Parental Insights into Improving Home Pulse Oximetry Monitoring in Infants

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Abstract

Introduction: Home pulse oximeters prescribed for infants with cardiorespiratory conditions generate many false alarms, which create caregiver stress and sleep disturbance and can lead to unsafe practices. Additionally, relationships among oximeters, alarms, and everyday living demands are not well understood. Therefore, we aimed to gather parent perspectives on home pulse oximetry monitoring during the problem analysis phase of a quality improvement (QI) initiative. Methods: We purposively sampled and interviewed parents of infants prescribed home pulse oximeters and receiving local home care company services. We based questions on systems engineering frameworks previously used in healthcare. Data were coded iteratively and analyzed deductively (theoretical frameworks) and inductively (emerging themes). Results: Generally, themes aligned with theoretical frameworks. Parents expressed dissatisfaction with the number of false alarms home pulse oximeters generate, which parents primarily attributed to poor probe adhesiveness and the inability of oximeters to account for infant movement. Interviews highlighted the burden associated with poor device tones and portability. Device-related issues had negative repercussions for the entire family related to sleep quality, mobility, and social interactions. Universally, parents developed workarounds, including cessation of monitoring. Conclusions: Parents of infants monitored at home using pulse oximetry face many challenges, resulting in compromises in safety. Continuing to instruct parents to comply with prescribed monitoring recommendations may be unrealistic. Instead, we suggest re-engineering the home monitoring system with the needs and goals of children and their families at the center. Our description of adapting qualitative research and systems engineering methods may benefit others developing QI work. (Pediatr Qual Saf 2022;7:e538; doi: 10.1097/pq9.0000000000000538; Published online March 30, 2022.)

INTRODUCTION

Clinicians prescribe home pulse oximetry monitoring for infants with various cardiorespiratory conditions.1–3 One of the most common conditions is bronchopulmonary dysplasia (BPD), a chronic lung condition resulting from premature birth.4 Providers use oximeters to detect a range of clinically significant events, from those requiring immediate intervention to others requiring only documentation to inform long-term care decisions, such as titration of supplemental oxygen therapy.5–7 Caregivers at home are alerted frequently, even for mild events that may not require intervention.1–3 The result is a system estimated to generate a median of 10 alarms per night,8 a burden that can create anxiety, sleep disruption, and/or alarm fatigue and lead families to miss actual events or stop using monitors altogether.2,11

Methodic problem analysis9,10 is necessary to design effective improvement interventions for such complex systems, as choosing the wrong problem to address is common in healthcare improvement work.9,10,11 Human factors-related frameworks, such as the systems engineering initiative for patient safety (SEIPS) model12,13 and dual-process theory (DPT),14 can augment traditional improvement models for safe redesign across a wide range of healthcare settings.15–18
These frameworks focus on system components, component interactions, and resulting processes (eg, decisions and adaptations) that shape outcomes. Qualitative methods, which provide naturalistic approaches to study experiences by allowing interpretation of peoples’ feelings, actions, and perspectives in the local context, promote a broader understanding of systems.

Previous qualitative studies of parental experiences of infant home monitoring are decades old and reflect when monitoring was prescribed for sudden infant death syndrome concerns. More recent qualitative work around home monitoring systems has focused on medically complex children. To devise a meaningful quality improvement (QI) initiative for home pulse oximetry monitoring for infants, we aimed to better describe parents’ experiences in a local population via semistructured interviews based on combined theoretical models of behavior (ie, SEIPS and DPT).

METHODS
Setting
This effort was part of a portfolio of systems improvement projects by the Patient Safety Learning Lab (PSLL) at a quaternary-care children’s hospital. The PSLL is a transdisciplinary team that includes clinicians, researchers, informaticists, and human factors engineers, who aim to improve systems of monitoring children. Children’s Home Care is the hospital’s affiliated home care program that provides specialized pediatric services within a 75-mile radius. The Institutional Review Board determined the work was consistent with QI activities and did not meet human subjects’ research criteria.

Participants and Recruitment
We conducted interviews August–December 2019 with English-speaking parents of children younger than 12 months of age dispensed a home pulse oximeter and/or pulse oximetry probes during the previous 6 months by Children’s Home Care (ie, a purposive sample). We excluded infants whose caregivers were instructed only to perform spot checks of oxygen saturation and those on continuous home ventilators, as the latter are nearly always supported by in-home nurses or other staff. We partnered with researcher specialists (W.E. and M.N.) at the University of Pennsylvania Mixed Methods Research Laboratory (MMRL), experts in qualitative methodology, who contacted families to schedule and conduct interviews via telephone.

Interview Structure and Content
The interview guide was based on (1) a hybrid of two conceptual frameworks: SEIPS and DPT and (2) reflexivity exercises by clinical members of PSLL. Generally, the frameworks suggest examining home resources, tasks, environment, and their interactions (ie, the work system) because they influence subjective parental state and shape parent responses (ie, the work process) (Fig. 1). In addition, reflexivity exercises attenuated potential biases of the PSLL team, with further bias mitigation facilitated by the MMRL independently refining the interview guide (see Appendix, Supplemental Digital Content 1, http://links.lww.com/PQ9/A361).

Data Collection
MMRL researchers, who had no clinical connections to families, conducted interviews. Before engaging in audio-recorded phone interviews, interviewers obtained verbal consent. Audio recordings were transcribed, de-identified, and uploaded to NVivo 12 Plus for data management.

Data Analysis
MMRL researchers initially reviewed representative transcripts to highlight recurring themes. Codes that emerged from the data (inductive analysis) were merged with overarching themes from the SEIPS and DPT frameworks (deductive analysis), then reviewed and iterated on per qualitative methods best practices. The resulting codebook was applied to all transcripts; interrater reliability was periodically assessed to assure agreement among the two coders.

RESULTS
MMRL conducted 13 interviews with parents (12 mothers and 1 father) of infants who ranged in age at the time of interview from 3 to 11 months and had primary diagnoses of bronchopulmonary dysplasia (n = 10), obstructive sleep apnea, (n = 1), cardiac anomaly (n = 1), and brief resolved unexplained event (n = 1) (Table 1). The interviews lasted approximately 30 minutes. Thematic saturation was achieved.

Analysis revealed six themes related to work system components of our home pulse oximetry monitoring conceptual framework (ie, persons, tools and technology, tasks, organization, external environment, and their interactions; Fig. 1): (1) the family unit; (2) home life with monitoring devices and alarms; (3) assessing if alarms represent emergencies; (4) goal setting; (5) communicating data with providers; and (6) logistics and mobility. Table 2 displays themes and subthemes alongside illustrative quotations. Three themes emerged related to work process components of our conceptual framework: (1) adjustments to the home environment; (2) alterations to tools and technology; and (3) decisions about time away from monitors. We collectively summarized these as adaptations and workarounds with illustrative quotations in Table 3. The following describes themes and parents’ advice to other families and suggestions for improvements in more detail:

Work System Themes
The Family Unit
Nearly all parents identified themselves as the primary caretaker responding to alarms. Typically, infants require...
more than a single caretaker. Parents reported that secondary caretakers and other family members involved in the infant’s care had difficulties monitoring and responding to alarms, which often led to the infant not being monitored when primary caretakers were away. In addition, care priorities of other family members, especially other children, had to be balanced with those of the monitored infant. In some instances, older children were involved with assessing alarms, while younger children’s actions could present distractions and difficulties.

Home Life with Monitoring Devices and Alarms

Few parents reported additional medical devices involved in-home monitoring outside of pulse oximeters. These included continuous positive airway pressure (CPAP) machines used while asleep, feeding pumps, and nebulizers, which added complexity to the home monitoring system and processes. Nevertheless, parents overwhelmingly reported that oximeters brought them peace of mind at home—a sense of reassurance that the infant’s condition was stable and a sense of progress and improvement over time. However, for many parents, the benefit came at the cost of navigating cumbersome devices and overly sensitive alarms, which often resulted in heightened stress and anxiety at constantly being alerted. This duality of emotions was persistent across day and night, with some parents reporting little perceived difference between day and night in their experiences with monitoring devices. Others maintained the most significant difference centered on managing cumbersome devices during the day and overly sensitive alarms at night that led to interference with adequate parental, infant, and other household members’ sleep.

Assessing if Alarms Represent Emergencies

Most parents reported they did not experience any alarm indicating a medical emergency requiring intervention. Parents described developing their strategies over time to assess if an alarm represented an emergency through combining previous experience with the monitor, information gleaned from the monitor in the moment, and a quick physical assessment of the infant. Some parents developed reasoning around alarms based on the context that allowed them to intuit when an alarm was actionable or if a physical intervention would resolve the alarm (eg, changing a foot probe). Over time, parents learned that crying, excessive movement, or unrelated minor illnesses like upper respiratory tract infections could increase the prevalence of false alarms. Physical indicators that led parents to believe the accuracy of the alarm ranged from objective—when an infant’s lips turned blue—to subjective—parents who described their infant as looking “off.”
## Table 2. Work System Themes and Representative Quotations

| Theme Subtheme | Quotations |
|----------------|------------|
| **Family unit** | **I know for my husband, it was a little bit different. It took a little while to get comfortable with the equipment and especially applying it to [our child].** P02 |
| | *"We slept in separate rooms because of the pulse ox, because I did not return to work but my partner did return to work. He slept upstairs and then I slept on the couch, and then the baby slept in the living with me. It worked out for that time being. …That way he could sleep, that he's not performing poorly at work." P04* |
| | *"We have another child, so he's kind of tripping over the cords and playing with the cords." P05* |
| | *"Well, my six-year-old has been neglected a little bit because of it but I try to set aside some time." P07* |
| **Home life with monitors** | *"[The monitor] eases your mind…instead of just immediately like, 'Oh my god, let me call the doctor or run to an ER,' I can check him and make sure he's okay." P03* |
| | *"Well, during the day, it would go off a lot because she's moving around. …You have a crying baby because she's hungry got a monitor that's screaming at you and then on top of that, a three-year-old that wants your attention, so the only thing we get mad at is the monitor, so you turn off the monitor. You take away all those variables and make it a little bit calmer." P04* |
| | *"We understand she needs it and it's necessary, but it's also tough because we try to take her upstairs to sleep, in her bedroom and you're lugging the equipment up and down. …We finally gave up and just said…we'll just have her in one room all the time …So you just feel almost like you're in a little cage or you're – you’ve got a chain tied to you and her." P05* |
| **Day and nighttime monitoring** | *"Sometimes it's scary because normally I am up 24/7. I'll rest as much as I can, but as he sleeps… I'm asleep, but at the same time I'm not asleep." P06* |
| | *"…It scares…him when it goes off… ‘cause it's loud and you have to keep it loud so you can hear it. So, if he's sleeping and he happens to toss or turn in the middle of the night, at his age…, that was a big thing cause they’re just getting in that sleep progression and stuff like that. So, every time it would go off…then he would start screaming." P07* |
| | *"At night it’s only probably the beeping of the monitor. During the day, it’s nothing, it’s fine… The monitor is when he sleeps, like anytime he sleeps. I normally just watch how he’s breathing and everything, so …I use the monitor, but not all the time. Just because like I said, he's been fine, and it wasn’t to a point where he desaturated or anything." P12* |
| **Assessing for true or false alarms** | *"Sometimes she’s kicking or when she sleeps, she’ll kick and [the monitor will] beep and then it goes to two zeroes, because it’s not reading, and then you wait a second and then it ticks back up, so yeah, most of the time it’s not true." P01* |
| | *"You also hit that silence button because nobody likes the noise, so you silence the alarm and make sure she’s okay and if she’s not, you fix the baby. If she’s fine, you fix the pulse ox." P04* |
| | *"…When I hear the alarm go off I check to see if, you know, the taping is around their feet correctly. Then I check them to see if, you know, they breathing correctly, if the oxygen is on right. Once I know that it’s a false alarm, you know, I just push the thing into the monitor, re-read the stuff or I turn it off or turn it back on so it can get the correct reading." P11* |
| **Reports of alarm fatigue or ignoring alarms** | *"There hasn’t been a time that it was an emergency. Normally if he’d taken it off his feet, or it was just not picking up." P12* |
| | *"At one point, …anytime [Child] would move his foot or it wasn’t a real waveform and/or the monitor wasn’t picking up, it would alarm very quickly. …it was getting almost annoying,…where I would turn it off and unplug it until he was sound asleep, just because of like monitor alarm fatigue." P06* |
| | *"It’s just really having to deal with the alarm ‘cause honestly, as any parent who has had to deal with their child and sit in a hospital with a child, that’s the one thing you don’t miss. I can’t wait to not hear these alarms go off or this beeping." P10* |
| **Goal setting** | *"It was kind of overwhelming because it was a lot that I had to do. I had to really keep on it and be patient about everything, but as time went by, I got used to it." P12* |
| | *"There is not an end date. I do follow-ups. At follow-ups they take [child] off for a little while to see if he drops any and see how far he drops. And maybe what activities he is doing while that’s going on. And then, after that, they make a determination if they are gonna wean him down." P10* |
| **Communicating data with providers** | *"I was feeling as though I wanted to keep track, because I thought at the time, [Child’s clinicians] weren’t seeing what he was doing at that time that it alarmed. And if he was screaming or kicking or throwing up or whatever it was, I wanted to document that. So I started the first couple weeks writing it down on a piece of paper, like in a diary, and reviewing that with our doctor on a weekly basis with the monitor data that was transmitted to [Hospital 1], to make sure that everything corresponded." P02* |
| | *"I’ll just let them know. I think if I’m not mistaken, they have a system, which they will go in the system and they’ll read something to them. I guess the results are how many times they had it on, what were his heart rates, and how low did it drop?" P06* |
| | *"And outside the home, like in her stroller, I kinda have like a little spot that I always put it, so that I can see we’re walking in the stroller… I made adjustments for the car like I got a plug to plug it in. So, if we ever need to plug it in the car, but that’s pretty much all," P01* |
| | *"…that was a six-hour drive. In that car ride, I couldn’t just spot-check him. I was in a car. There wasn’t an adapter connected to the car, which I tried to look for… but I couldn’t find anything. So I just didn’t [monitor Child], I just sat in the back seat with him the whole car ride and made sure he was good." P03* |
| **Logistics and mobility** | *"If we’re taking her out, we’ll just shut it down and say we’re done with this for now." P05* |
| | *"We don’t go on trips unless there’s someone sitting in the backseat. I don’t go anywhere like long distances… without anyone because it would go off every 30 seconds." P07* |
| | *"Yeah, it’s a two-person job. It’s definitely two people are needed to go out." P09* |
| | *"During the day when I have to go places and I have to carry all their stuff around, you know, it’s just like a little stressful." P11* |
Table 3. Work Process Themes and Representative Quotations

| Theme | Quotation |
|-------|-----------|
| Adaptations and workarounds | "... I went out and bought the Owlet Smart Sock, so, I alternate between the two like when... it's okay without the alarm and like just... So that way we're kind of like limit the alarm going off from movement." P07 |
| Advice to parents | "I would tell them not to be afraid to ask or to call the company to see what's going on. Because some people -- I know at first when I first got it, I didn't want to call for every little thing. I felt like I was bugging them probably, but feel free to ask any questions because at the end of the day they are there to help us and make things better for us." P15 |
| Improvement suggestions | "Well, I was thinking when she started to alarm, it was a slower, quieter alarm, and then as her numbers dropped and it became more intense... At home it's just one single tone, it's loud and it's loud beeps when it's turned on, you will jump to that... so he's a sound sleeper in his crib..." P02 |

False alarms were a significant source of stress, and most parents expressed some degree of irritation about their frequency. However, a minority of parents described instances in which they were so frustrated by the prevalence of false alarms that they chose to ignore them rather than assess their accuracy. Instead, most parents described times when their frustration with the alarms led them to disconnect or turn off the monitor.

Goal Setting
Most participants could not report a specific goal given to them by the medical team regarding their infant’s monitoring, sometimes due to the uncertain trajectory of the child’s physical development. However, other parents specifically mentioned they were on a weaning plan in which they were to monitor their infant’s progress while incrementally lessening oxygen use as their child improved.

Communicating Data with Providers
Parents’ level of involvement varied when tracking alarm events at home. Most parents reported they did not have a standard process for recording or reporting events at home. Rarely, parents kept detailed logs of each alarm event and what may have caused it. Others chose to make notes only of events that caused them concern. A small number of parents reported they did not track events whatsoever. There was also variability in parent understanding of if and/or what data monitors communicated to providers. Generally, parents described relying most often on verbal reports of the infant’s condition and progress generated from parental recall.

Logistics and Mobility
Parents’ abilities to navigate life outside the home with their monitored infant differed. Most made every effort to monitor their child continuously, and others shared that they would cease monitoring during outings. Although few caregivers had access to fully portable devices, most parents described extensive planning to bring their infant out of the house. Parents had to account for many details, including leaving the house with fully charged batteries and ensuring access to electrical outlets in transit or at the final destination. These parents also described relying on teamwork with other caregivers to execute outings without incident. Car rides posed at least two unique challenges to parents: (1) inability to power the monitor without a special power adapter and (2) trying to silence false alarms safely while driving.

Work Process Themes
Adaptations and Workarounds
Parents described a myriad of alterations to their home environment, tools and technology, and decision-making due to challenges they faced with the current system for home monitoring. Home adjustments to simplify monitoring revolved around physical changes like moving furniture, ensuring enough grounded electrical outlets,
and arranging devices to be easily accessed. There was a high prevalence of discussion related to probe connectivity, the probe's poor adhesive tape, types of clothing most conducive to ease of probe attachment, and special socks to ensure the probe's connectivity. An additional example included investing in a consumer infant physiologic monitor (e.g., Owlet\(^{32-34}\)), without an explicit recommendation from the healthcare team, which helped reduce the number of alarms parents experienced because it “only go(es) off like when it’s really going low and (the infant is) laying still.”

Parents developed adaptations and routines to decide when to remove their infant from their monitors or turn off the device. Parents most often base the decisions on assessing their child’s condition, an attempt to reduce false alarms due to a particular activity, or out of logistical necessity. Instances of monitor cessation occurred for simple daily activities, such as diaper changes and bath time. Other times parents removed their child from monitoring to bring the child out of the house on errands or to doctor’s visits unencumbered by the devices and cords. Some parents elected to watch the infant sleep during the day without the monitor, even though it was prescribed for sleeping, to reduce alarms, relying on their observation skills to assess danger. Regardless of their reasoning for time away from the monitors, most parents reported feeling uneasy when not monitoring their infant.

### Advice for Other Parents and Suggestions for System Improvements

Advice for other parents focused on patience, communication, and not becoming fixated on monitor readings. Additionally, parents stressed that trusting both the device and their parental expertise regarding their infant’s condition were key to avoiding panicked reactions. They also emphasized communicating and coordinating with the medical team and other caregivers involved in the infant’s daily life.

Parents had many suggestions for improvement, which revolved around reducing false alarms and improving probe connectivity. For example, many parents expressed a desire for the oximeter to better interpret when the infant was moving. Parents also wanted better adhesive probes, noting that they would not stick to the infant’s skin even when opening new probes.

Other suggestions included aspects of machine design that would increase user-friendliness, such as eliminating the loud beeping sound when turned on, different sounds and volume levels to indicate severity, including remote control, which could silence false alarms from a distance, and increasing portability so that parents could be more mobile with their infants while continuously monitoring them.

One parent raised an opportunity for easing information exchange between parents and providers by suggesting parents keep a collaborative document detailing causes of alarm instances that they could upload to the patient portal. This parent used this method with their child’s care team and felt it eliminated confusion about causes and resolutions of alarms.

### DISCUSSION

Interviews of parents with infants monitored at home using pulse oximetry revealed challenges and strategies used by families to incorporate medically prescribed monitoring into their everyday lives. Unfortunately, the strategies sometimes introduced potential compromises to infant safety, such as turning off monitors or switching to a non-FDA cleared consumer pulse oximetry monitoring device. Nevertheless, parents generally expressed reassurance from monitors.

Salient ideas for improving monitoring technology and supporting infrastructures emerged from this work. For example, for device manufacturers, our results support the importance of reducing false alarms due to motion artifact, improving probe adherence to the skin, exploring wireless probe options to reduce cable hazards, and investigating opportunities for remote alarm silencing. For medical teams, opportunities include modifications to monitor prescriptions that might safely reduce alarm burden (e.g., parameter limits), more transparent communication about what data, if any, is transmitted to the clinical team, and development of written strategies to help parents in rapid evaluation to determine if an alarm represents a true emergency so that these do not have to be developed by each family over time.

Our findings support previous work suggesting that motivated parents struggle to adhere to home monitoring as prescribed.\(^2,35\) Consistent with older studies on the parental experience of home monitoring, these parental efforts come at the cost of personal and familial stress.\(^2,32,22\) Additionally, parents in our interviews described simultaneous yet conflicting emotions of frustration and reassurance related to devices, similar to parents prescribed infant home monitoring for other indications.\(^21,22\) Through our systems engineering approach, we now understand the factors influencing parent experience of home monitoring. Our combined framework based on the SEIPS model and DPT captured factors and their interactions (i.e., work system components) that parents are weighing related to monitoring in the non-hospital environment (e.g., needs of other family members, physical home environment, burdens of the current technology, parents’ own emotions). It supported our understanding of how those factors lead to parents’ decisions (i.e., the work processes), ultimately affecting outcomes, like patient safety. For example, parents described analytical type 2 reasoning of DPT when they shared how initially they kept detailed reports about their infant’s alarms. However, over time, they developed shortcuts, or heuristic-based type 1 reasoning of DPT that saved them time (e.g., quick look if child is “off”).\(^14\)

All together, the outputs provide rich descriptions of root causes of problems and change ideas directly from people.
experiencing them, which can be integrated into more specific key driver diagrams as we narrow our focus in the next phase of our QI work (Fig. 2). More generally, our process supports using qualitative methods as an effective means of engaging parents in QI initiatives.

These findings need to be interpreted within the context of limitations to our approach. First, we modified research methods for QI purposes, which may have created gaps in specific areas (e.g., 30-minute interviews did not further explore how and why monitors were reassuring to parents despite also causing frustration). These gaps may be future opportunities for investigation. Second, we interviewed a small sample of parents from a single home care organization, and most infants had a diagnosis of bronchopulmonary dysplasia (BPD). Almost all interviewees were mothers, and we did not collect detailed sociodemographic data for stratification. Although this means our findings will be directly applicable to our local population, it may come at the potential cost of generalizability of the findings to other contexts.

However, many workarounds, including cessation of the device, have been reported in other pediatric home care settings. Otherwise, very little has been published about parents’ perspectives, so these insights into the problems families face and our methodologic approach may be helpful to others trying to improve local systems for home monitoring using pulse oximetry.

CONCLUSIONS

Parents of infants monitored with home pulse oximeters experience high rates of false alarms and face a wide range of device-related challenges, resulting in compromises to infant safety. Our findings suggest rather than continuing to instruct parents to comply with prescribed monitoring that may be unrealistic, we should promote understanding of home monitoring technology within a more complex system and engage parents in system changes given their crucial role and unique insights. Our system engineering approach was successful in the problem analysis.

Fig. 2. Hypothetical key driver diagram informed by parent interviews. Findings can enrich key driver diagrams. For example, in our interviews, we identified concerns about safety, parent satisfaction, and overall value of home monitoring. Each could be an aim for a more specific QI project. The themes and examples that emerged from interviews can be incorporated into primary and secondary drivers. Furthermore, parent suggestions for improvement might be added to list of change ideas (not pictured) and/or be used to aid in effort versus impact prioritization (not pictured). Arrows can be challenging to follow since many drivers interact with one another. Drivers in a single column may influence one another but are not denoted with arrows.)
phase of QI project design and complemented traditional QI methods. Our results immediately inform local QI interventions and may serve others as the foundation for additional investigations.

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DISCLOSURE
The authors have no financial interest to declare in relation to the content of this article.

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