
MEDICAL HUMANITIES RESEARCH PROSPECTUS · CONCEPT PAPER



From Lived Experience to Research Questions

A Medical Humanities Prospectus Inspired by The Silence Between Two Heartbeats

by A T M Haidar Khan

Prepared for medical humanities, narrative medicine, and interdisciplinary neonatal research audiences

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This prospectus reads a memoir as a source of researchable questions, never as evidence of medical fact. It offers no diagnosis, clinical judgment, or medical advice, and it evaluates no clinician's or institution's care.

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SCOPE

This work is a medical-humanities research prospectus. It uses lived experience and a published memoir to develop questions for scholarly and scientific consideration. It does not provide medical advice, establish clinical diagnoses, or constitute a clinical research protocol.

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This prospectus treats a published family memoir as a source of researchable questions, never as evidence of medical fact. *The Silence Between Two Heartbeats* (A T M Haidar Khan, First Edition, 2026) recounts, from a narrating father's perspective, an infant's difficult birth, three weeks of neonatal intensive care, and the months of home caregiving that followed.

The index case is Chapter Nine, "Six Months Without a Night," in which a caregiver watches a sleeping infant through the night for signs of what the book calls "the invisible storm." From it we derive one primary question: **after NICU discharge for high-risk infants, is there a safe, practical, non-invasive, clinically validated way to capture abnormal electrographic brain activity in the home when caregivers observe concerning movements?**

A rapid scoping review finds that the tools needed to answer this exist in pieces but not together. Video-EEG remains the diagnostic standard; caregiver smartphone video has validated value; portable neonatal EEG and seizure-detection algorithms are maturing in hospital settings. We did not identify a validated, caregiver-deployable EEG pathway for infants at home. The paper then derives ten further questions from the manuscript and sets out pathways to university collaboration and funding.

Keywords: narrative medicine; neonatal encephalopathy; post-discharge care; home EEG; caregiver observation; parental mental health; research agenda-setting

1. Introduction and epistemic stance

Family narratives notice things that clinical records are not designed to capture: what happens at 3 a.m., what a caregiver fears, what could not be documented. Narrative medicine has long argued that such accounts deserve careful reading. This prospectus asks a narrower question: what can a memoir contribute to *research agenda-setting*?

What this paper claims, and what it does not

The manuscript is treated as	The manuscript is not treated as
A record of caregiver observation, fear, and interpretation	Clinical documentation of diagnosis, treatment, or outcome
A prompt for questions clinicians and scientists can test	Evidence that any event was medically what the narrator believed it to be
A window into gaps between hospital care and home life	A judgment about the quality of any clinician's or institution's care
One family's account, partly reconstructed	Representative of families in general

The book's own copyright page states that some conversations and passages were artistically reconstructed and that the fairytale chapters are metaphorical. We therefore draw only on Part I (Chapters One to Sixteen), and we read even that as narrative testimony. Every research question below is worded so that the answer could turn out to be "no."

Why this memoir

The narrative describes events consistent with severe perinatal oxygen deprivation, delayed transfer to a specialized unit, 21 days of neonatal intensive care, and post-discharge fear of recurring seizures. It does not supply clinical records, and this paper does not attempt to reconstruct them. Its value lies in the caregiver's-eye view of the months after discharge, a period where the literature is comparatively thin.

A note on terminology: the manuscript uses the phrase "the invisible storm." In Chapter Nine the narrator lists its warning signs as abnormal eye movements, sudden stiffening, rhythmic jerking, changes in breathing, and unusual mouth

movement.**KEYWORDS** Medical Humanities · Narrative Medicine · Hypoxic-Ischemic Encephalopathy (HIE) · Neonatal Seizures · NICU Post-Discharge Care · Home EEG · Neuromonitoring · Caregiver Experience · Family-Centered Care · Pediatric Neurology

2. Methods

2.1 Reading the manuscript

We used the definitive print manuscript (First Edition, 2026; ISBN 979-8-18255-919-5). All of Part I (front matter, Prologue, and Chapters One to Sixteen, pp. 1–150) was read in full: Chapters One to Twelve from the print PDF, and Chapters Thirteen to Sixteen from the author's ebook edition, whose text matches the print edition. Page numbers follow the print table of contents. Part II (Chapters Seventeen to Twenty-Nine) is an allegorical fairytale and was excluded by design.

We coded passages where the narrator (a) observes a bodily sign, (b) describes a care task, (c) reports a clinical conversation, or (d) describes his own physical or emotional state. Each coded passage was kept only if it pointed to a question that existing clinical or social science methods could investigate.

2.2 Rapid scoping review

The index question was scoped using the Population–Concept–Context frame recommended for scoping reviews.

Element	Definition used
Population	Infants discharged from neonatal intensive care at elevated neurological risk (for example, neonatal encephalopathy or neonatal seizures), birth to 24 months
Concept	Methods that capture, or help interpret, possible electrographic seizure activity outside continuous hospital monitoring
Context	The home, or methods plausibly transferable to it
Sources	PubMed-indexed literature, ILAE position papers, trial registries, device regulatory information; searched September 2026

This was a rapid, single-reviewer scoping pass, not a PRISMA-ScR review. It is sufficient to frame the question, not to settle it. A registered, dual-reviewer scoping review is proposed as the first deliverable of any collaboration (Section 7).

Evidence was sorted into three tiers:

- **Established:** supported by guidelines, randomized trials, or consistent peer-reviewed findings in the relevant population.
- **Experimental:** peer-reviewed or registered work that is promising but unvalidated for infants at home.
- **Speculative:** plausible ideas with no direct evidence in this population; offered as hypotheses only.

3. Index case: "Six Months Without a Night" (Chapter Nine, pp. 60–72)

The chapter describes the first six months after discharge. The monitors are gone, but the narrator writes that "the fear had come home with her." He sits beside the sleeping infant through the night, often until dawn, watching for signs.

3.1 What the narrator observes

The chapter catalogs the movements that alarmed him: a twitch of the fingers, a sudden arm stretch, a tightening of the face, movement beneath the eyelids, a strange sound, a change in breathing. He researches warning signs online and memorizes them: abnormal eye movements, stiffening, rhythmic jerking, breathing changes, unusual mouth movements.

He also names the problem precisely. "The more he learned, the more he watched. And the more he watched, the more there was to fear." Each ambiguous movement became a question he had no way to answer. In retrospect, he writes, watching could not control what happened; it could only keep him awake.

3.2 The gap the passage exposes

Read as testimony, the chapter describes an **information gap**, not a medical event. The caregiver had:

- an event that might or might not be clinically meaningful,
- no method to record it in a form a clinician could interpret, and
- no way to learn which movements were benign.

The passage does not tell us whether any observed movement was epileptic. That uncertainty is exactly what makes it a research prompt.

3.3 Primary research question

After NICU discharge for high-risk infants, is there a safe, practical, non-invasive, clinically validated way to capture abnormal electrographic brain activity in the home when caregivers observe concerning movements?

For study purposes, each qualifier needs an operational definition:

Qualifier	Proposed working definition
Safe	No skin injury, no cords or devices posing entanglement or unsafe-sleep hazards, no increase in unnecessary medication

Qualifier	Proposed working definition
Practical	Can be started by a trained caregiver within minutes of an observed event, without a technologist on site
Non-invasive	Scalp-surface or contactless; no needles or implanted sensors
Clinically validated	Signal quality and seizure detection compared against standard video-EEG in infants, with reported sensitivity, specificity, and false-alarm rate
Abnormal electrographic activity	Electrographic seizures as defined by current ILAE and ACNS criteria, not movements alone
Home	The infant's usual sleep and care environment, outside continuous clinical supervision

3.4 Sub-questions

1. How often do caregivers of high-risk infants observe movements they find concerning after discharge, and what do they do next?
2. What proportion of such caregiver-flagged events have an electrographic correlate when properly recorded?
3. Can caregivers apply and start a recording device reliably, and is the signal interpretable?
4. Does access to a validated capture method change caregiver anxiety, sleep, or health-care use, for better or worse?

3.5 What the later chapters add to the index case

Chapters Thirteen to Fifteen sharpen the index question in three ways.

- **Vigilance did not coincide with the event.** In April 2024, after days of fever and little sleep, the father left the house briefly to buy food. On the way back, the mother called: "Fareesa is shaking." The narrator writes that the moment he had watched for over six months arrived "during the few minutes he was away" (Ch. 14, pp. 104–126). Continuous parental watching is not a reliable capture method, and it carries a real cost to the caregiver.
- **The observed event was reported by a second caregiver, by phone.** The first description a clinician could have received was a single word, "shaking," relayed under extreme stress. This is exactly the kind of report the literature finds hard to interpret without video or EEG.
- **Ambiguity persisted even in hospital.** In the ICU, a cold towel used to lower the fever made the infant "jerk," and the father's fear returned instantly (Ch. 15, pp. 127–146). A startle to cold is not a seizure, yet to a primed observer it looked the same. Distinguishing the two is the problem the primary question asks technology to solve.

The book reports that the fever, the virus, and "the invisible storm" resolved within three days (Ch. 15). This prospectus makes no inference about what the April event was clinically.

4. Scoping review: capturing electrographic activity at home after NICU discharge

The answer to the primary question, as of September 2026, appears to be **not yet**. Each component exists, but we found no peer-reviewed study validating a caregiver-started, non-invasive EEG method for infants at home after NICU discharge.

4.1 Established evidence

Movements alone cannot establish a seizure in young infants. The ILAE's 2021 neonatal classification places EEG at the center of diagnosis, notes that many neonatal seizures are electrographic-only, and excludes clinical events without an EEG correlate ([Pressler et al., 2021](#)). In its data collection, seizures in neonatal encephalopathy of hypoxic-ischemic type were usually electrographic ([ILAE proof](#)).

Even trained observers struggle. In a video study, 137 health professionals from eight NICUs classified paroxysmal movements without EEG ([Malone et al., 2009](#)). Experienced neonatologists recognized seizures in only 22–57% of seizure-positive records in one analysis ([Karamian et al., 2022](#)). This is the central fact behind Chapter Nine: a caregiver's watchfulness, however devoted, cannot answer the question he was asking.

The risk the narrator feared is real but not universal. In one cohort of cooled infants with moderate-to-severe encephalopathy, 15% developed epilepsy by 24 months ([2026 cohort](#)). A single-center study found that stopping antiseizure medication at discharge was not associated with more epilepsy by 12 months ([Iowa cohort, 2024](#)). Most at-risk infants, in other words, will not go on to have epilepsy, and caregivers have no way to know which group their child is in.

Caregiver video helps, within limits. In adults, expert review of outpatient smartphone videos predicted a video-EEG diagnosis of epileptic seizures 89.1% of the time ([Tatum et al., 2020; summary](#)). In infants with epileptic spasms, those whose events were captured on smartphone video were diagnosed and treated a median of 17 days earlier ([J Pediatr, 2023](#)). A pediatric team review of home videos cut "uncertain" referrals from 15 to 2 ([Evelina, 2025](#)). Video still records movement, not brain activity, and cannot detect electrographic-only events.

Home video-EEG works in older children. A pilot of 20 home video-EEG studies found it feasible, but participants were aged 2.1 to 17.2 years, and video quality was a limitation ([Heliyon, 2024](#)). These are scheduled, technologist-applied recordings, not recordings started in response to an event.

4.2 Experimental approaches

Portable and reduced-montage neonatal EEG. Devices such as NeuroBell are designed for EEG in NICUs that lack specialist staff ([NeuroBell](#)), and an observational study is comparing its signal quality with conventional EEG in term neonates ([registry](#)). The trade-off is coverage: fewer

electrodes may miss focal seizures, and neonatal data show fewer detected seizures as electrode count drops ([review](#)).

Automated seizure detection. The ANSeR randomized trial, in 264 term neonates across eight European centers, found that a real-time algorithm raised correct recognition of seizure hours from 45.3% to 66.0%, but did not improve identification of which infants had seizures ([Pavel et al., 2020](#); [commentary](#)). It ran on full NICU EEG, with clinicians present.

Video AI for infant events. A foundation video model trained to recognize epileptic spasms reached an AUC of 0.96 and was validated against video-EEG ([2025](#)). It addresses one seizure type, from video, and is not yet a clinical service.

Wearable seizure detectors. Current FDA-cleared wearables are for older children and adults: EpiMonitor from age 6 ([Empatica](#)), EpiWatch from age 5, NightWatch validated in ages 4–16 ([Danny Did](#); [Epilepsy Alliance America](#)). They target convulsive seizures, and one 2026 study found a wrist device detected every tonic-clonic seizure but none of the focal ones ([Medscape](#)).

4.3 Speculative ideas (hypotheses only)

- **Event-triggered home EEG kit:** a pre-fitted infant cap a trained caregiver starts after a concerning movement, streaming to remote review.
- **Paired capture:** synchronized smartphone video and brief reduced-montage EEG, so each event carries both movement and brain signal.
- **Tiered triage:** AI screening of caregiver video, escalating only flagged events to tele-neurophysiology.

None of these has been tested in this population. Each raises safety questions (skin, cords, safe sleep), equity questions (connectivity, cost, literacy), and a real risk of false reassurance or false alarm.

4.4 Summary by tier

Approach	Tier	Records brain activity?	Validated in infants at home?
In-hospital continuous video-EEG	Established	Yes	Hospital standard only
Caregiver smartphone video, expert review	Established (adults; infant spasms)	No	Partly (spasms)
Scheduled home video-EEG	Established (ages 2+)	Yes	No
Portable reduced-montage neonatal EEG	Experimental	Yes	No (NICU only)
Automated EEG seizure detection	Experimental	Yes (analysis)	No (NICU only)
Video AI for infant events	Experimental	No	No
Wrist-worn seizure detectors	Established for ages 4–6+	No	No

Approach	Tier	Records brain activity?	Validated in infants at home?
Event-triggered caregiver EEG kit	Speculative	Yes	Untested

4.5 Where the gap sits

The missing piece is not a sensor or an algorithm. It is a **validated pathway**: who applies the device, when, how the signal is reviewed, how fast, and what the family is told. That pathway is where a humanities-informed, family-centered study could contribute.

5. Ten further questions from the manuscript

Each instance follows the same six-part structure. Research questions are deliberately cautious: they ask whether and how, never assume the answer.

#	Chapter	Theme	Main discipline
5.1	1–2	Timing of neuroprotective care after transfer	Neonatology, health services
5.2	2	Lactation when mother and infant are in different hospitals	Lactation science, nursing
5.3	4	Prognostic conversations under uncertainty	Communication, ethics
5.4	5, 10	Oral feeding after discharge	Speech-language pathology
5.5	1, 8	Giving bitter liquid medicines at home	Pharmacy
5.6	9, 14	Caregiver hypervigilance, sleep loss, and lasting trauma	Perinatal mental health
5.7	12	Interpreting ambiguous sleep behaviors	Pediatric epilepsy, sleep
5.8	14–15	Febrile event, emergency response, and parents at the bedside	Pediatric neurology, emergency medicine
5.9	16	Intensity of early therapy after rehospitalization	Developmental pediatrics
5.10	13	An acute breathing episode during a respiratory illness	Pediatric emergency medicine, caregiver training

5.1 The hours before transfer (Chapters One–Two)

- **Manuscript observation:** The narrator writes that the infant went "nearly eleven agonizing hours without the treatment that could have protected her vulnerable brain" before transfer to a specialized unit (p. 7).
- **Potential clinical relevance:** Therapeutic hypothermia for moderate-to-severe neonatal encephalopathy is time-sensitive.
- **What is known:** Guidelines recommend cooling within 6 hours of birth ([Timing study](#)). Outborn infants may have worse outcomes, and the benefit of starting at 6–12 hours remains uncertain ([PLOS One, 2026](#)).

- **What is not known:** How families understand treatment timelines, and how their recollections compare with documented times.
- **Research question:** *How do parents of outborn infants understand the timing of neuroprotective care, and how closely do their recollections align with clinical records?*
- **Expert validation:** Neonatologist, neonatal transport specialist, clinical ethicist. This prospectus makes no judgment about the care described.

5.2 Milk with nowhere to go (Chapter Two)

- **Manuscript observation:** The mother is discharged the same day, separated from her infant. Six days later she calls at midnight in pain from engorgement; she has no breast pump, and the father drives one to her (pp. 20–25).
- **Potential clinical relevance:** Separation after transfer can delay milk expression and add physical and emotional burden.
- **What is known:** Earlier expression is linked to earlier lactation and higher volumes (RCT, 2018). Mothers describe expression during separation as exhausting and emotionally charged (BMC review, 2024).
- **What is not known:** Whether lactation support follows mothers discharged from a birth hospital when the infant is in a different hospital.
- **Research question:** *When a newborn is transferred to another hospital, what lactation support do mothers receive at discharge, and where are the gaps?*
- **Expert validation:** Lactation consultant (IBCLC), obstetric nurse, NICU family-support lead.

5.3 "She may never walk" (Chapter Four)

- **Manuscript observation:** Midway through the NICU stay, the team tells the parents the infant may never walk, speak, or eat by mouth, and may need a gastrostomy tube. She later feeds orally and goes home at 21 days (pp. 35–45).
- **Potential clinical relevance:** Prognosis after neonatal brain injury is uncertain, especially in milder cases, and framing shapes family coping.
- **What is known:** Prognostic ambiguity is greatest in mild-to-moderate encephalopathy (2021 study). In one cooled cohort, 77% of infants fed orally at discharge and 14% had gastrostomy tubes (2025).
- **What is not known:** How worst-case prognostic statements are recalled by families years later, and how they shape later narratives.
- **Research question:** *How do parents recall and make meaning of early prognostic conversations when later outcomes differ from what was discussed?*
- **Expert validation:** Neonatal communication researcher, palliative-care clinician, narrative medicine scholar.

5.4 One bottle, one hour (Chapters Five and Ten)

- **Manuscript observation:** After prolonged intubation, the infant reaches required oral volumes within a week. At home, one bottle takes nearly an hour, and she feeds best while asleep (pp. 73–82).
- **Potential clinical relevance:** Prolonged feeds can signal oral-motor difficulty; feeding in a drowsy state raises questions a feeding specialist should assess.
- **What is known:** Infants with hypoxic-ischemic encephalopathy of all severities are at increased risk of feeding and swallowing difficulty ([SAJCD, 2025](#)). In one case series, 9 of 29 showed penetration or aspiration, mostly silent ([2022](#)).
- **What is not known:** Typical post-discharge feeding durations in this population, and how families adapt without follow-up.
- **Research question:** *What feeding patterns do caregivers report in the months after discharge, and which warrant specialist review?*
- **Expert validation:** Pediatric speech-language pathologist, neonatal follow-up clinician. Nothing here is feeding advice.

5.5 The bitter medicine (Chapters One and Eight)

- **Manuscript observation:** In the NICU the infant takes a "harsh alcohol-based medication" (p. 7). At home, a twice-daily medicine is so bitter she refuses it, so the father places it on the bottle nipple (pp. 52–59). The drug is not named.
- **Potential clinical relevance:** Palatability affects adherence; some pediatric liquids contain excipients of concern.
- **What is known:** One licensed UK phenobarbital elixir contains 38% v/v ethanol, and UK guidance prefers ethanol-free forms ([Pharmaceutical Journal](#); [NHS SPS, 2026](#)). Excipient amounts are often not stated on labels ([review](#)). We do not infer which medicine was used.
- **What is not known:** How caregivers actually administer refused medicines to infants at home, and with what effect on dosing.
- **Research question:** *What strategies do caregivers use to give unpalatable liquid medicines to infants after discharge, and are they given guidance?*
- **Expert validation:** Neonatal or pediatric pharmacist.

5.6 Six months without a night (Chapters Nine and Fourteen)

- **Manuscript observation:** The narrator stays awake most nights for six months, researching warning signs online, and recognizes later that fear drove the vigilance (pp. 60–72). Years after the April 2024 hospitalization, he writes, speaking about that night could still change his breathing and break his voice: "memory does not always understand that an event has ended" (pp. 104–126).

- **Potential clinical relevance:** Sustained sleep loss and hyperarousal affect caregiver health and capacity.
- **What is known:** Anxiety and post-traumatic stress are common in parents of neonatal-unit infants, highest in the first month, when nearly 2 in 5 report symptoms ([meta-analysis](#)). Fathers' own mental health predicted their hyperarousal symptoms ([2022](#)).
- **What is not known:** Whether fear of seizure recurrence is a distinct driver of nighttime vigilance, and whether monitoring tools reduce or amplify it.
- **Research question:** *Among caregivers of infants discharged after neonatal seizures, how is fear of recurrence related to sleep, vigilance, and use of monitoring?*
- **Expert validation:** Perinatal psychologist or psychiatrist; father-inclusive research team.

5.7 Laughter in sleep (Chapter Twelve)

- **Manuscript observation:** While watching the sleeping infant at home, the father sees her laugh loudly and joyfully, and experiences it as a moment of wonder (pp. 89–91).
- **Potential clinical relevance:** Parents primed to watch for danger must sort many benign sleep behaviors from rare concerning ones.
- **What is known:** About 9% of infants have paroxysmal movement events in the first year, most of them benign ([2025](#)). Expert video review can reclassify many feared events as non-epileptic ([Evelina, 2025](#)).
- **What is not known:** How caregivers of high-risk infants interpret ambiguous but benign behaviors, and what reassures them.
- **Research question:** *How do caregivers of high-risk infants decide which sleep behaviors are normal, and would structured video review change those decisions?*
- **Expert validation:** Pediatric epileptologist, pediatric sleep specialist. The passage is not read as a clinical event.

5.8 The April hospitalization (Chapters Fourteen–Fifteen)

- **Manuscript observation:** In April 2024 the infant develops a viral fever. After several days, the mother reports by phone that she is "shaking"; emergency services respond and she is taken by ambulance to hospital. In the emergency department, repeated attempts at intravenous access in her hand fail and access "through the bone" is used. She cries for nearly an hour, then loses consciousness, and is admitted to intensive care, where staff cool her with a towel and suction her congested nose. The parents decide to stay at the bedside together, recalling that they could not accompany her at birth. The book reports recovery within three days and her first Eid spent in hospital (pp. 104–146).
- **Potential clinical relevance:** Febrile events in infants with a history of neonatal seizures raise questions of discharge planning, emergency response, procedural pain, and family presence.

- **What is known:** A minority of cooled infants develop epilepsy by age 2 (15% in one cohort), and seizures after rewarming have been associated with later epilepsy (2026; 2020).
- **What is not known:** What fever and seizure guidance families receive at NICU discharge and retain months later; and how parents who were separated from their infant at birth experience presence during emergency procedures.
- **Research question:** *What guidance on fever and seizure response do families of high-risk infants receive at discharge, what do they recall during a first emergency, and how do they experience being present for emergency procedures?*
- **Expert validation:** Pediatric neurologist, pediatric emergency physician, neonatal discharge nurse, child life specialist. The memoir does not specify what the April event was, and this paper does not infer it.

5.9 Four therapies a day (Chapter Sixteen)

- **Manuscript observation:** After returning home from the April hospitalization, the family enters "an exhausting whirlwind of evaluations, endless doctor's visits, and appointments." They call her their "glass girl." At "just six months old" she is described as facing "four different therapies every single day" (p. 147). The book's timeline here is approximate: April 2024 falls several months after her late-summer 2023 birth.
- **Potential clinical relevance:** Therapy dose and family burden must be balanced.
- **What is known:** International guidelines support early intervention for infants at high risk of cerebral palsy (overview). Evidence on optimal dose is mixed; one trial of ultra-early parent-delivered physiotherapy did not improve 4-month motor scores (Best Start, 2024).
- **What is not known:** How many sessions families actually receive, how the schedule is set, and its time and financial cost to caregivers, especially after a rehospitalization.
- **Research question:** *What therapy schedules do families of high-risk infants follow in the first year, how are they decided, and how do families experience the burden?*
- **Expert validation:** Developmental pediatrician, pediatric physical and occupational therapists, health economist.

5.10 One breath (Chapter Thirteen)

- **Manuscript observation:** In December 2023, during a cold with a badly blocked nose, the infant vomits while resting on her father's chest and then appears unable to draw breath. He repositions her and cries out in prayer; after what feels like an endless interval she gasps and begins breathing again (pp. 92–103). The chapter does not describe a hospital visit afterward.
- **Potential clinical relevance:** Nasal obstruction and vomiting can compromise breathing in young infants. Caregivers need to know how to respond and when to seek care.
- **What is known:** The American Academy of Pediatrics defines a brief resolved unexplained event (BRUE) as a sudden episode under 1 minute in an infant under 1 year, with color change,

abnormal breathing, tone change, or altered responsiveness, that remains *unexplained* after history and examination; episodes with a clear cause, such as choking after vomiting, are classified by that cause (StatPearls; AAP). In 335 parents of high-risk infants across five NICUs, CPR training reduced anxiety and burden and increased sense of control, with gains still present at 6 months (Moser et al., 1999).

- **What is not known:** How often caregivers of high-risk infants face acute breathing episodes at home, what they do in the first seconds, and whether they seek evaluation afterward.
- **Research question:** *Among caregivers of infants discharged from neonatal intensive care, how often are acute breathing episodes experienced at home, how do caregivers respond, and does pre-discharge resuscitation and airway training change those responses?*
- **Expert validation:** Pediatric emergency physician, neonatal nurse educator, resuscitation trainer. Nothing here is first-aid guidance; families should follow training from qualified instructors.

6. Ethics, limitations, and expert validation

6.1 Ethical commitments

- **The child cannot consent.** The memoir is published, but its central figure is a young child. Studies should analyze the text as a public work, never seek her clinical records, and avoid any detail that adds identification beyond the book itself.
- **No retrospective clinical judgment.** No part of this program evaluates the care any clinician or hospital provided.
- **Author as partner, not investigator.** The author's role is best framed as a lived-experience advisor. Clinical questions need independent investigators without a personal stake in the answers.
- **Prospective work needs ethics review.** Any study recruiting families or testing devices requires institutional review board approval, informed consent, and a data-safety plan.

6.2 Limitations

1. **One family, one voice.** The account is a single case told from one parent's perspective.
2. **Reconstruction.** The book states that some passages were artistically reconstructed; details may be compressed or reordered.
3. **Metaphor.** Terms such as "the invisible storm" are literary; clinical meaning cannot be assumed.
4. **Scope.** Part I only. The fairytale chapters were excluded, so any insight they carry about caregiving is not captured here.

5. **Rapid review.** The scoping review was single-reviewer and time-limited; it may have missed relevant studies, particularly device work not yet published.

6.3 Required expert validation

Before any question advances, a small panel should confirm it is well-posed, not already answered, and feasible.

Expertise	Questions reviewed	What they validate
Pediatric epileptologist / clinical neurophysiologist	Index question, 5.7, 5.8	Seizure definitions, device performance thresholds, safety
Neonatologist (neurocritical care)	5.1, 5.3, 5.8	Clinical framing, existing standards of care
Biomedical engineer (EEG)	Index question	Signal quality, electrode design, remote review
Speech-language pathologist	5.4	Feeding assessment and safety
Pediatric pharmacist	5.5	Formulations, administration practices
Lactation consultant	5.2	Lactation physiology and support models
Perinatal mental-health clinician	5.6	Measures of anxiety, sleep, trauma symptoms
Developmental pediatrician / therapists	5.9	Therapy dosing and burden measures
Narrative medicine scholar and ethicist	All	Reading method, consent, representation
Parent advisors (beyond this family)	All	Relevance, acceptability, language
Pediatric emergency physician / resuscitation trainer / child life specialist	5.8, 5.10	Emergency response, caregiver training, family presence during procedures

7. Pathways to university collaboration and funding

The realistic route is a university-led team in which a clinician or scientist is principal investigator, a humanities scholar shapes method and interpretation, and the author serves as a lived-experience advisor. Most funders require an institutional applicant; the Gerber Foundation, for example, makes no grants to individuals ([Gerber Foundation](#)).

7.1 Who to partner with

Partner type	Contribution	Fit with this program
Narrative medicine or health humanities program	Reading method, qualitative design, teaching use of the text	All questions; natural lead for Phase 1
Pediatric neurology or neonatal neurocritical care program	Clinical PI, EEG expertise, patient access	Index question, 5.7, 5.8
Neonatal EEG engineering group (e.g., teams behind automated neonatal seizure detection)	Devices, algorithms, signal validation	Index question

Partner type	Contribution	Fit with this program
NICU follow-up clinic	Recruitment, feeding and developmental outcomes	5.3, 5.4, 5.9
Perinatal mental-health researchers	Validated caregiver measures	5.6
Parent organizations and research-network community boards	Advisory input, recruitment reach, dissemination	All

7.2 Phased roadmap

Phase	Timing	Work	Output
0. Validate	Months 0–3	Convene the expert panel (Section 6.3); register a full scoping review protocol	Refined questions; registered protocol
1. Listen	Months 3–12	Qualitative interviews with 20–30 caregivers of discharged high-risk infants about night-time observation and events	Paper on caregiver observation after discharge
2. Test feasibility	Months 12–24	Small study of caregiver-started, reduced-montage EEG paired with video, reviewed remotely against clinical assessment	Feasibility, safety, and signal-quality data
3. Validate accuracy	Year 3+	Prospective diagnostic-accuracy study against standard video-EEG	Sensitivity, specificity, false-alarm rate in infants at home

The ten further questions in Section 5 can run as parallel, lower-cost qualitative or survey studies, often suited to student theses or a narrative medicine course.

7.3 Funding routes

Funder type	Why it fits	Notes
Gerber Foundation (Pediatric Research)	Prioritizes infants from pre-birth to 3 years and seeks new diagnostic tools that are less invasive (Research grants)	Novice grants up to \$30,000 (Univ. of Utah); rarely funds parent-education projects (Pediatric research)
NIH exploratory and small-grant mechanisms (NICHD, NINDS)	Feasibility and pilot device studies	Requires institutional PI; confirm current mechanisms and deadlines with a university grants office
Patient-centered outcomes funders	Caregiver-defined outcomes, comparative approaches	Strong fit for Phases 1–2
Epilepsy and HIE foundations	Mission alignment, seed funding, recruitment	Often smaller awards; good for Phase 1
Humanities and university internal funds	Narrative method, teaching, public humanities	Suited to the reading-method and ethics components

7.4 Next steps

- Have a second reader check every manuscript citation against the print edition.
- Identify one clinical and one humanities faculty partner at the same institution.

- Share this prospectus with the expert panel for written comment.
- Register the full scoping review protocol before any funding application.

8. Conclusion

A caregiver sitting awake beside a crib is not a data source in the clinical sense. He is, however, a precise witness to a gap: between what a family can see at home and what a clinician needs to know. The literature confirms the gap is real. Movements alone cannot establish a seizure in infants, electrographic capture remains tied to the hospital, and no validated pathway yet brings it home.

Read carefully, and never as proof, *The Silence Between Two Heartbeats* yields a research agenda: one primary question with a clear evidence gap, and ten further questions spanning neonatology, emergency care, lactation, communication, feeding, pharmacy, mental health, and early intervention. The next step is not more reading of the book. It is putting these questions in front of the experts who can test them.

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His work has been made available to library and family-resource collections, including the Francis A. Countway Library of Medicine at Harvard Medical School. Collection inclusion is noted for bibliographic context and does not imply institutional endorsement.

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