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Mapping the Home-Care Experiences of Parents of Preterm Infants With Bronchopulmonary Dysplasia Receiving Home Oxygen Therapy: A Descriptive Qualitative Study

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Abstract

Background Bronchopulmonary dysplasia (BPD) remains one of the most common and burdensome complications of prematurity. Although home oxygen therapy (HOT) has become an increasingly standard component of post-discharge care for preterm infants with BPD.

Little is known about how parents navigate the transition from hospital monitoring to independent home caregiving. how parents experience this caregiving trajectory and where nursing support is most needed across different stages of home care.This study aimed to develop a journey map of parents' home-care experiences while caring for preterm infants with BPD receiving HOT, to identify stage-specific care needs and inform the refinement of discharge preparation and transitional care services.

Methods

A descriptive qualitative study was conducted using semi-structured interviews with 21 parents of preterm infants with BPD receiving HOT in a tertiary children's hospital in Chongqing, China. Interviews were held by telephone or face to face. Data were analyzed using directed content analysis guided by a provisional journey-map framework. COREQ guidelines informed the study's design and reporting.

Results

Parents' experiences were organized into four stages: discharge preparation, home transition, oxygen-therapy adaptation, and oxygen-weaning adjustment. Caregiving tasks shifted from learning oxygen-related knowledge and skills, preparing equipment and the home environment, and acquiring emergency-care skills to independently monitoring oxygen saturation, coordinating oxygen use with feeding, preventing infection, attending follow-up visits, supporting rehabilitation, and managing oxygen weaning. Emotional experiences included expectation, uncertainty, hypervigilance, sleep disruption, fatigue, social restriction, increasing confidence, and continuing concerns about oxygen discontinuation, recurrent illness, and long-term development. Major pain points included information overload, difficulty interpreting oxygen saturation changes and warning signs, feeding and growth problems, unclear oxygen-weaning criteria, limited access to timely professional support, travel burden for specialist follow-up, and sustained family caregiving pressure.

Conclusions

Journey mapping revealed stage-specific caregiving tasks, emotional experiences, and unmet support needs among parents of preterm infants with BPD receiving HOT. These findings highlight the need for continuous, nurse-led, family-centered transitional care that extends beyond discharge education and provides individualized support throughout home oxygen management and oxygen weaning.

Clinical trial number

Not applicable.

Introduction

Advances in perinatal medicine have substantially improved the survival of preterm infants in China; however, the incidence of BPD has not declined correspondingly. Multicenter studies in China report that the incidence of BPD among extremely preterm infants ranges from 37.0% to 51.5% depending on the diagnostic criteria applied[1]. Because infants with BPD have impaired pulmonary function and prolonged oxygen requirements, a proportion of them require ongoing oxygen support after discharge.

HOT for clinically stable infants with BPD receiving low-flow oxygen is therefore an important strategy to shorten hospitalization, reduce the consumption of health-care resources, and promote mother-infant attachment [2]. Data from the Chinese Neonatal Network show that approximately 26.8% of preterm infants with BPD require HOT after discharge [3]. In addition to oxygen dependence, infants with BPD may experience continuing respiratory and developmental problems after discharge, which can substantially affect parental and family quality of life [4, 5].

HOT is not simply a continuation of in-hospital treatment but a long-term process of transition from hospital-based monitoring to family care. After discharge, parents must independently perform multiple tasks at home, including operating and maintaining the oxygen concentrator, monitoring oxygen saturation, coordinating oxygen support during feeding, recognizing abnormal conditions, and deciding whether to seek medical care. Existing studies have focused mainly on the safety of HOT, and rehospitalization risk; few have systematically described parents' experiences and needs throughout the entire course of home care.

A journey map is a patient-centered, evidence-informed visual or descriptive representation of an individual's or family's trajectory through a defined episode of care, organized chronologically to integrate care stages, service touchpoints, and users' experiences and needs, thereby identifying pain points and opportunities for improvement[6]. In recent years, journey mapping has been successfully applied to complex care contexts, including cervical dystonia[7], work-focused health care for employees with cardiovascular disease[8], community-based anticipatory medication care at the end of life[9], and health management of patients with chronic obstructive pulmonary disease[10], demonstrating its value in identifying stage-specific care needs and improving services. To the best of our knowledge, no journey map has yet been developed to systematically depict the home-care experiences of parents of preterm infants with BPD receiving HOT. Accordingly, this study used a descriptive qualitative design to construct a journey map to depict this caregiving trajectory, with the aim of informing discharge preparation, and improving transitional care services.

Methods

Study design

We conducted a qualitative descriptive study informed by a journey-mapping approach. Semi-structured interviews were used to explore parents' home-care experiences, and the findings were organized chronologically to construct a journey map of the care trajectory. The study was reported in accordance with the 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist; the completed checklist is provided as Supplementary File 1.

Participants

From May to November 2025, parents of preterm infants with BPD who were discharged from the neonatal department of a tertiary children's hospital in Chongqing, China, and required HOT were recruited using purposive sampling. Eligible participants were parents who: (1) were the primary caregivers of a preterm infant diagnosed with BPD [11]; (2) had personally participated in the infant's care during HOT; (3) were aged ≥ 18 years; and (4) were able to communicate in Mandarin and provide informed consent. Parents were excluded if they had cognitive or communication difficulties.

A maximum-variation sampling strategy was followed, with infant gestational age, length of hospital stay, mode and duration of oxygen use after discharge, and parental age, educational level, and occupation as the main dimensions. The distribution of the enrolled sample was assessed dynamically, and additional cases were recruited purposively to fill sampling gaps until information saturation was reached. The study was approved by the Medical Ethics Committee of Children's Hospital of Chongqing Medical University (Approval No. 353 (2023). All participants provided written informed consent. Only the parent who assumed primary responsibility for the infant's home care and management of HOT was recruited from each family.

Journey map construction

Journey-map construction followed an iterative three-step process informed by published guidance[6]. First, the research team developed a provisional framework through a literature review and team discussion. The framework comprised four care stages (discharge preparation, home transition, oxygen-therapy adaptation, and oxygen-weaning adjustment) and three dimensions (caregiving tasks, emotional experiences, and pain points).Although the provisional framework informed initial coding, stage boundaries and categories were treated as flexible and were revised when participants' accounts did not fit the predefined structure. Second, semi-structured interviews were conducted, and the interview data were used to test, refine, and populate the provisional framework. This process produced a preliminary journey map. Third, the preliminary map was reviewed by two participants, one qualitative research expert, and two neonatal clinical experts. Reviewers assessed the clarity, completeness, chronological organization, and correspondence of the map with parents' experiences. Feedback was documented and discussed by the research team, and substantive changes were incorporated into the final map. Nursing opportunities were derived from pain points identified in the interview data and refined through team discussion, clinical expert consultation, and participant review.

Interview guide construction

The initial interview guide was constructed through a literature review, consultation with clinical experts, and research team discussion based on the above provisional framework. Two parents of preterm infants with BPD receiving HOT who met the inclusion criteria were invited to participate in pilot interviews, and the guide was revised and finalized based on feedback from these pilot interviews. Two pilot participants were not included in the final sample and their data were not included in the analysis.

The final guide included the following main questions: (1) Please describe the entire process, from first learning that your baby would require HOT after discharge to providing care at home and subsequently weaning your baby from oxygen. Which experiences or events left the deepest impression on you? (2) During HOT, what caregiving tasks did you perform? What difficulties or challenges did you encounter, and how did you cope with them? (3) How did your emotional state change while caring for your baby during HOT? Which events caused the greatest emotional changes? (4) How did HOT affect your daily life, and how did you adjust and adapt? (5) Which people or resources were most helpful to you during HOT? In what ways and through which channels would you like healthcare professionals to provide support? (6) Looking back on this experience, what would you most like healthcare professionals to know, and what advice would you give to other parents preparing to undertake HOT?

Data collection

Semi-structured interviews were conducted in Mandarin by two researchers.Both interviewers were neonatal nurses at the study hospital and had completed training in qualitative research and semi-structured interviewing before data collection.The purpose, significance, content, and confidentiality principles of the interview were explained before each interview. Interviews were conducted either by telephone or face to face, depending on geographical accessibility and participant preference. Telephone interviews were scheduled in advance. Face-to-face interviews were conducted during outpatient follow-up visits in a quiet, private assessment room. The same interview guide was used in both modes. No one other than the participant and interviewer was present, and no repeat interviews were conducted. With permission, all interviews were audio-recorded and lasted approximately 20 to 30 minutes. The interviewers listened attentively, used techniques such as probing, restating, and clarification when appropriate, and documented participants' tone, pauses, and emotional responses, as well as relevant non-verbal information during face-to-face interviews. Data collection and preliminary analysis occurred concurrently. After each interview, the researchers reviewed the emerging codes and themes. Recruitment ceased when two consecutive interviews generated no new themes.

Data analysis

Within 24 hours of each interview, the interviewer transcribed the audio recording verbatim in Chinese and supplemented the transcript with relevant information documented in the interview notes. The data were analyzed using directed content analysis as follows[12]: (1) the predefined journey-map framework guided the coding process and informed the initial coding categories; (2)

meaningful text segments were first assigned to the predefined categories, while new codes were created for data that could not be accommodated within the existing framework; (3) codes were continuously compared, categorized, and merged to generate themes for each stage; (4) coding disagreements were resolved by consensus through research-team discussion or consultation with clinical experts; and (5) the resulting themes and subthemes were organized chronologically within the journey-map framework to describe parents' caregiving tasks, emotional experiences, and pain points at each stage.Coding was conducted manually without qualitative data-analysis software. Quotations selected for publication were translated from Chinese into English by a bilingual member of the research team.

Trustworthiness

Two interviewers were neonatal nurses at the study hospital and had pre-existing clinical relationships with some participants. To reduce the potential influence of these relationships and the researchers' prior assumptions on data collection and interpretation, the interviewers avoided leading questions, maintained reflexive journals, and discussed their assumptions during research-team meetings.Trustworthiness was addressed according to the criteria of credibility, transferability, dependability, and confirmability proposed by Lincoln and Guba [13]. Credibility was enhanced through independent coding by two researchers, cross-checking of the findings, and resolution of disagreements through research-team discussion. After the preliminary findings had been developed, two participants reviewed them to assess whether they accurately reflected their experiences. In addition, one qualitative research expert and two neonatal clinical experts reviewed the findings and provided methodological and clinical feedback. Transferability was supported through maximum-variation sampling and detailed descriptions of the participants, study setting, and care context. Dependability was enhanced by documenting interview notes and reflexive journals throughout data collection and maintaining successive versions of the codebook and records of analytical decisions, thereby creating an audit trail. Confirmability was supported through reflexive journaling, maintenance of the audit trail, independent coding, and participant feedback, which helped minimize the influence of researchers' assumptions on the interpretation of the findings.

Results

Participant characteristics

A total of 21 parents participated, seven interviews were conducted by telephone and 14 were conducted face to face. All eligible parents who were approached agreed to participate, and no participants withdrew after enrollment.The infants' gestational ages ranged from 25^{+5} to 32^{+0} weeks, birth weights from 700 to 1700 g, and durations of HOT from 3 to 180 days. The participants comprised 17 mothers and four fathers aged 27–50 years. Twenty infants received HOT via low-flow nasal cannula, and one received high-flow nasal cannula oxygen. Participant characteristics are presented in Table 1.

Table 1
Participant characteristics (n = 21)

ID	GA of infants (weeks)	BW of infants (g)	Gravida/Para	LOS (days)	Mode of HOT	HOT duration (days)	Role	Age (years)	Education	Occupation
P1	29^{+6}	1300	G2P1	44	Nasal cannula	7	Mother	30	High school	Clerk
P2	27^{+2}	1000	G4P1	18	Nasal cannula	7	Mother	33	High school	Self-employed
P3	28^{+4}	790	G1P1	91	Nasal cannula	7	Father	30	Bachelor	Self-employed
P4	28^{+4}	1040	G4P3	63	Nasal cannula	7	Mother	33	Junior high school	Staff
P5	32^{+0}	1600	G3P2	66	Nasal cannula	7	Mother	31	Bachelor	Self-employed
P6	27^{+1}	1030	G1P2	27	Nasal cannula	7	Mother	32	Master	Health-care worker
P7	31^{+6}	1540	G1P1	37	Nasal cannula	7	Mother	30	Bachelor	Teacher
P8	29^{+4}	850	G2P2	73	Nasal cannula	15	Mother	40	Master	Legal professional
P9	28^{+3}	1200	G3P2	60	Nasal cannula	15	Father	34	Junior high school	Unemployed
P10	28^{+0}	800	G2P2	65	Nasal cannula	14	Mother	38	Master	Physician
P11	32^{+0}	1590	G3P2	71	Nasal cannula	30	Mother	39	Junior high school	Self-employed
P12	27^{+1}	1010	G5P2	223	Nasal cannula	30	Mother	31	Bachelor	Clerk
P13	28^{+3}	1105	G2P2	82	Nasal cannula	14	Mother	35	Bachelor	Clerk
P14	30^{+6}	1480	G1P1	49	Nasal cannula	15	Father	32	Bachelor	Clerk
P15	30^{+3}	1700	G1P1	44	Nasal cannula	14	Mother	27	High school	Unemployed
P16	25^{+5}	700	G3P1	107	Nasal cannula	3	Mother	50	Primary school	Unemployed
P17	25^{+5}	750	G1P1	111	Nasal cannula	7	Mother	28	Technical secondary school	Nurse
P18	28^{+3}	1400	G1P1	26	Nasal cannula	7	Mother	37	Bachelor	Accountant
P19	26^{+3}	980	G3P3	165	Nasal cannula	45	Mother	35	Bachelor	Nurse
P20	26^{+2}	880	G2P2	71	Nasal cannula	15	Mother	30	Bachelor	Teacher
P21	29^{+0}	1200	G2P2	104	High-flow	180	Father	31	Junior high	Self-employed

ID	GA of infants (weeks)	BW of infants (g)	Gravida/Para	LOS (days)	Mode of HOT	HOT duration (days)	Role	Age (years)	Education	Occupation
					nasal cannula				school	

GA, gestational age; BW, birth weight; LOS, length of hospital stay; HOT, home oxygen therapy

Journey map framework and stage definitions

The journey-map framework was organized chronologically into four stages: discharge preparation, home transition, oxygen-therapy adaptation, and oxygen-weaning adjustment. Three experiential dimensions were examined at each stage: caregiving tasks, emotional experiences, and care needs and pain points. The operational definitions of the four stages are presented in Table 2.

Table 2
Operational definitions of the journey map stages

Stage	Time/event definition	Main care-seeking behaviors and touchpoints	Stage characteristics
Discharge preparation	From confirmation that the infant requires HOT after discharge to formal discharge	Discharge education, handover of oxygen equipment, home environment preparation, and transitional care such as family-centered wards	Intense tasks; information overload
Home transition	First 1–2 weeks after discharge; period of adjustment to the care model	Coordinating oxygen saturation monitoring with feeding, first outpatient follow-up, and seeking medical care for abnormal conditions	High vigilance; adjustment to independent care
Oxygen-therapy adaptation	Ongoing oxygen management after the infant's condition stabilizes, before the initiation of weaning	Regular follow-up, formula transition, routine growth and neurodevelopmental assessments, and vaccination	Multiple parallel tasks; social withdrawal
Oxygen-weaning adjustment	From initiation of oxygen weaning through complete weaning or continued long-term oxygen management	Gradual oxygen reduction with reassessment of saturation, developmental screening and home-based rehabilitation, and management of recurrent infections	Hope coexisting with uncertainty

Core findings across the four care stages

In this section, P1–P21 denote participant codes; each quotation is accompanied by the participant's parental role.

Discharge preparation

Acquiring technical caregiving competence. During discharge preparation, parents needed to acquire substantial knowledge and practical skills within a limited period, including monitoring oxygen saturation, adjusting oxygen flow, replacing the nasal cannula, recognizing abnormal conditions, selecting and installing an oxygen concentrator, and preparing the home environment for safe oxygen use. One mother described the difficulty of choosing appropriate equipment: "It took me several days just to buy the oxygen concentrator. There were too many models online and I had no idea which one suited my baby; in the end, I ordered one only after a nurse recommended a specific model" (P1, mother). Several parents sought additional information from books and the internet, but inconsistent sources increased the burden of evaluating and reconciling information.

Anxiety about assuming clinical responsibility. Learning that the infant would still require oxygen after discharge generated anxiety about disease progression and home safety, as well as uncertainty about the transition from continuous professional monitoring to family-managed care. "When the doctor said we still needed oxygen at home, I panicked. In the hospital, nurses were watching over us, but at home it was just me. What if the oxygen tube came off and I did not even notice?" (P5, mother). Assuming the roles of observer, equipment operator, and initial decision-maker also created role uncertainty and a sense of helplessness when making care decisions. One father explained, "In the hospital, I simply followed the doctors' orders, but once home I suddenly felt like I had become the 'attending physician.' I had to make the first judgment about anything happening to my

baby—the pressure was enormous" (P9, father). Nevertheless, some parents anticipated returning to family life, and experience in family-centered wards increased their confidence in providing care at home.

Navigating information overload and ambiguous guidance. Parents described difficulty retaining the large amount of information delivered before discharge and reconciling information obtained from different sources. "The nurse taught me all at once how to read the oxygen saturation, adjust the flow rate, and change the nasal cannula, along with a pile of precautions. I thought I had understood everything at the time, but once I got home and tried to do it, I had forgotten it all" (P3, father). They also expressed a need for specific guidance on oxygen-flow adjustment, oxygen-saturation thresholds, and indications for seeking medical attention. As one mother stated, "I still do not know when to adjust the oxygen flow rate, because I have not actually used it yet" (P2, mother).

Based on these pain points and participant-expressed needs, the research team identified three potential nursing opportunities: contextualized multimodal education, access to consistent and authoritative information, and transitional support through family-integrated care.

Home transition

Performing oxygen care while learning to interpret the infant's condition. After discharge, parents independently operated the oxygen concentrator, fitted the nasal cannula, and monitored oxygen saturation. They also coordinated oxygen delivery with feeding and modified feeding practices according to the infant's condition. "When he first came home, feeding was quite difficult and he needed oxygen; he would feed for a while and then rest" (P6, mother). As parents gained experience, they began to assess changes in oxygen saturation, respiration, and temperature and to decide when medical attention was required. "On the very first night at home, he developed a fever and severe tachypnea. I realized something was wrong and took him to the hospital immediately" (P12, mother).

Sustained vigilance and exhaustion. Parents remained highly alert to equipment function, oxygen-saturation readings, and subtle changes in the infant's condition. "I had to keep checking whether the oxygen was properly in place and whether the saturation probe had fallen off … we were shut in at home every day" (P19, mother). Continuous nighttime monitoring and responding to the infant's crying disrupted sleep and contributed to physical and emotional exhaustion. "I could not sleep well at night, because whenever he cried or fussed, I had to comfort him immediately" (P3, father).

Interpreting ambiguous signs with limited family support. Parents found it difficult to distinguish normal fluctuations or behavioral cues from abnormalities requiring intervention. "At first, he probably was not used to it. When he cried, we could not tell whether he was hungry or unwell" (P15, mother). Several families also had insufficient caregiving support, with mothers assuming most nighttime monitoring, feeding, equipment management, and observation responsibilities. "Caring for him alone is really exhausting; sometimes I am overcome by drowsiness, and I still have to prepare his milk" (P4, mother). These accounts indicated a need for actionable home-observation criteria, clear pathways for managing abnormal findings, and better allocation of caregiving responsibilities within families.

Based on these findings, the research team identified potential nursing opportunities in the form of actionable home-observation checklists, clearly defined pathways for responding to abnormal findings, and guidance on care support and allocation of caregiving responsibilities.

Oxygen-therapy adaptation

Integrating oxygen therapy into increasingly complex daily care. As the infant's condition gradually stabilized, families began to establish new routines. Parents incorporated oxygen-therapy management—including changing the humidifier water, cleaning the nasal cannula, checking equipment function, and monitoring oxygen saturation—into feeding, sleeping, and play. With increasing familiarity, these tasks became less disruptive, allowing parents to attend to other activities. "I was a little frightened when we first came home, but now we have become accustomed to it. We continue to monitor the baby's oxygen saturation, and I sometimes have time to do other things" (P21, father). Alongside routine oxygen management, parents also coordinated formula changes, follow-up appointments, growth monitoring, and neurodevelopmental assessments. These overlapping responsibilities created

uncertainty about how to prioritize and coordinate care. “We had no idea how to change the formula. Did we need to make an appointment with a neonatologist?” (P8, mother).

Persistent worry, cumulative fatigue, and social restriction. Although parents became more proficient in routine oxygen care, recurrent symptoms, difficulty accessing professional support, and concerns about development contributed to continuing worry and self-doubt. “Our baby also has a problem with head control—he does not lift his head well. Because he was premature, I am still worried about his brain development” (P10, mother). The cumulative demands of caregiving and disrupted sleep contributed to persistent fatigue and, for some parents, burnout. “He never fell asleep before midnight … when he was not sleeping, it was mostly me holding him … he only stopped crying when he was picked up” (P11, mother). Dependence on stationary oxygen equipment also substantially restricted families’ activities outside the home. “During the oxygen period, we never went out because the concentrator was large and inconvenient to carry” (P9, father).

Limited access to consistent professional guidance. Parents living outside the local area encountered substantial travel burdens when attending specialist follow-up. “Because we live far away, we had to drive to follow-up visits … taking the high-speed rail took at least three hours” (P12, mother). Parents also described uncertainty when professional advice was inconsistent, particularly regarding vaccination. “Because our baby received intravenous immunoglobulin during hospitalization, we did not know when vaccination should be given. Everyone said something different—some doctors said 8 months, and others said 1 year” (P19, mother). These findings indicated a need for accessible specialist consultation and consistent, individualized guidance.

Based on these needs, the research team identified potential nursing opportunities, including proactive follow-up led by neonatal specialist nurses, structured triage and response mechanisms for remote consultation, and individualized vaccination decision support.

Oxygen-weaning adjustment

Balancing oxygen reduction with longer-term developmental care. During oxygen weaning, parents reduced oxygen flow, shortened the duration of oxygen administration, or used oxygen intermittently while monitoring oxygen saturation, often in collaboration with clinicians. As respiratory status improved, parents increasingly focused on swallowing, gross-motor, and neurodevelopmental assessment and home-based rehabilitation. “His gross motor development is still relatively slow, so since coming home we have been strengthening his training” (P18, mother). Recurrent respiratory infections, wheezing, deterioration after colds, and rehospitalization nevertheless prolonged the management trajectory for some families.

Hope coexisting with continuing uncertainty. Parents remained concerned about feeding safety, recurrent illness, development, and long-term prognosis. “The baby is now 8 months corrected age. When he eats food with a thicker consistency, he chokes and vomits, so we do not dare feed him” (P17, mother). Prolonged restrictions on activities outside the home contributed to low mood in some parents. Nevertheless, accumulating caregiving experience helped others develop confidence and a sense of achievement. “At first, I was nervous and anxious and did not know how to care for him, but now I am used to it” (P21, father). Improvement in the infant’s condition also generated optimism: “The baby is recovering very well now, and I am quite satisfied” (P16, mother).

Uncertain weaning criteria and limited continuity of support. Parents lacked clear, actionable criteria for reducing or discontinuing oxygen and managing fluctuations in oxygen saturation. This uncertainty made them reluctant to adjust oxygen independently, even when saturation appeared satisfactory. “Sometimes his saturation is 97% or 98%, and I think we can stop the oxygen, but sometimes it drops to 93%. When can we really stop? I do not dare decide on my own” (P9, father). Long-term rehabilitation also required substantial commitments of time and financial resources. “For this baby’s rehabilitation, just the exercise sessions cost several thousand yuan a month, all out of pocket” (P19, mother). Community and primary-care support remained limited, and families continued to rely on tertiary hospitals for complex care needs. “I hope there is a more direct and authoritative consultation channel, such as being able to contact a doctor quickly to get answers” (P21, father).

Based on these findings, the research team identified potential nursing opportunities including standardized written decision support for oxygen weaning, coordinated hospital–community follow-up, and linkage to rehabilitation and financial-support resources.

Integrated journey map

The findings across the four care stages and three experiential dimensions were integrated into the final journey map (Fig. 1). The map illustrates how parents' caregiving tasks, emotional experiences, and pain points evolved throughout the home-care trajectory. It also presents the potential nursing opportunities identified at each stage. Although the map is organized chronologically, individual caregiving trajectories were not always linear. Experiences could overlap across stages, and recurrent illness or rehospitalization could return families to earlier patterns of vigilance and uncertainty.

A systematic overview of the stage-by-dimension findings, including all 34 subthemes, is provided in Supplementary Table S1.

Discussion

This study used journey mapping to characterize how parents' caregiving tasks, emotional experiences, care needs, and pain points evolved across four stages of caring for preterm infants with BPD receiving HOT. The initial need to acquire technical competence was followed by intensive vigilance during the transition home, gradual integration of oxygen therapy into family routines, and continuing uncertainty during oxygen weaning. Journey mapping therefore offered more than a chronological description of parents' experiences, and it identified how the focus of professional support should change throughout the home-care trajectory.

Providing stage-specific, continuous training with an emphasis on oxygen adjustment and weaning

Parents' learning needs changed as they progressed through the home-care trajectory, indicating that HOT training should extend beyond discharge preparation. This finding suggests that discharge education should not be treated as a one-time intervention, but rather as the starting point of a continuous process. Previous research has emphasized the importance of appropriate discharge preparation and organized follow-up to support the safe management of HOT[2, 14]. Training should therefore be continuous and stage-specific, responding to parents' evolving caregiving responsibilities and decision-making needs.

Particular attention should be given to oxygen adjustment and weaning because these were among the most challenging and uncertain aspects of HOT. Oxygen-weaning practices vary among centers, and universally accepted evidence-based criteria for infants with BPD remain lacking[5, 15, 16]. Decisions regarding oxygen reduction or discontinuation may require consideration of respiratory stability, oxygen saturation during sleep, feeding, and activity, as well as growth and developmental status. Yeh et al.[17] reported that some families initiated oxygen weaning without direct medical guidance, potentially exposing infants to unrecognized hypoxemia and associated cardiopulmonary risks[15, 18]. Training should therefore help parents understand the purpose of HOT, distinguish routine fluctuations from clinically important changes, accurately document oxygen use and saturation readings, and recognize when professional reassessment is required.

Discontinuity of professional support across the home-care trajectory

Limited access to timely and consistent professional guidance was particularly evident during the oxygen-therapy adaptation and oxygen-weaning adjustment stages. As parents assumed increasingly complex responsibilities, they required support not only in managing episodic clinical concerns but also in making decisions related to oxygen adjustment, vaccination, developmental assessment, rehabilitation, and eventual oxygen discontinuation. Long travel distances for specialist follow-up, delayed responses to online consultations, inconsistent advice from different professionals, and limited community-based support compounded uncertainty and reinforced families' reliance on tertiary hospitals. Similar needs for accessible and actionable post-discharge guidance have been reported among parents of very preterm infants not specifically selected for BPD or HOT[19]. These findings underscore the importance of establishing an integrated hospital–community professional support system for families of very preterm infants, with particular attention to those caring for infants receiving HOT.

These findings should be interpreted within the Chinese healthcare context. The strong reliance on tertiary hospitals and informal digital communication channels may partly reflect limited access to community-based professionals experienced in managing medically complex preterm infants. Consequently, the transferability of these service-related findings to settings with established

community neonatal or home-oxygen programs should be considered carefully. Nevertheless, the underlying need for continuity between hospital and home is consistent with broader evidence supporting structured post-discharge care for high-risk infants. Nurse-led transitional-care programs may complement physician-led clinical follow-up by providing caregiver education, reinforcing individualized care plans, and coordinating services across hospitals, families, and communities. Nurse-led programs have improved maternal competence and selected post-discharge outcomes among preterm infants[20], while digital health and telenursing interventions may improve access to support for families unable to attend frequent in-person visits [21, 22].

Potential components of this hospital-community support system include proactive follow-up at key stages, access to remote consultation, structured recording of oxygen use and symptoms, and clearly defined escalation pathways. Video-based consultations may enable healthcare professionals to observe infants in their home environment, guide parents through aspects of clinical assessment, and provide more individualized advice regarding home-care concerns [22, 23]. However, advanced approaches such as automated alerts or remote physiological monitoring were not evaluated in this study. Their feasibility, safety, acceptability, and effectiveness should be examined in future implementation research rather than assumed from the present qualitative findings.

Dynamic emotional burden and the need for family-level support

Parents' emotional experiences changed as caregiving demands evolved. Initial fear and confusion gave way to intense vigilance and sleep disruption after returning home. As HOT became integrated into family routines, some parents developed greater confidence and a sense of achievement, but practical adaptation did not mean that psychological distress had fully resolved. Concerns about recurrent illness, developmental delay, oxygen discontinuation, and long-term prognosis persisted, while dependence on oxygen equipment restricted activities outside the home and contributed to social isolation. These findings are consistent with earlier accounts of families caring for infants receiving continuous oxygen[24] and with evidence that BPD adversely affects parental health-related quality of life[4]. They also extend previous research by showing how sources of distress changed across the home-care trajectory rather than remaining static.

The concentration of daily caregiving responsibilities in one primary caregiver may intensify fatigue, sleep deprivation, and emotional strain. Although fathers and other co-caregivers were underrepresented in the sample, participants' accounts suggest that psychological support should be directed toward the family system rather than only the individual parent attending follow-up. Routine follow-up should therefore include assessment of emotional distress, social restriction, and available family support. Involving fathers, grandparents, and other co-caregivers in training may distribute responsibility more equitably, while peer support and referral pathways for persistent psychological distress may reduce isolation. Given that parental anxiety can persist after neonatal intensive care discharge[25], support should continue beyond the period in which parents demonstrate technical competence.

Implications for stage-specific transitional care

The journey map provides a framework for matching professional support to families' changing needs rather than applying a uniform post-discharge program to all stages of care. Its clinical value lies in helping healthcare professionals identify when the focus of support should shift and when additional assessment or intervention may be required. However, the nursing opportunities identified in this study were derived from participants' expressed needs and refined through participant and expert review; they should not be interpreted as interventions whose effectiveness has already been established. Future research should co-design stage-specific transitional-care programs with parents, neonatal professionals, and community healthcare providers and evaluate their feasibility, acceptability, safety, and effects on caregiver competence, psychological well-being, healthcare use, and infant outcomes.

Strengths and limitations

A principal strength of this study was the use of maximum-variation sampling, which captured experiences across diverse infant clinical characteristics and parental sociodemographic backgrounds. This approach broadened the range of perspectives represented and enhanced the richness and potential transferability of the findings.

Several limitations should be considered. First, participants were recruited from a single tertiary children's hospital in Chongqing, which may limit the transferability of the findings to regions with different populations, healthcare resources, or models of post-discharge support. Second, mothers constituted most of the sample (17/21); consequently, the experiences of fathers and other co-caregivers were less fully represented. In addition, 20 of the 21 infants received low-flow nasal cannula oxygen, meaning that the journey map primarily reflects experiences associated with low-flow HOT and may not capture the technical and caregiving demands of home high-flow respiratory support. Third, telephone interviews enabled participation by geographically distant parents but limited observation of non-verbal communication and may have produced different interactional dynamics from face-to-face interviews.

Conclusion

The journey map demonstrates that parents' caregiving responsibilities, emotional experiences, and support needs evolve throughout the home-care trajectory of preterm infants with BPD receiving HOT. These findings underscore the importance of continued, stage-specific training on home care and an integrated hospital-community professional support system. Future studies should evaluate the feasibility and effectiveness of interventions developed from the nursing opportunities identified across the four stages.

Declarations

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Author contributions

Xiaochuan Zhu: Conceptualization, Investigation, Data curation, Formal analysis, Visualization, Writing - Original Draft. Huayun He : Methodology, Investigation, Formal analysis, Writing - Review & Editing. Xiaojun Tao , Jianhui Wang , Qian LI ,Lu Wei and Mei Zhou: Investigation, Data curation, Writing - Review & Editing.Juan Fan: Conceptualization, Supervision, Resources, Writing - Review & Editing, Project administration,Funding acquisition.All authors read and approved the final manuscript.

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Data availability

Due to confidentiality requirements and the sensitive nature of the interview data, full transcripts cannot be shared publicly. De-identified excerpts supporting the findings are included in the article, and additional information may be made available from the corresponding author upon reasonable request .

Ethics approval and consent to participate

This study was approved by the Medical Ethics Committee of Children's Hospital of Chongqing Medical University (Approval No.353 (2023). All participants received information about the study and provided informed consent before participation. Data collection and use followed the principles of confidentiality and anonymity.

Consent for publication

Not applicable.

Declaration of generative AI

During the preparation of this work, the authors used Chat-GPT to improve language. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Competing interests

The authors declare no competing interests.

References

1. Yang G, Wang L, Gao C, et al. Variations in bronchopulmonary dysplasia prevalence and outcomes by definition: a multicentre cohort study from the Chinese Neonatal Network. BMJ Open. 2026;16:e106960.
2. Pirr S, Peter C. Home oxygen therapy after hospital discharge. Semin Fetal Neonatal Med. 2020;25:101082.
3. Jiang WX, Wang YC, Song HX, et al. Characteristics of home oxygen therapy for preterm infants with bronchopulmonary dysplasia in China: results of a multicenter cohort study. World J Pediatr. 2023;19:557–67.
4. Berlin KEK, Scott W, Dawson S, et al. Health-related quality of life for parents of infants with bronchopulmonary dysplasia. J Pediatr. 2024;264:113773.
5. Everitt LH, Awoseyila A, Bhatt JM, et al. Weaning oxygen in infants with bronchopulmonary dysplasia. Paediatr Respir Rev. 2021;39:82–9.
6. Bulto LN, Davies E, Kelly J, et al. Patient journey mapping: emerging methods for understanding and improving patient experiences of health systems and services. Eur J Cardiovasc Nurs. 2024;23:429–33.
7. Benson M, Albanese A, Bhatia KP, et al. Development of a patient journey map for people living with cervical dystonia. Orphanet J Rare Dis. 2022;17:130.
8. Hagendijk ME, Zipfel N, Oomen FJ, et al. Work-focused healthcare from the perspective of employees living with cardiovascular disease: a patient experience journey mapping study. BMC Public Health. 2023;23:1765.
9. Fennessy R, Paterson A, Ward J, et al. Mapping patient journeys: exploring patient and informal carer experiences of injectable anticipatory medication care in the community to identify opportunities for practice improvements. Palliat Med. 2026;40(7):1034–46.
10. Chen S, Li Y, Zhang Y, et al. Construction of a patient health management patient journey map based on health action process approach theory for patients with chronic obstructive pulmonary disease. Chronic Respir Dis. 2026;23:14799731261469848.
11. Higgins RD, Jobe AH, Koso-Thomas M, et al. Bronchopulmonary dysplasia: executive summary of a workshop. J Pediatr. 2018;197:300–8.
12. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15:1277–88.
13. Lincoln YS, Guba EG. Naturalistic inquiry. Newbury Park: Sage; 1985.
14. Zafar A, Hall M. Types of home respiratory support in children with bronchopulmonary dysplasia and factors determining its duration: a scoping review. Pediatr Pulmonol. 2024;59:834–44.
15. Hayes D Jr, Wilson KC, Krivchenia K, et al. Home oxygen therapy for children: an official American Thoracic Society clinical practice guideline. Am J Respir Crit Care Med. 2019;199:e5–23.
16. Fitzgerald DA. The infant with bronchopulmonary dysplasia on home oxygen: the oxygen weaning conundrum in the absence of good evidence. Paediatr Respir Rev. 2023;47:11–5.
17. Yeh J, McGrath-Morrow SA, Collaco JM, et al. Oxygen weaning after hospital discharge in children with bronchopulmonary dysplasia. Pediatr Pulmonol. 2016;51:1206–11.
18. Collaco JM, Romer LH, Stuart BD, et al. Frontiers in pulmonary hypertension in infants and children with bronchopulmonary dysplasia. Pediatr Pulmonol. 2012;47:1042–53.
19. Zhang L, Li X, He J, et al. Maternal discharge preparation needs for preterm infants with less than 32 weeks of gestation: a qualitative study. J Adv Nurs. 2026;82:1515–26.
20. Kavitha K, Patil MM, Sikandar BJ, et al. Effectiveness of the nurse-led multi-component BRIDGE program on maternal competence and selected post-discharge outcomes of preterm babies: a randomized controlled trial. Int J Nurs Stud.

2025;165:105027.
21. Praharaj M, Tripathy P, Nanda D, et al. Digital health interventions for mothers and their high-risk neonates discharged from NICU: a systematic review and meta-analysis. J Neonatal Nurs. 2025;31:57–67.
22. Göger S, Meşe Tunç A, Çevirme A. The effect of tele-nursing on premature infants and their mothers: a systematic review. BMC Nurs. 2026;25:328.
23. Albayrak B, Cordier LJ, Greve S, et al. Feasibility of video consultation for preterm neurodevelopmental follow-up care during the COVID-19 pandemic: a cohort study. JMIR Pediatr Parent. 2023;6:e40940.
24. Young LY, Creighton DE, Sauve RS. The needs of families of infants discharged home with continuous oxygen therapy. J Obstet Gynecol Neonatal Nurs. 1988;17:187–93.
25. Span LC, van Dokkum NH, ter Horst HJ, et al. Parental anxiety trajectories 2 years after NICU discharge. Pediatrics. 2026;158(2):e2025074834.

Figures

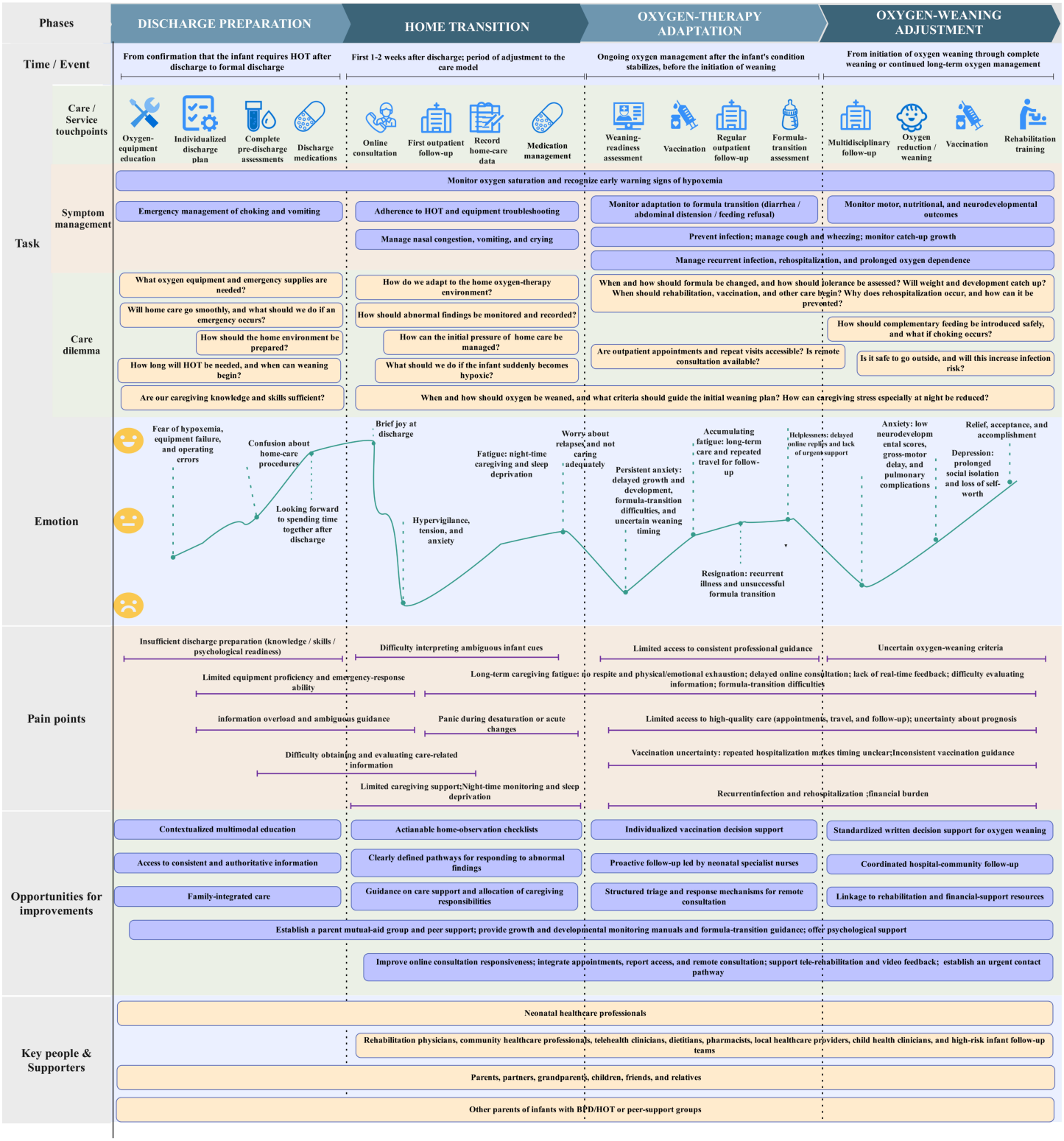


Figure 1

Journey map of the home-care experiences of parents of preterm infants with BPD receiving HOT

Supplementary Files

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- SupplementaryFile1COREQChecklist.docx

- SupplementaryTableS1.docx