Studies concerned with parental challenges when having an infant born late preterm (34–36 completed weeks of gestation), extremely preterm (<26 weeks of gestation), and extremely low birth weight (<1000 g) were included as well as studies on parents of preterm infants with complications of prematurity (eg, retinopathy of prematurity and chronic lung disease). Interventional studies (eg, effects of home visiting programs and educational programs with parents), studies concerning differences in parenting preterm and term infants were included as well. Qualitative and empirical studies, published in the English language during the period from 1980 to 2014, were included. This period was selected as the purpose of the review was to identify as much available evidence as possible to better understand the postdischarge parenting of preterm infants and delineate the important aspects of transition to home in this population.

Studies concerned with parenting and caregiving of infants with congenital malformations and genetic conditions were excluded. The reason for exclusion was the assumption that parenting and caregiving of such infants bring additional psychoemotional and physical stress for the parents.²⁷ Reports were excluded if they were related to physiological transitions in preterm infants or transfers between hospitals or hospital departments. Textbooks, chapters in textbooks, dissertations, editorials, opinion papers, and abstracts of unpublished works as well as primary care clinical management papers, and reports related to an instrument development were excluded.

Search results

Figure 1 shows the findings of the systematic literature search. By using search terms *transition*, *parent*, *parenting*, *preterm infant*, *hospital discharge*, *transition from hospital to home*, *mother*, *father*, *follow up care*, and *transitional care* in various combinations, over 911 published reports were found. Duplicate records were removed; the abstract of each article was reviewed to

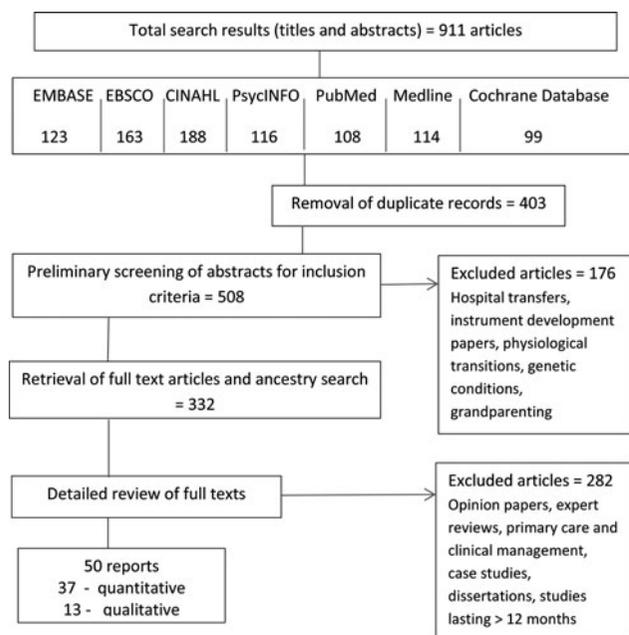


Figure 1. Literature search diagram.

determine whether the inclusion criteria were met. The number of relevant articles decreased to 332. Full texts of all relevant articles were obtained for further evaluation. A wide ancestry search and hand searching of journals were performed because oftentimes there was an absence of the term “transition” in titles and abstracts, yet the study itself concerned parenting and caregiving of preterm infants postdischarge. Only 50 selected publications that met the inclusion criteria are included in this review to illustrate research areas, concepts, and aspects of parental experiences postdischarge.

Data evaluation and analysis

Retrieved publications included descriptive studies, comparative studies, qualitative studies, experimental studies, interventional studies, reviews, and epidemiological investigations. The publications presented in Table 1 include *only* reports of the *selected* empirical studies, both quantitative and qualitative, in chronological order. To get a better understanding of the phenomenon of transition to home, no report was excluded based on sample size, attrition, or methodological rigor. As transition to home in parents of preterm infants appears to be rather an unexplored area, any report was treated as a valuable source of information important for clarification of this phenomenon and identification of possible parental challenges postdischarge.

Each retrieved report was evaluated as to whether or not it met the inclusion criteria. A coding scheme was designed to review the studies, and each study was systematically read and coded. Coding variables were the

focus of the study, method, sample characteristics, time frame, and the main findings as related to postdischarge experiences and needs of parents. In addition, studies were assessed for presence of a definition of transition, theoretical framework, and instruments used.

The categories of studies were identified and the content of the reports was synthesized to answer the research question proposed in this integrative review. Primary sources were divided into subgroups according to the chronology and type of research (qualitative or quantitative studies, correlational or comparative studies, and intervention and experimental designs) and analyzed by topic. Data extracted from primary sources were entered into a table. This allowed a systematic comparison of the studies' results that were considered relevant to parenting and caregiving of preterm infants postdischarge.

RESULTS

The majority of the research reports that parenting and caregiving for preterm infants postdischarge are challenging. Several patterns in parental experiences emerged from the studies concerning parenting and caregiving during the first year of life, with tightly interwoven concepts that comprise parental transition. These patterns are described next.

Parental role development and parenting style

From the findings of reviewed studies, the difficulty in parental role acquisition in parents of preterm infants during the postdischarge period is evident. Reviewed studies reported that discharge home is joyful but also a stressful event filled with difficulties of parental role development. Accepting parental responsibilities was one of the major difficulties at 1 month postdischarge.^{28,29} The premature onset of parenthood, the disruption of bonding at the beginning of the infant's life, the absence of the rites of passages like a baby shower, and the mother's discharge home without the infant create a feeling of “not being a parent” reported in several reviewed studies.^{28–31} Delayed acquisition of parental role and identity was found in mothers of preterm infants.^{32,33} It also appears that initially distorted parental role and infant hospitalization can result in inadequate parenting style: one study reported parental determination to do everything for the infant,³⁴ indicating a risk for the development of compensatory parenting style, first described by Miles and Holditch-Davis³⁵ in mothers of 3-year-old children who were born prematurely.

Interactions and parent-infant relationships

It appears that parents of preterm infants are at risk for developing strained relationships with their infants

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Brachfeld et al ³⁶ —the United States	Effect of prematurity and health status on interactions/comparative observational/30 dyads/8 and 12 mo	None/NA/Home Observation for Measurement of the Environment Inventory, Bayley Scales of infant development	Preterm infants interacted less than full term. Parents of preterm infants were more active than parents of term infants at 8 mo, but not at 12 mo
Crnic et al ⁷³ —the United States	Effect of stress and social support on mother-infant interactions/descriptive comparative/52 mothers of-preterm and 53 mothers of full term-infants/1 and 4 mo	None/NA/Life Experience Survey, Social Support Measure, Satisfaction With Parenting Scale	Maternal attitudes at 1 mo and interaction at 4 mo predicted by stress and support. More positive behaviors and attitudes in mothers with greater social support. Intimate support was helpful. Support from friends and others only moderated stress (if mother perceived it was needed)
Minde et al ⁶² —Canada	Maternal caretaking/descriptive comparative/40 dyads/1, 2, and 3 mo	None/NA/author developed	Interactions and feeding were problematic in preterm dyads. Preterm mothers worried about development; full-term mothers worried about weight and behavior. Confidence in preterm mothers increased with time
Watt and Strongman ¹⁴⁴ —New Zealand	Interactions between mothers and infants (term, preterm, and small-for-gestational-age infants/comparative observational/33 dyads/2, 3, and 4 mo	None/NA/Bayley's mental development index	Preterm mothers smiled less and looked more at their infants at 2 mo. Preterm mothers' interactions dropped at 2–3 mo—infant's interactive behavior rose. Preterm and small-for-gestational-age dyads' interactions differed from full-term dyads
Affleck et al ⁷² —the United States	Social support and maternal adaption in the transition from hospital to home/descriptive correlational/42 mothers/2 mo	None/no/Inventory of Socially Supportive Behaviors, Arizona Social Support Interview Schedule, Profile of Mood States, Impact of Event Scale, Sleep-Feeding-Crying Questionnaire	Mothers' satisfaction with emotional, informational, and tangible supports associated with more positive adaptation to home. Satisfaction with support was unrelated to the amount of perceived support. A large support network not related to better adaptation
Cupoli et al ⁵⁷ —the United States	Grief in mothers of preterm infants/descriptive longitudinal/37 dyads/at discharge, first home visit (≈12 wk) and first clinic visit (≈22 wk)	None/NA/self-developed instrument and interview	Four reaction patterns of grief were identified: early resolution, late resolution (most frequent), delayed reaction and denial. Shorter gestation associated with less intense grief, which increased later and was difficult to resolve

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Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Gennaro ⁴⁶ — the United States	Anxiety and depression in mothers of preterm and term infants/comparative/ 82 mothers/1 and 6 wk	None/NA/Neonatal Risk Categorization Schema, State Trait Anxiety Inventory, Depression Adjective Checklist	Mothers of preterm infants significantly more anxious and depressed than mothers of term infants in the first week, but this difference did not persist over time
Brooten et al ⁴⁵ — the United States	Anxiety, depression, and hostility in mothers of preterm infants/descriptive/ 47 mothers/at discharge and 9 mo	None/NA/Multiple Affect Adjective Checklist, State Trait Anxiety Inventory	Mothers were more anxious and depressed before discharge than at 9 mo. Multiparas were more depressed before discharge than primiparas. Mothers of infants with longer hospital stay less depressed at discharge than mothers with infants who had shorter hospital stay. Sociodemographic characteristics not associated with anxiety and depression
Affleck et al ⁷¹ —the United States	Effect of home parent support program on mothers' adaptation from hospital to home/randomized controlled trial/ 94 mothers/6 mo	Crisis theory/no/Arizona Social Support Interview Schedule, Ways of Coping, Profile of Mood States, Parenting Stress Index, Infant Characteristics Questionnaire	Mothers in the intervention group perceived more control; more competent to provide care, and more responsive if infant's condition was severe. Program had a negative impact on mothers if infants with low risk or relatively well
Zahr ⁷⁴ — the United States	Relationships between infant temperament, maternal background, social support, confidence, and mother-infant interactions/ predictive/49 dyads/4 and 8 mo	No/NA/Feeding and Play Scales by Egeland, NET-HELP scale, ¹⁴⁶ Maternal Confidence Questionnaire, Infant Characteristics Questionnaire	Length of hospitalization, birth weight, temperament, and social support significantly correlated with interaction scores at 4 mo; at 8 mo it were temperament and social support
McCluskey-Fawcett et al ³¹ — the United States	Impact of preterm birth, NICU stay, and transition to home/qualitative/ 13 mothers/12 mo	NA/no/ NA	Preterm labor viewed as a crisis. Mothers frightened and stressed about infant's condition. Stress decreased through improved condition, and information from health professionals. Parent's ability to care disrupted by hospital routine and policies. Mothers fearful and anxious about discharge; afraid of baby getting sick again

(continues)

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Kenner et al ⁴¹ —the United States	Transition from hospital to home in parents of NICU infants and parents of healthier infants/descriptive comparative/67 mothers/1 and 4 wk	Transition Model/no/ Transition Questionnaire	Parents had similar concerns about infant care and health. Health concerns and feeding more prominent in NICU parents. Fatigue and grief were observed. Mothers feared the prognosis even after discharge. Some concerns—regular parenting concerns. Informational needs tied to medical diagnosis and caretaking ability
Zabielski ³² —the United States	Maternal role attainment and maternal identity/mixed methods/41 mothers of term and preterm infants/12 mo	Mercer's attainment of maternal role/NA/ semistructured interview; Neonatal Morbidity Scale; Family Inventory of Life Events; How I Feel About My Baby; Myself as a Mother; Gratification Checklist	Maternal identity delayed in mothers of preterm infants. No relationship between quality of maternal role attainment and length of gestation No differences in affective perception of the infant, competence, and role satisfaction in mothers of term and preterm infants
Gennaro ⁷⁰ —the United States	Impact of having preterm infant on family/descriptive longitudinal/224 families/1, 3, and 6 mo	None/NA/the Impact of Family Scale, Bayley scales of infant development	Use of services high. Family impact (finances, social isolation, distress, and mastery) high. Families with rehospitalized infants had a greater impact on family functioning
Vasquez ⁶⁵ —the United States	Adaptation to caring for a preterm infant at home/qualitative/14 parents/1, 3, and 5 mo	Roy's adaptation model and own hypothesized/no/NA	A process named "Creating Paths" identified, consisting of 3 stages: gathering (information and resources), emerging (relationship development), and affirming (development of family sense)
Harrison and Magill-Evans ³⁹ —Canada	Interactions between mothers and fathers of full-term and preterm infants/descriptive observational/103 dyads/3 and 12 mo	None/NA/Nursing Child Assessment Teaching Scale, Parenting Stress Index, Dyadic Adjustment Scale	Parents of preterm infants interacted less. Differences were not explained by infant's behavior, stress, marital support, or level of involvement with the infant. Fathers interacted less than mothers. Interactions decreased with the time.
May ⁴² —the United States	Caregiving and information seeking in mothers for preterm infants/qualitative/14 mothers/4–12 mo	None/no definition/ NA	Searching for normalcy through caregiving includes learning caregiving, maintaining vigilance for progress, normalizing going alone with caregiver burden, and help-seeking (continues)

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Williams and Williams ⁶⁷ —the United States	Caregiving burden in parents of apnea-monitored and nonmonitored preterm infants/path analysis/74 mothers/at discharge, 1 wk, and 1 mo	Author developed/no/ Multidimensional Assessment of Fatigue, Sleep Scale, Perceived Stress Scale, Family Crisis Oriented Personal Evaluation scale, Family Adaptability and Cohesion Scale II	Fatigue was a major impacting variable in monitored group Mothers reframed their stress and learned coping Decreased sleeping effectiveness for mothers and increased stress impacted infant's care
O'Brien et al ⁴⁸ —the United States	Impact of preterm birth on depression in mothers and family functioning/ descriptive correlational/ 45 mothers/during hospitalization, 1–2 and 6 wk	None/NA/Feetham Family Functioning Survey, the Impact on Family, Center for Epidemiologic Study-Depression Scale	Depression present at all 3 times. Demographic factors and infant's birth weight not associated with family functioning. Lower family functioning and intimate support were present in mothers with depression
May and Hu ⁶⁶ —the United States	Perception of infant health, caregiving at home and help seeking by mothers/descriptive comparative/60 dyads/ 1–21 wk	Neuman Systems Model/no/Author Developed and the Norbeck Social Support Questionnaire	Preterm mothers perceived poorer infant health and more caregiving burden than term mothers. Mothers used nonprofessionals for questions on infant care and minor health problems
Pridham et al ¹³⁶ —the United States	Mothers' evaluations of caregiving, depression, infants' responsiveness, and intimate support satisfaction/comparative observational/103 dyads/1, 4, 8, and 12 mo	None/NA/What Being the Parent of a Baby Like, What My Baby is Like, Parent-Child Early Relational Assessment, Center for Epidemiologic Study-Depression Scale	Mothers viewed themselves as relating well to infants. Depression was low. Maternal evaluations at 1 mo differed from evaluations at later time. Infants' maturity and lung disease not associated with caregiving evaluation Infant responsiveness important. Intimate support led to higher caregiving satisfaction Caregiving and depression significantly negatively associated
Weiss and Chen ⁶⁹ —the United States	Effects of infant's vulnerability and caregiving on mental health of mothers/descriptive correlational/125 dyads/1, 3, 6, and 12 mo	None/NA/Global Assessment of Functioning Scale, Brief Symptom Inventory, Family Adaptability and Cohesion Scale, Family Satisfaction Scale, Family Crisis Oriented Personal Evaluation Scale, and Nursing Child Assessment Feeding Scale	Infant's unresponsiveness and severity of medical problems associated with more mental health problems and less cohesion/adaptability in the family Maternal satisfaction with received family support, lower stress led to better mental health

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Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Davis et al ³⁸ —Australia	Mother-infant interactions and psychosocial maternal characteristics/descriptive comparative/50 dyads/1 and 3 mo	None/NA/Coping Health Inventory for Parents, EPDS, Depression Anxiety and Stress scale, Nurse Parent Support tool, Social Support Interview, Nursing Child Assessment Feeding Scale	Feeding interactions did not differ from normative population Preterm infants were less responsive. Mothers with better coping skills had more responsive infants Depression and stress not associated with interactions. Use of coping strategies (in hospital and home) important factors for managing stress of preterm birth
Mew et al ⁵³ —the United States	Depressive symptoms in mothers/descriptive correlational/39 dyads/ during hospitalization and 6 mo of corrected age	Preterm Parental Distress Model/NA/CES-D Scale, Stress Support Scale, Neurobiologic Risk Scale, Parental Stressor Scale: NICU	Depression decreased with the time. Multiparas had less decrease. Changes in correlates were related to parity, social support, infant neurologic insults, and the length of ventilator support
Kersting et al ⁵⁹ —Germany	Posttraumatic stress response in mothers of very low birth infants/ comparative/80 dyads (preterm and term)/ 1–3 days, 14 days, 6 and 14 mo postpartum	None/NA/Impact of the Event Scale, Beck Depression Inventory, Montgomery Asberg Depression Scale, State-Trait Anxiety Inventory, Hamilton Anxiety Scale, psychiatric assessment	Mothers of the preterm infants had significantly higher traumatic experiences, anxiety, and depressive symptoms. No reduction in posttraumatic symptoms.
Veddovi et al ⁵⁰ —Australia	Impact of preterm infant behavior and hospitalization on mother's depression, coping, competence, infant development, and interactions/descriptive observational/42 dyads/ 12 mo	Sameroff's Transactional Model/NA/Neurobehavioral Assessment of the Preterm Infant, Griffiths Mental Development Scale, Bayley Behavior Rating Scale, Knowledge of Infant Development Inventory, EPDS, Ways of Coping Questionnaire, Parenting Stress Index	Positive reappraisal, more knowledge of infant development, better coping, and previous experience associated with better infant development, less depression, and better mother-infant relationships. Infant's activity and responsiveness associated with higher parenting stress
Lee et al ⁵⁶ —Taiwan	Emotional adjustment in mothers/Qualitative/50 mothers/6 wk	NA/no/NA	Five themes: self-blame, concern about the infant, reluctance to express negatives, fear of stigmatizing by others, and delayed joy in mothering Culture influenced maternal experiences
Feeley et al ⁶⁴ —Canada	Predictors of interactions between mother and infant/descriptive correlational/72 dyads/3 and 9 mo	None/NA/Nursing Child Assessment Teaching Scale, Revised Nursery Neurobiologic Score, State Trait Anxiety Inventory, Support in Parenting Scale	Better educated, less anxious at 3 mo, with higher perceived support mothers—more interactive and responsive to infants

(continues)

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Amankwaa et al ¹⁴⁰ —the United States	Maternal responsiveness/descriptive correlational/23 mothers/2 wk postpartum, 2 wk and 3 mo after discharge	None/NA/EPDS, Postpartum Support Questionnaire, Everyday Stress Index, Self-Esteem Scale, Well-Being Scale, Maternal Attitude Questionnaire, Maternal Infant Responsiveness Instrument	Social support and self-esteem positively associated with maternal responsiveness. Maternal responsiveness stable over time. Stressors (finances, employment, parenting concerns, role overload, interpersonal conflicts) negatively associated with maternal responsiveness. No relationships between maternal well-being, depression, and maternal attitudes about being a mother
Coppola et al ³⁷ —Italy	Effect of preterm birth trauma, infant's medical risk, maternal characteristics on maternal attachment, sensitivity, and interactions/comparative/40 dyads/7 days; 1, 5 and 3 mo of age	Attachment theory, Sameroff's Transactional Model/NA/Impact of Event Scale, Adult Attachment Interview, Emotional Availability Scales	Increased sensitivity in secure mothers when forced to deal with a problematic infant. Insecure mothers less sensitive in the same situations Caregiving required additional efforts to cope with the infant's difficulties and immaturities
Flacking et al ³⁰ —Sweden	Becoming a mother and breastfeeding after NICU/qualitative/25 mothers/1–12 mo	Author developed/NA/NA	Emotional exhaustion in mothers. Progress from insecure to secure bonding, more reciprocal breastfeeding relationships after discharge. Unresolved grief and feeling of shame found. Feelings of being "socially inappropriate" because they could not feel happy. NICU environment affected bonding
Garel et al ⁴⁴ —France	Physical and psychological distress in mothers/qualitative/21 mothers/2–12 mo	None/NA/NA	Fatigue, depressive mood, anxiety (worry and fear), and physical symptoms found. Depression associated with social isolation, PTSD, withdrawal and feelings of guilt. Infants described as difficult and tiring. Mothers' mood more negative at 12 mo
Hill and Aldag ⁵⁵ —the United States	Quality of life/comparative/184 mothers (term and preterm)/1 and 3 wk	None/NA/Maternal Postpartum Quality of Life tool	Quality of life higher at third week. Preterm mothers had lower quality of life, lower satisfaction related to medical conditions of an infant. Feelings of guilt and loss of control also present in mothers of preterm infants

(continues)

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Olshtain-Mann and Auslander ⁴⁹ —Israel	Parental stress, emotional state, and functioning/ descriptive comparative/ 320 mothers and fathers of preterm and term infants/ 2 mo	None/no/Parental Stress, Self-Perception of the Parental Role (subscale)	Stress high; competence low. Preterm mothers of preterm infants showed higher stress and lower competence Preterm fathers had higher parental stress. No differences in competence between fathers of preterm and term infants Parental age, religiosity, and education related to parental competence. More educated parents felt less competent
Boykova ⁵⁴ —Russia	Parent's experiences and evaluation of postdischarge services/descriptive correlational/32 mothers/ 1 mo	Kenner's Transition Model/no/Transition Questionnaire	Mothers knew how to care for an infant, but informational need was high, even with higher supports. Gestational age or birth weight not related to parental transition. Parents wanted more individualized approach. Low competency of primary care health professionals
Jones et al ¹³⁵ —Australia	Appraisal, coping, and social support as predictors of psychological distress and parenting efficacy in low-risk preterm infants/descriptive correlational/25 couples/week before discharge and 3 mo after	Lazarus and Folkman's Stress and Coping Model/no/ Stress Appraisal Measure, Coping Health Inventory for Parents, Family Support Scale, Parent Satisfaction Scale, Parent Expectations Survey, General Health Questionnaire	No high levels of distress. No relationship between distress and parenting efficacy. Postdischarge distress related to pre-discharge appraisal. Appraising situation as stressful (but not threatening)—lower distress and higher efficacy postdischarge Many social sources of support not available
Korja et al ⁴⁷ —Finland	Attachment in mothers/ comparative/35 mothers of preterm and 45 mothers of term infants/12 mo	None/NA/the Working Model of Child Interview	No differences in attachment (balanced, disengaged, and distorted). Qualitative differences (less coherence, acceptance and more unrealistic fear of infant's safety). Maternal depression associated with distorted attachment. Mothers of preterm infants able to develop balanced attachment with their infant.

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Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Padovani et al ⁵¹ —Brazil	Anxiety, depression, and dysphoria in mothers of preterm infants/comparative/75 dyads (50 preterm and 25 term infants) In the hospital and 3 mo postdischarge	None/NA/State-Trait Anxiety Inventory, Beck Depression Inventory, Life Events Scale	Anxiety was higher in preterm mothers. Anxiety was higher in the hospital than at home. Depression did not significantly differ between groups of mothers and remained similar in mothers of preterm infants
Wakely et al ⁶⁸ —Australia	Experiences of parents of preterm infants in rural areas/qualitative/5 mothers and 2 fathers/12 mo	NA/no/ NA	Three themes emerged: “coping through optimism,” “stoic survival,” and “striving for normal.” Initial shock, then feeling like a parent
Voegtline and Stifter ⁴³ —the United States	Infant negativity and maternal psychological state/comparative/132 dyads (term and late preterm)/ 2 and 6 mo	None/NA/Brief Symptom Inventory	Preterm infants rated as more negative. Higher depression and anxiety in preterm mothers related to maternal ratings
Brandon et al ³³ —the United States	Emotional distress in mothers of late preterm and term infants/comparative mixed method/60 mothers/in the hospital and at 1 mo	None/ no/State Trait Anxiety Inventory, EPDS, Perinatal PTSD Questionnaire, Child Health Worry Scale	Greater emotional distress (anxiety, depression, PTSD, worry) in preterm mothers after delivery Higher distress levels at 1 mo (related to alterations in delivery and labor processes and poorer-than-expected infant health outcomes)
Forcada-Guex et al ⁵⁸ —Switzerland	Perinatal PTSD, maternal attachment, and interactions/comparative/72 mothers of preterm and term infants/6 and 18 mo	None/NA/Perinatal PTSD Questionnaire, Working Model of the Child Interview	Balanced representations in only 23% of preterm mothers. Preterm mothers with high PTSD more controlling in interactions Mothers with low PTSD more heterogeneous in interactions
Griffin and Pickler ²⁸ —the United States	Experiences of mothers after discharge/qualitative/10 mothers/2–4 wk	NA/no/NA	Five themes emerged: “dealing with unexpected pregnancy outcome,” “experiencing the reality of taking care of a baby alone,” “struggling to adjust to the maternal role,” “enhancing maternal inner strength,” and “changing the maternal lifestyle”
Miles et al—the United States ¹⁴⁵	Development of maternal role/mixed methods/81 mothers of medically fragile infants/6 and 12 mo	Developmental and systems perspective, Rubin’s theory of maternal role attainment/NA/Maternal Identity Scale, Home Observation for Measurement of the Environment	Higher levels of identity in mothers with less worry. Higher presence in mothers with less alert infants. Competence higher with more alert infants, lower parental role stress, higher education, and being married

(continues)

Table 1. Reports for the review on parenting challenges postdischarge (selected), 1980–2014 (Continued)

Author—country	Focus/design/sample/time frame postdischarge	Theory/definition of transition/instruments	Findings related to transition to home
Murdoch and Franck ⁶³ —Canada	Caregiving experiences/qualitative/9 mothers/8 mo	NA/no/NA	Six themes emerged: apprehension (infant's fragility and loss of the support of the NICU team), confidence, responsibility (for performing infant medical care), awareness (of infant's needs), normalcy, and perspective. Mothers' experiences dominated by responsibility for performing infant medical care. Concerns about normalcy after discharge
Gray et al ¹³⁸ —Australia	Parenting stress and psychological well-being in mothers/comparative/210 mothers of preterm and term infants/4 mo	None/no/Parenting Stress Index, Edinburgh Postnatal Depression Scale, Dyadic Adjustment Scale, Short Temperament Scale for Infants	Nonsignificant difference in stress. No differences in depression. Parental stress does not appear to differ between groups. Depression, marital satisfaction, and infant temperament were risk factors for high parenting stress
Hutchinson et al ²⁹ —the United States	Parent experiences of having an infant in NICU and after discharge/qualitative/9 mothers and 3 fathers/3 wk	Meleis's Transitions Theory/yes/NA	Model of parental progression emerged: premature parental onset, parental incompleteness, involvement, and completion. Feeling of "not being a parent" due to absence of bonding, discharge home without the infant. Lack of control overcome by involvement in care. Joy, fatigue, and changes in social life
Phillips-Pula et al ³⁴ —the United States	Maternal experiences of caring at home/qualitative/8 mothers/6 mo	NA/no/NA	Four themes emerged: fear of unknown, exhaustion due to care-giving demands, determination to do everything for the infant, and thankfulness for having a child. Maternal uncertainty about their readiness to take their infants home
Turner et al ⁴⁰ —Australia	Parental emotional experiences after NICU and transition to home after participating in a support group/qualitative/9 mothers/12 wk	None/no/NA	Anxiety and concerns about the infant getting sick again or requiring rehospitalization. Maternal uncertainty about being prepared to take baby home. Family and friends added to anxiety. Difficulties in coping with ongoing medical needs, feeding, parenting postdischarge. Support group viewed as important
Garfield et al ⁵² —the United States	Concerns of mother and fathers during transition to home/qualitative/25 parents /2–3 mo postdischarge	NA/NA/NA	Uncertainty was the major theme. Parents questioned their abilities to care, have lingering concerns about medical issues of their infant. Balancing work and family, sleep deprivation, around the clock care, knowledge gaps were common. Paternal and maternal concerns differed in terms of fathers' concerns about mother's health

Abbreviations: EPDS, Edinburgh Postpartum Depression Scale; NA, not applicable; NICU, neonatal intensive care unit; PTSD, posttraumatic stress disorder.

because of the absence of the normal beginning of parenthood and altered parental role during hospitalization. As preterm infants are often less active and less responsive in interactions,^{32,36-39} parents may limit their involvement in interactions and decrease their positive affect toward their infant.

Anxiety, worry, and depression

Preterm birth and hospitalization of an infant are the events producing high levels of emotional and psychological distresses in parents. Although parents look forward to taking their infant home, they are also anxious and worried about their abilities to provide proper care at home.^{28,31,34,40} Several studies found that fear of the unknown and the uncertainty about the infant's prognosis and developmental trajectory cause stress and anxiety in parents.^{34,41-43} Anxiety was also related to the fear of the infant's repeated sickness, the occurrence of breathing problems, and parental perceived inability to perform proper caregiving.^{31,40} Clinically significant anxiety and depressive symptoms are often present; higher levels of stress, anxiety, uncertainty, worry, and depression were found in most of the studies.^{31,33,44-52} One study found that correlates of depression are changing with the time.⁵³

Grief and guilt

Two other psychological consequences of preterm birth, feelings of grief and guilt, were also present in parents of preterm infants postdischarge. The majority of qualitative studies reviewed here presented evidence for those feelings in parents during the first 12 months postdischarge.^{30,41,42,44,54-57} The inability to express feelings and share them with others produced additional stress on parents.⁵⁶ The experience of becoming a mother interwoven with breastfeeding and inability to feed the baby creates feelings of guilt and shame.³⁰

Posttraumatic stress disorder

Preterm birth and hospitalization also produce significant psychological trauma for parents. Several reviewed studies found that parents of preterm infants suffer from symptoms of posttraumatic stress disorder (PTSD).^{33,44,58,59} These symptoms include re-experiencing the memories of the traumatic events, avoidance of feelings and thoughts associated with the event, and increased arousal.⁶⁰ Like the parental role alteration that occurs during the hospital stay and continues postdischarge, PTSD related to the infant's hospitalization⁶¹ also continues to affect parents at home settings⁵⁹. Importantly, PTSD was associated with increased parental depression and fatigue.⁴⁴

Learning caregiving and parenting

From the reviewed literature, it appears that learning the skills of caregiving and parenting is difficult for parents of preterm infants, thereby adding more stress. In several studies, parental learning and informational needs were related to the infant's caregiving concerns.^{31,38,41,52,54,62} Preparation for discharge plays important role in successful transition to home: studies reported that mothers felt unprepared and wanted more hands-on experiences before discharge.^{34,40} Often, parents seek information from a variety of resources; sometimes they have to learn how to care for their infant through trial-and-error when resources are not available.⁶³ In addition, social support and maternal education influenced interactions between a mother and an infant,⁶⁴ reflecting the interconnectedness of informational and social needs in parents of preterm infants. Parents want not only to know how to "feed" their infant but also to nurture their infant. Their learning needs seem to change with the time and situation. Immediately after discharge, parents want more information about their infant's routine caregiving routine. With time, the focus changes to the developmental needs and milestones rather than the medical conditions or direct caregiving.^{41,50,62,65} Learning and knowing how to give care and nurture the infant were also related to the development of the parental role and the parent-infant relationships: Vasquez⁶⁵ named gathering information and resources to sustain the life and to protect the infant as the first stage of becoming a parent of preterm infant.

Caregiving burden and fatigue

Fatigue and caregiving burden were underlined in several reviewed studies.^{34,40-42,44,66,67} Maternal experiences often are dominated by the responsibilities of advanced caregiving at home such as gavage feedings, medication administration, and oxygen therapy,⁶³ which occurs often in this population of NICU infants. Tiredness, exhaustion, and sleep deprivation interfered with parental joy of being home and produced feeling of self-blaming for inability to enjoy the infant.

Normalcy versus uniqueness

Parents want to be "normal" parents and they do not want to feel stigmatized or "labeled" by their infant's premature birth, appearance, or diagnosis. An important part of the postdischarge experiences, a theme called "seeking for normalcy" was mentioned in several qualitative studies reviewed here.^{42,63,68} Feeling that their family life or infant is not "normal" adds to the psychological and emotional stress in parents of preterm infants. Prematurity stereotyping and social stigmatization

can lead to social isolation, which is also related to an increased parental willingness to avoid exposure to infections or other health risks.^{39,42}

Social isolation and social support

Parents often report social isolation. Separation from social life, isolation due to the infant's vulnerability and time constraints, fear of stigmatization for having preterm infant, and overvigilance were found in several reviewed studies.^{28,56,63} Having a preterm infant affects family as a whole.^{55,69,70} The social aspects of parenting are important, and the introduction of an infant to the outside world was named as the third stage of becoming a parent of a preterm infant.⁶⁵ However, parents look for adequate social support, and they want this support to be positive and not intrusive. Affleck with colleagues⁷¹ found that the provision of professional support (home support program) for parents of high-risk infants postdischarge had a negative impact on mothers when the infant was relatively healthy. In this study, the home visit transitional program only benefited those mothers who needed such support but not those mothers who were in low need for support.⁷¹ For mothers with low preintervention support needs, the program even had negative effects on their maternal adaptation and perceived as a threat to normalization of life.⁷¹ Maternal transition to home is not always related to the available amount of social support or availability of larger social networks, but rather to the perception and need for such support.^{71,72} Importantly, mothers who had higher social support postdischarge had a greater decrease in depressive symptomatology⁵³; social support was also linked to the interactions with the infant.^{73,74}

Professional support

The availability and perception of professional support also influenced the parental transition to home: more complete information from health professionals and more accurate knowledge of infant development were associated with less anxiety, stress, depression, increased confidence in parents, and better mother-infant relationships.^{31,50,63} Parents also want more individualized approach after discharge, prefer to be in contact with their hospital NICU team reassurance, and have difficulties trusting health professionals in primary settings.^{52,54}

Other findings

While searching the available literature, a lack of definition and conceptualization of transition from hospital to home in parents of preterm infants was found. It appears that transition in parents postdischarge is rather an unexplored area of research and practice, despite a

large amount of related research. Even when the term "transition" was found in the title or the abstract, transition was rarely given a conceptual definition in the reports.⁷⁵⁻⁷⁷ It appears that a clear conceptual definition of transition to home is lacking.

Only a few of the studies reviewed here described a theory or conceptual framework used to guide their research. There were several other reports, opinion papers, that provided some conceptual underpinnings and described factors influencing transition in parents of preterm and high-risk NICU infants.^{67,75,76,78-86} One integrative review was found, with 7 articles included into analysis, where the importance of home visits as the most efficient way to help parents postdischarge was underlined within the differences in the ways of easing transition to home in this population.⁸⁷ All authors suggested that care coordination, communication among healthcare team members and parents, focus on family needs, comprehensive discharge summary, continuation of care postdischarge, parent-to-parent support, and education and training of parents and primary health professionals are essential for successful transitioning to home and primary healthcare settings. In several articles, authors presented their hypothesized models or frameworks and delineated concepts needed to be considered into transition to home and parenting preterm infants.^{67,75,76,79,83,85,86} The concepts/categories mentioned by the researchers were similar in many aspects (such as presence of stress, grief, fatigue, and isolation in parents of NICU and preterm infants); however, none of the theories or frameworks have been tested or validated specifically with parents of preterm infants during transition to home.

Measurement of transition to home varied as well. Researchers used a variety of instruments to identify and measure various parenting and caregiving challenges postdischarge (eg, depression, anxiety, self-efficacy, confidence, worry, stress symptoms, and social support). However, none of the instruments used in the studies was *specific* to the population of parents of preterm infants. This fact may influence the results of the research; it has been suggested that widely available instruments may not adequately address the scope of parenting difficulties in parents of preterm infants postdischarge.^{88,89} Considering recent research, which showed that health professionals might overestimate transitional challenges in parents of former NICU infants,⁹⁰ there is a need for the specific instrument addressing transition to home in this population.

DISCUSSION

The purpose of this integrative review was to examine the evidence and provide a clearer picture

of postdischarge concerns and experiences of parents of preterm infants that would help better conceptualize the construct of transition from hospital to home in this population. Researchers studied numerous aspects of parental challenges and experiences postdischarge: interactions, attachment, parental role development, confidence, caregiving, social support, stress, anxiety, depression, coping to name a few. Over 3 decades of research provide enough evidence that there is large amount of various challenges parents of preterm infants face after discharge, suggesting that transition from home to home is complex and multidimensional.

Many transitional challenges in parents evolve from infant hospitalization. Decades ago, Miles et al⁹¹ found that parents of preterm infants suffer from parental role alteration because of hospital environment and the medical fragility of the infant. It appears that this alteration does not go away with hospital discharge, but continues to manifest itself in the parents of preterm infants after discharge. Other studies also showed, that in the absence of anticipated response from the infant, parents often began to question their own parenting abilities and exhibited lower parental self-confidence and competence.⁹²⁻⁹⁴ Other studies, which went beyond first 12 months after discharge, also reported that attachment and interactions between the parent and infant were affected by infant's appearance, behavior, and specific health needs⁹⁵; mothers who had experienced NICU stay trauma in the perinatal period were found to be less sensitive and more controlling in their interactions.⁹⁶ Many studies reported continuation of the psychological consequences (depression and anxiety) up to 2 years postpartum, affecting attachment to the infant, parent-infant interactions, and infant's development.^{53,97-103} One study⁵³ showed that correlates of depression in mothers changed from environmental stressors and the infant's appearance in the hospital to the previous experience of having a baby and being multiparous. This study⁵³ also brings the infant's neurological complications and longer ventilator support as the variables related to maternal depression at 6 months' corrected age. This evidence provides support for the assumptions that the parental continuous worries about infant's development after the initial survival and trauma of initial hospitalization can be reasons for depression postdischarge. Importantly, postnatal depression was also linked to higher parenting stress 6 weeks after discharge¹⁰⁴; maternal anxiety and higher perception of infant vulnerability were also associated with lower developmental levels in infants and behavioral problems in children.¹⁰⁵⁻¹⁰⁷ Importantly, fatigue and sleep quality were related to depressive symptoms and a lower quality of life in another study of parents

of preterm infants.¹⁰⁸ When depression and low social support were combined, it influenced the development of an infant: infants of mothers with clinically elevated depressive symptoms and low social support had lower scores on cognitive development later in their lives.¹⁰⁹ In other studies, which went beyond first 12 months after discharge and were conducted a long time ago,¹¹⁰ parents also often reported social isolation—as well as in more recent studies. In studies with longer periods for inquiry that were not included into this review, researchers reported that in addition to the parental grief over the loss of “a perfect child” and feelings of guilt for the inability to carry the pregnancy to term, mothers often have difficulties in expressing their grief and forming secure relationships with their infants.¹¹⁰⁻¹¹³ Two studies found the presence of unresolved grief,¹¹⁰ even a chronic sorrow.¹¹⁴ Universal screening for PTSD was recommended as more than half of the mothers of NICU infants experience PTSD^{99,115} as well as screening for postpartum depression.¹¹⁶ Of note, recent research showed that many mothers who brought their infants to the emergency departments were not screened for postnatal depression.¹¹⁷

Several other studies that were not included in this particular review but confirming findings of this review also highlighted the need for professional support postdischarge and importance of adequate informational support.¹¹⁸⁻¹²¹ Deficits in communication among healthcare providers and their lack of experience with preterm infants affected parental experiences postdischarge, causing more stress for parents.¹²¹⁻¹²³ Importantly, parents might use medical follow-up clinics adequately, but they are rarely aware of other parenting services.^{118,124} It has been also suggested that PTSD could be the reason for parental noncompliance with follow-up care recommendations when parents do not want to go back to the hospital for health checks.⁶⁰

As 20 years ago,^{125,126} parents still report higher informational needs at present. Changing informational needs (from caregiving to developmental ones) are also supported by the results of the multicenter study that included more than a thousand of parents of preterm infants.¹²⁷ In essence, parental concerns do not differ from those of the parents of term infants; usually, in both instances, these concerns are health- and caregiving related (eg, feeding, growing, sleeping, and crying); however, parents of preterm infants have a higher intensity of the caregiving concerns, especially immediately after the birth and hospital discharge.^{126,128,129} Feeding as the major concern postdischarge was reflected in research as well: maternal worries about adequate consumption of milk by the infant, milk composition, and problems with the mechanics of breastfeeding were reported.¹³⁰⁻¹³⁴

However, there are some inconsistencies in findings of the studies. Some studies included into this review do not confirm elevated stress and depression levels^{51,135,136} or the effects of depression on interactions between preterm infants and their parents¹³⁷; some reported that depression and anxiety decrease over time.⁴⁶ The other study did not reveal greater parenting stress.¹³⁸ One study showed that the higher perception of the infant's vulnerability was related to the maternal anxiety at discharge but not to the overuse the healthcare service postdischarge.¹⁰⁵ Samra¹³⁹ with colleagues also did not find a relationship between prematurity and maternal overprotection/perception of child vulnerability in mothers of former late preterm infants. De Ocampo with colleagues¹⁰⁷ also suggested that parental protection should be treated differently from parental perception of child vulnerability. In this review, one research³⁶ found that parents of preterm infants, despite infant's low responsiveness, were more active with their infants than parents of term infants. This evidence suggested that parents of preterm infants can be more eager for interactions and stimulation of their infant as they are "searching for normalcy."⁴² Thus, interactions in preterm dyads and families may be more vigorous, and not diminished. The other study also found that maternal responsiveness was stable over time.¹⁴⁰ Although Feeley with colleagues⁶⁴ found that better educated mothers were more competent and interactive with infants, Olshtain-Mann and Auslander⁴⁹ reported that more educated parents felt less competent in parenting and caregiving of preterm infants. Social support groups have been found to be helpful for parents of preterm infants⁴⁰; however, it is not true for everyone. Family and friends of parents of preterm infants, a well-known and accepted resource of social support, were also found to add stress, increase parents' anxiety, and produce feelings of stigmatization.^{141,142} Thus, the assumptions of higher and lasting depression, anxiety, parenting stress, need for supports, and overuse of services may not stand true for all parents of preterm infants; the discrepancies in some results dictate the need for more research.

Factors and concepts influencing transition to home are tightly interwoven. The findings in most research and theoretical/practical assumptions of researchers about transition from hospital to home are similar and iterative. Deep psychosocial consequences of the preterm birth on parents influence the perception of the infant, distort parent-infant relationships, and may affect infant development and healthcare service use. Altered parental role may lead to lower perception of caregiving confidence and competence in parents, higher levels of stress related to the need to care for a baby independently and without direct supervision

from health professionals in home settings. Parents want to feel like the parent they envisioned; they want to develop a strong, positive relationship with their infant. However, to do so, they have to learn how to read the infant's cues and understand the behavior. Building healthy and safe relationships with vulnerable infants requires additional knowledge and information that parents of preterm infants lack. Information need appears to be a core need that helps parents to cope with stress of preterm birth, anxiety and uncertainty about their caregiving skills, and infant outcomes. Surprisingly, the professional support that is vitally important for preterm infants and parents is not reflected adequately in available research, although the transfer of the infant's care from hospital to primary care settings is also a part of transition to home in parents of preterm infants. Transition to home influences parental and infant health and well-being and involves issues of trust, consistency of information, and advice given by primary healthcare professionals, treatment continuation, and clear communication between parties. Discrepancies in information given by health professionals to parents after discharge may lead to a lack of trust of the healthcare specialists in primary healthcare settings. Barriers in communication can increase stress levels in parents, compromise their ability to provide adequate care, and decrease compliance with recommended follow-up care. It appears that professional support, as a category of transition to home, should be considered as belonging to transition to home construct. This concept should include not only infant's healthcare support but professional support for parents as well (eg, counseling services and treatment modalities for posttraumatic stress disorder or depression). Professional support for an infant and parents is vitally important, but appears to be underrepresented in research.

The variety and combination of numerous factors that influence transition to home suggest the need for individual assessment of transition in each parent of preterm infant. Inconsistencies in findings require more research on transition, its definition, and measurement. Having a sound and valid transition instrument could help assess parents before they begin to have severe transition problems. A transition screening tool appears to be needed. Parents need to be assessed for the problems during transition to home, their emotional state, availability and quality of social supports, and whether or not a referral to social support groups is indicated. Although there are some premature parent-related instruments available (eg, the PTSD screening tool developed by Dr Michael Hynan with colleagues¹⁴³), there is no theoretically sound and validated tool for measuring a very important human experience that every parent of preterm infant has postdischarge—a transition to home.

Several other important observations occurred during the process of reviewing the literature. From the first glance on the vast abundance of research conducted with parents of preterm infants, it appeared that the main categories in research on parenting and caregiving for a preterm infant were not mutually exclusive, but interconnected. Many interwoven aspects of parenting and caregiving were studied, even in a one single study. The main focus of 3 decades of research in this population has been on parent-infant interactions, attachment and parental role acquisition, parental confidence/competence, psychoemotional consequences of preterm birth and infant hospitalization on parents and infant development (such as stress, anxiety, and depression), differences between mother and fathers, and effects of interventions (such as teaching and home visiting) on infants and parents.

Definitely, research on parenting of a preterm infant and transition to home in parents of preterm infants is growing over the past decades. Some trends can be observed in the studies, within the constant comparisons of the preterm and term infants. It appears that, conceptually, the research themes have changed from a focus in the 80s on interactions—mainly parent-child interactions—to the service use and costs in the 1990s such as rehospitalizations and use of emergency departments and other services. From 2000 to 2010, research on depression, social support, and stress, and coping seems to have increased. Finally, in first 5 years of this decade (2010–2015), research in parents of preterm infants is growing even faster and it is expanding in the scope. More and more interconnected aspects of transition to home in parents of preterm infants are studied at present: depression, anxiety, and effects of it on infants; competence and confidence in parenting, stress, PTSD and resources; paternal parenting and differences between mothers and fathers of preterm infants, just to name a few. The impact of healthcare professionals' support postdischarge, specifically in primary healthcare settings, and its effect on transition seemed to be less investigated in this population.

In summary, the complexity and multidimensionality of transition is obvious; findings from qualitative studies are in accord with the results of the studies that applied quantitative methods. The majority of qualitative studies described transition to home as a process that consists of acceptance and development of the parental role, learning caregiving and parenting, with higher needs in social and professional supports, while nurturing and protecting a vulnerable infant and developing relationships with the infant. The following themes appeared to emerge from research in parents of preterm infants: (a) disruption of parental role development, (b) strained development of parent-infant relationships, (c) psycho-

logical consequences of a preterm birth and infant hospitalization, (d) learning caregiving and parenting, and (e) need for social and professional supports.

CONCLUSION

The findings of this review reveal certain aspects of parenting and caregiving challenges in parents of preterm infants during transition from hospital to home. The emerged themes appear to reflect parental challenges during transition from hospital to home after discharge. One concept, specifically professional support, which is vitally important and relevant to the successful transition from hospital to home in parents of preterm infants, should be included into conceptualization of this transition. It appears that transition to home is an individualized process requiring careful individualized *assessment* of parental personal characteristics, psychoemotional state, stress levels, coping strategies, parental informational needs, and needs in social and professional supports if we are to provide effective, efficient, and safe care and services postdischarge. At present, there is no instrument to assess parental transition after hospital discharge to home. Such an instrument would help identify parents of preterm infants who are in need for supports. The development of a valid and reliable tool for measuring parental transitional challenges is warranted.

LIMITATIONS

There are several important limitations that the reader must consider. In this article, only a snapshot is given of parenting and transition to home in parents of preterm infants; the time frame for search was broad and only selected research from each decade was presented here. Thus, the findings presented here should be considered only as the first effort to integrate a vast amount of research on parents of preterm infants. The problem formulated for this review was very broad; conceptualization and definition of transition were limited. The search for studies related to parenting and caregiving for preterm infants postdischarge was rather complicated due to absence of a clear conceptualization and definition of transition from hospital to home in this population. The inclusion criteria were broad. Also, search results may not be replicable as a wide ancestry and the author-performed journal hand searches due to reasons named earlier. The longitudinal studies that were started in the hospital and continued longer than 12 months postdischarge were excluded; thus, a large amount of valuable information related to parenting and caregiving during the first few weeks and months after discharge had been omitted. Because of space

limitations for this publication, a large amount of important research on feeding issues and effect of interventions was not included into this review. A historical overview of the research on parenting and caregiving for preterm infants as well as a more comprehensive integration of research evidence related to the transition from hospital to home in this population is warranted.

IMPLICATIONS FOR RESEARCH AND PRACTICE

This article is the first effort to integrate findings from all the studies on parents of preterm infants as related to transition from hospital to home in this vulnerable population. This article helps nurses and other health professionals to begin to conceptualize the transition to home and better understand the phenomenon.

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