

**INCIDENCE AND PARENTAL PERCEPTION OF HOME CARDIORESPIRATORY
MONITOR USE IN PRETERM INFANTS**

BY

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Abstract

Background: Achievement of physiological stability is essential for safe hospital discharge of a premature infant. While there is no scientific evidence that use of home cardiorespiratory (CR) monitoring decreases the incidence of Sudden Infant Death Syndrome (SIDS), the impact on the length of hospitalization and on parents' experience has not been described in the literature.

Methods: A retrospective patients record review was conducted to assess CR monitor use at discharge in preterm infants born at The University of Kansas Health System (TUKHS) from January 1, 2016, to December 31, 2017. Full-term infants, infants with a family history of SIDS, preterm infants discharged home on oxygen and those with major congenital/chromosomal anomalies were excluded. Data were collected on patient demographics, caffeine prescription, hospital readmission within 30-days of discharge and median length of stay (LOS). Eligible participants received a telephone survey administered by a research assistant post-discharge that examined parents' CR monitor experiences and use.

Results: Over the 2-year study period, forty-four infants were discharged home on CR monitor with the incidence of 8.1%. Of these, eight (18.2%) preterm infants were discharged home on caffeine for apnea of prematurity. Only four readmissions were noted within 30-days of discharge; one infant was readmitted due to bradycardia spells observed on CR monitor (2.8%). Total 28 responses out of 44 were received at the follow up telephone survey (63.6%). Most parents reported feeling secure (67.8%) but anxious (60.7%) using the CR monitor. Parents who reported experiencing false alarms frequently also reported having feelings of anxiety while using the CR monitor ($\chi^2 = 5.1, p = 0.02$).

Conclusion: Readmissions due to false alarms while using CR monitors at home for preterm infants were rare in our cohort. Many parents reported feeling anxious in presence of frequent

false alarms when using the monitor as prescribed by the neonatologists. Providers should monitor parental feelings of anxiety and provide interventions as needed.

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Chapter 1: Introduction

Apnea of Prematurity (AOP) is defined as a pause in breathing for either greater than 20 seconds or greater than 10 seconds if accompanied by bradycardia, oxygen desaturation or cyanosis in infants less than 37 weeks gestational age (1). The primary etiology of AOP is the immaturity of the neurological and respiratory systems (2). The incidence of AOP increases with decreasing gestational age. Apnea occurs in virtually all infants born less than 28 weeks' gestation, decreases to 85% at 30 weeks and 20% at 34 weeks (3). AOP usually resolves by 37 weeks postmenstrual age (PMA), but AOP can rarely persist until about 43 weeks PMA (4). Caffeine is considered as the pharmacologic treatment of AOP. Caffeine is usually discontinued when the infant reaches a PMA between 32 and 34 weeks and there have been no apneic episodes requiring intervention for approximately five days (4).

Physiologic Stability for Discharge

Achievement of physiological stability is essential for safe hospital discharge of a premature infant. It is understood as maintenance of steady heart rate, blood oxygenation, and a regular breathing pattern. Most preterm neonates achieve such physiological stability around term gestation, coinciding with the achievement of thermoregulation, oral feeding skills and consistent weight gain. Despite achieving the latterly described skills, many preterm neonates continue to experience episodic drops in heart rate and oxygen saturation. Although such brief cardiorespiratory "spells" are of uncertain clinical significance, these babies continue to be observed in the Neonatal Intensive Care Units (NICU) adding to the health care costs.

Use of Home CR Monitor: Yes or No?

In some NICUs, including The University of Kansas Hospital System (TUKHS), preterm infants with persistent brief cardiorespiratory spells are discharged home on CR monitors after they have demonstrated the ability to maintain temperature and gain weight on non-gavage feeds

for 48 hours. Discharging infants on CR monitor theoretically may decrease the overall NICU stay. However, there is no evidence of the CR monitors preventing untoward occurrences or Sudden Infant Death Syndrome (SIDS). A major problem in assessing the role of CR monitors to prevent infant death is difficulty in establishing its clinical efficacy. Randomized controlled trials are impractical because death is a rare event in these infants, and because families are unlikely to consent to randomization. There are no established guidelines from the American Academy of Pediatrics (AAP) for use of CR monitors for preterm infants. Currently, the preterm infants are discharged home on CR monitors based on the discharging physician's discretion (5). Multiple factors including monitoring, diagnosis and treatment results in center-to-center variability of in-hospital treatment with caffeine and use of home monitors at discharge.

As mentioned above, our center usually discharges infants on CR monitor use at home once they are otherwise deemed ready for discharge to promote shorter length of stay. We have noted the practice of discharging home on the monitor has liberalized in the past few years. The study done by Montenegro et al (6) reported that outpatient management of discharge-delaying events in preterm infants was a cost-effective alternative to prolonged inpatient observation. Usually, once infants outgrow AOP around 44 weeks, CR monitor is discontinued. It may be cost-effective to discharge infants early on CR monitor as opposed to in-patient observation.

The aim of this study was to identify the incidence and the clinical indications of CR monitor and caffeine prescription for preterm infants discharged from TUKHS NICU in the last two years (2016-2017). The study also intended to address the length of stay in NICU and identify whether known readmissions within a month from discharge due to alarms on the monitor occurred.

Perception of Parents

Another variable that is poorly understood in this area is parents' experiences at home with CR monitoring. While there is no scientific evidence that home CR monitoring decreases the incidence of SIDS, the impact on the length of hospitalization and on parents' experiences have not been well described in the literature previously. The question remains as to whether the use of CR monitor at home causes emotional distress to the parents for the next few weeks prior to discontinuation and how this might relate to feelings of security. Abendroth et al. conducted a study to compare the emotional distress and family functioning of parents whose infants use home monitors and of parents whose infants don't use home monitors (7). They reported significant differences in the depression and hostility aspect (noted early in the parents of infants who used the monitor). However, on a 12-month survey, most parents reported that the monitor was helpful and made them feel more secure. This study reports the use of the monitor for a prolonged period (~12 months).

Research Questions and Specific Aims

1. To examine the incidence of home CR monitor use, caffeine prescription, length of stay and re-admission in preterm infants discharged from TUKHS NICU in the past two years.
2. To identify the clinical indications documented in patient charts for the use of the CR monitors and caffeine.
3. To examine parents' perceptions on the usefulness of home CR monitoring when their preterm infants are discharged from the hospital.

Chapter 2: Methods

Study Location and Patient Population

This retrospective study was conducted at level III NICU of TUKHS between January 2016 – December 2017. Preterm infants who were discharged from the NICU were screened using the Vermont Oxford Network (VON) database. The VON Databases maintain data on very low birth weight infants and infants meeting other eligibility requirements and include over 1,000 centers around the globe that voluntarily submit data about the care and outcomes of high-risk newborn infants. They hold critical information on more than 2.2 million infants, representing more than 67 million patient days (8).

The study population included all the preterm infants born less than 37 weeks (23 0/7 to 36 6/7 weeks of gestation) who were discharged home on the CR monitor. Infants with a family history of SIDS, infants who required oxygen at discharge, infants with major congenital/chromosomal anomalies and preterm infants who were discharged home without CR monitors were excluded. The study was approved by TUKHS Institutional Review Board (IRB). A separate IRB approval was obtained for conducting a follow up survey of parents.

Study Design and Data Collection

Main study.

A retrospective chart review on all included patients was conducted to collect patient-specific baseline characteristics and other variables of interest from nursing and medical records. Data included demographic characteristics (gestational age, race, gender, length of stay [LOS]) and medications (including caffeine at the time of discharge). The clinical data included in the chart review captured reasons for CR monitor use and readmissions within 30 days of discharge (Appendix A).

Follow-up study and survey.

Infants discharged home on the CR monitors during years 2016 and 2017 were identified. Parents of eligible infants were identified and contacted via a telephone call to be a part of the survey. A verbal consent to participate in the survey was obtained over the phone from the parents by a research assistant. The parents were reached out different times during the day or the week including the weekend to maximize response to the survey. A standardized script was used to conduct the survey (Appendix B). The telephone survey examined parents' experiences and the usage of CR monitors (Appendix C).

Statistical Analysis

Descriptive analyses were performed utilizing frequencies with percentages for categorical variables and the median with interquartile range (IQR) for continuous data. To evaluate differences in proportions, chi-square tests were conducted. All statistical analyses were performed using Microsoft Excel for Mac 16.19 (USA) and SPSS 19.0 (IBM Corp, Armonk, USA).

Chapter 3: Results

Patient Demographics

Between January 2016 and December 2017, 543 preterm infants between gestational ages 23 0/7 to 36 6/7 weeks were admitted to the NICU. Of these, 44 preterm infants (8.1%) with minimum gestational age of 23 3/7 and maximum gestational age of 36 3/7 weeks were discharged home on the CR monitors. Gestational age of infants discharged home on CR monitors varied (Table1). Only 18.2% infants (8 out of 44) were discharged home on caffeine. The median length of stay was 52.5 days at 27-29 weeks, 31 days at 30-32 weeks and 18.5 days at 33-36 weeks gestational ages (Table 2).

Table 1: Demographic Characteristics of the Patients (N= 44)

<i>Characteristics</i>	<i>Number (%)</i>
Gestational Age	
<24 weeks	1 (2.3)
24-26 weeks	3 (6.8)
27-29 weeks	14 (31.8)
30-32 weeks	12 (27.3)
33-36 weeks	14 (31.8)
Race	
Caucasian	28 (63.6)
African American	10 (22.7)
Others	6 (13.6)
Gender (Female)	22 (50)
Caffeine (Yes)	8 (18.2)

Categorical data presented as frequency and percentage.

Table 2: Comparison of Length of Stay (LOS) in various Gestational Age Groups

<i>Gestational age</i>	<i>LOS (days)</i>	<i>LOS (days)</i>
	<i>TUKHS</i>	<i>VON</i>
<24 weeks	94 (94)	131 (113-154)
24-26 weeks	94 (75-96)	100 (88-111)
27-29 weeks	52.5 (46-56)	65 (57-72)
30-32 weeks	31 (23-41)	35 (31-40)
33-36 weeks	18.5 (15-27)	14 (12-16)

Abbreviation- TUKHS: The University of Kansas Health System; VON: Vermont Oxford Network; IQR: Interquartile range. Data presented as median (IQR)

Indications for discharge home on CR monitoring included bradycardias/desaturations (27.3%), isolated bradycardias (22.7%) and AOP (20.5%) F Post-discharge, eight infants could not be tracked. The readmission rate for was 9% (4/36); only one patient was readmitted for bradycardia spells.

Table 3: Indications of the CR monitor (N= 44)

<i>Indications</i>	<i>Number (%)</i>
AOP	9 (20.5)
Isolated bradycardias	10 (22.7)
Periodic breathing	7 (15.9)
Bradycardias/desaturations	12 (27.3)
Others	
Desaturations	2 (4.5)
BPD	3 (6.8)
GERD	1 (2.3)

Abbreviation: AOP: Apnea of Prematurity; BPD: Bronchopulmonary Dysplasia; GERD: Gastroesophageal Disorder. Categorical data presented as frequency with percentage.

Follow-Up Survey for Parent’s Perception of Monitor Use

Sixty-three percent (n=28) of parents whose preterm infants were discharged home on CR monitor completed the telephone survey. Descriptive analysis indicated that majority of parents were using the apnea monitor every night as prescribed (Figure 1). Over half (53.6%) of parents reported almost always or often experiencing false alarms while using the CR monitor at home. Over two-thirds (67.8%) of parents reported feeling secure, but 60.7% were anxious using the CR monitors. Parents who reported experiencing false alarms more frequently also reported a higher feeling of anxiety of using CR monitors than those that reported experiencing false alarms less frequently $\chi^2=5.1$ ($p<0.025$) (Figure 3). Parents who reported less frequent false alarms showed a tendency to feel more secure. Parents were more anxious in 2016 cohort (13/19) as compared to parents in 2017 cohort (4/9) (Figure 4).

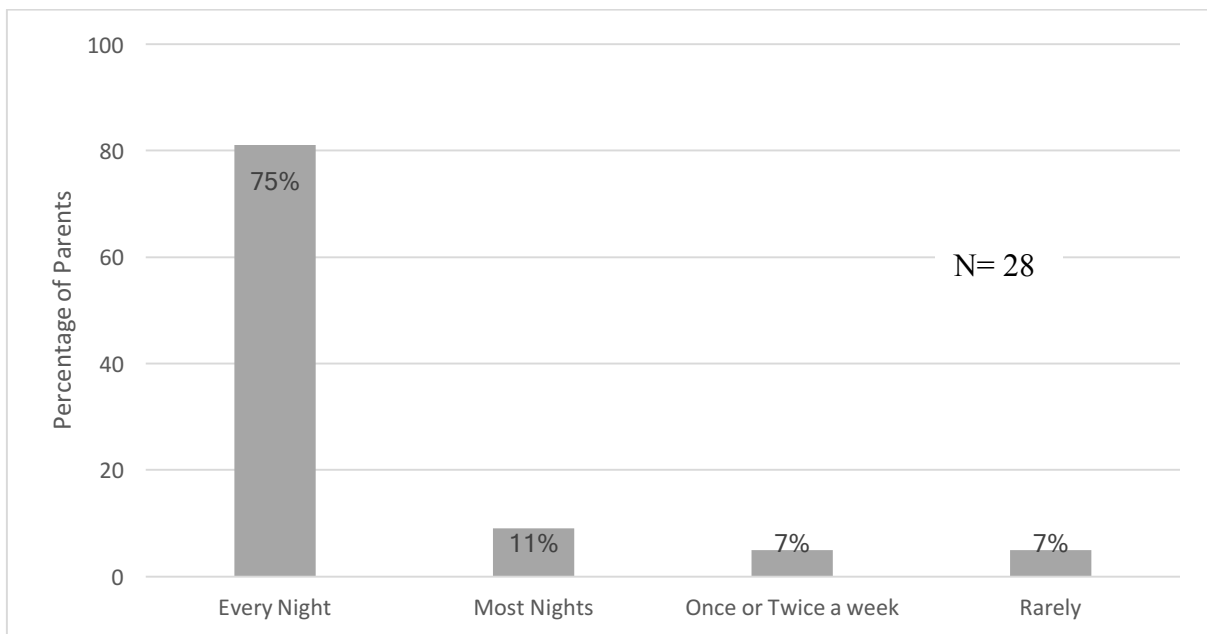


Figure 1: Frequency of Use of CR Monitor at Home.

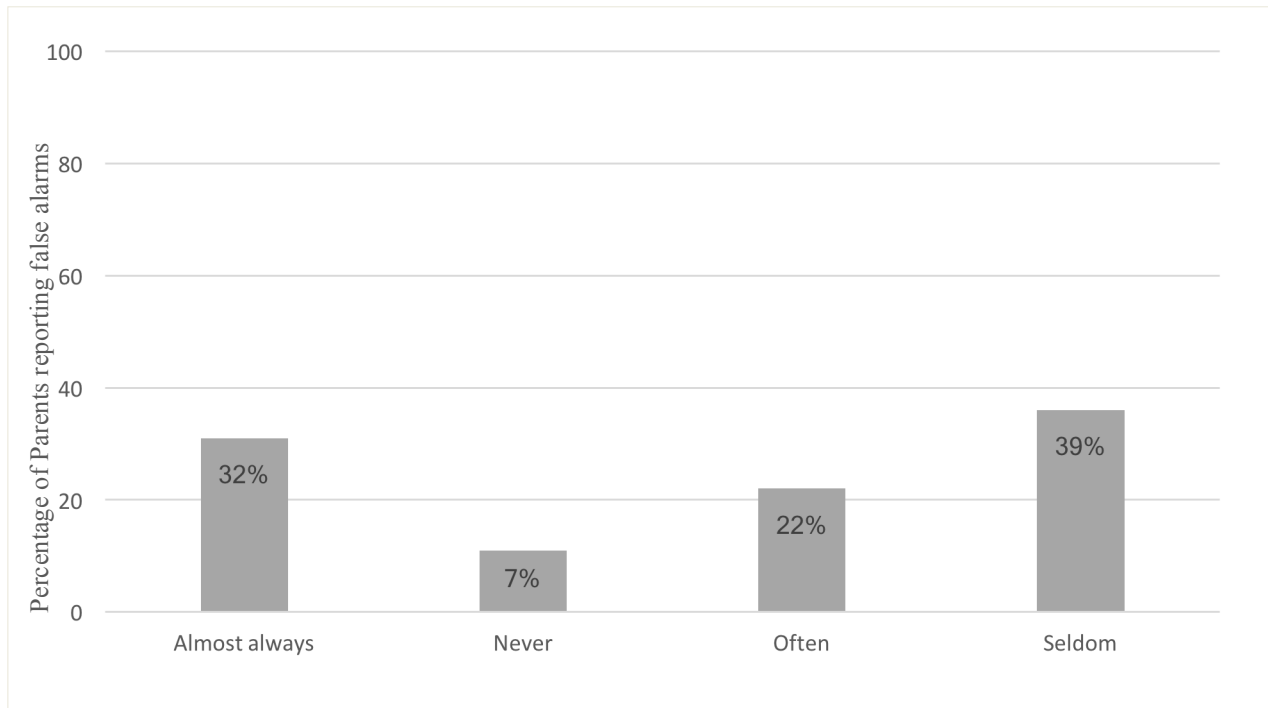


Figure 2. Frequency (in percentage) of False Alarms while using CR Monitor

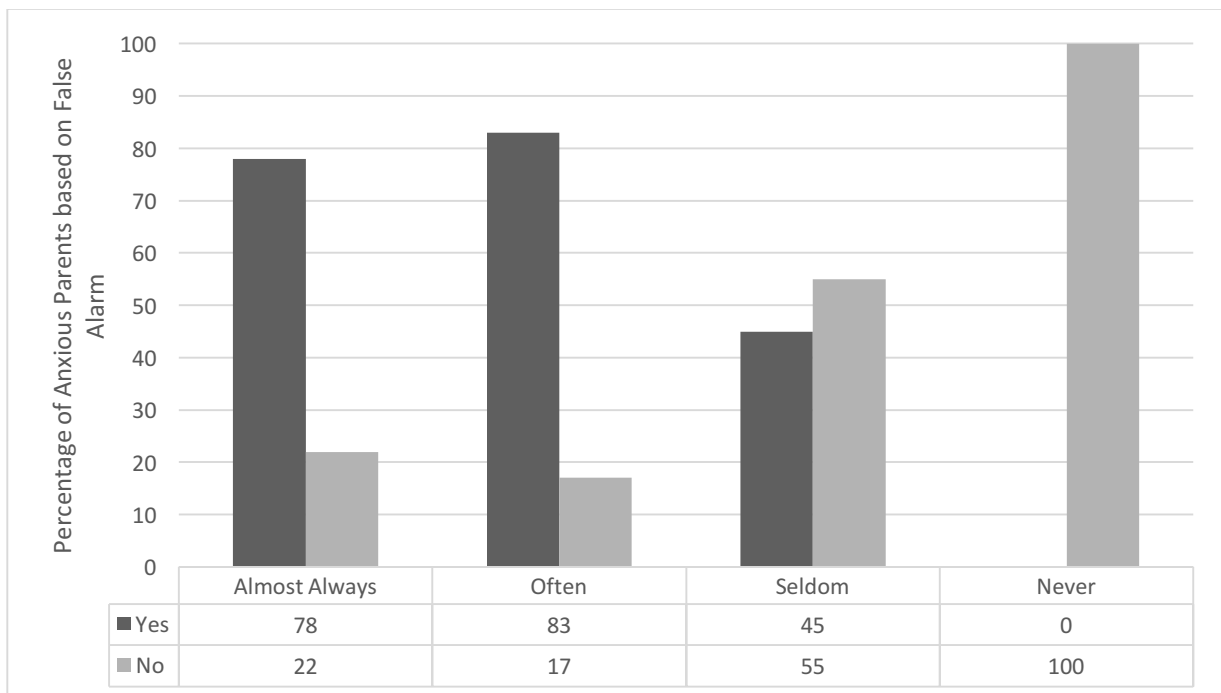


Figure 3. Percentage of Anxious parents based on False Alarms

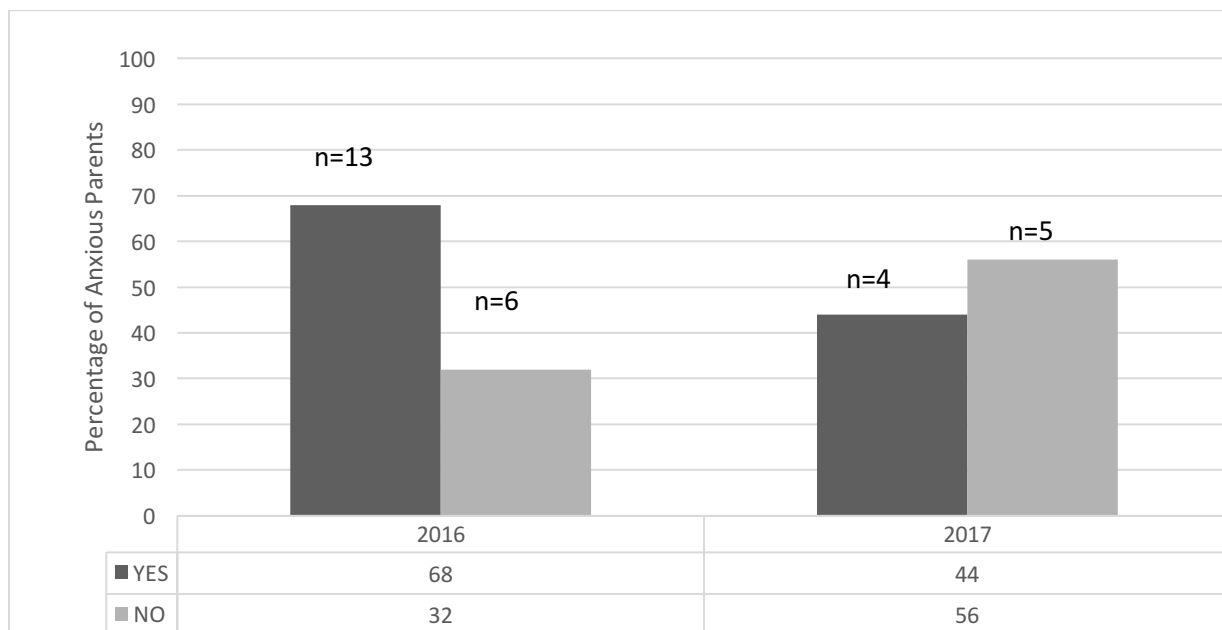


Figure 4. Percentage of Anxious Parents using CR Monitor in 2016 and 2017

Chapter 4: Discussion

Home CR monitors have been available for approximately 30 years and were originally used with the intent to prevent sudden infant death syndrome (SIDS) in at-risk infants. Preterm infants are at a higher risk for SIDS than term infants (10,11). Due to increased risk of SIDS and apnea of prematurity, these infants have been discharged home on CR monitors from our center. The incidence of preterm infants being discharged home on the monitor is 8.1% in our cohort which seems less when compared with 16% as reported in the study done by Powell et al (5). However, there are many preterm infants who are diagnosed with Bronchopulmonary dysplasia (BPD), who have gone home on oxygen and hence excluded in our cohort. These infants are discharged home on pulse oximeter instead of apnea monitor. Very few infants (8/44) were discharged home on caffeine, which reflects that the infants were not having apneic spells when they were ready to be discharged and just had self-resolving desaturations/bradycardias which they would eventually outgrow soon.

The Vermont Oxford Network (VON) median length of stay at respective gestational ages are 65, 35 and 14 days respectively. It is observed that the median stay is lower in infants 27-32 weeks in our cohort as compared to the national data (Table 2). Statistical significance for this observation could not be calculated due to unavailability of detailed data from VON. Whether small reduction in length of stay is a solid reason for sending infants home on apnea monitors is debatable. It is also unclear whether the monitor would have unseen consequences on the parents and lead to 'alarm fatigue'.

When we interviewed parents of infants who were discharged home on the monitor in the last couple of years, many parents stated that they experienced feelings of security as well as anxiety with CR monitor use. The parents who experienced false alarms frequently reported of

feeling anxious. There is also a trend of parents feeling more secure in the absence of false alarms. The presence of false alarms did not result in multiple readmissions in our cohort. However, the results suggest that providers should consider monitoring parental feelings of anxiety and provide interventions as needed.

This study assessed parents' experiences with the use of home CR monitoring and captured their insight to some extent. Sixty-three percent of the parents completed the telephone survey which is a good response especially after the event of interest. The study helps us to quantify the indications and incidence of caffeine and CR monitor uses in preterm infants born at TUKHS in the last two years. The results of this study would also form a basis for quality improvement initiative streamlining the clinical practice by adhering to consistent guidelines.

The major limitation is the lack of comparison with a cohort of preterm infants with cardiorespiratory spells who are not discharged home on the monitor. There is a recall bias which could have affected parents perception of the use of home monitor as the survey was done long time after the monitor was discontinued. We hoped to minimize the effect of year of discharge in our interpretation and hence included patients discharged only in the past two years in the study.

Readmissions due to false alarms while using CR monitors at home for preterm infants were rare. Many parents reported feeling secure despite reporting frequent false alarms when using the monitor as prescribed by the neonatologists. Providers should monitor parental feelings of anxiety and provide interventions as needed.

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APPENDIX A: DATA COLLECTION SHEET

Use of the Home Cardio Respiratory Monitors in Preterm Infants
Data Collection Sheet

Study ID Number _____
GA _____ Birth Weight _____ Gender _____ Race _____

Major Morbidities (Circle if present) _____ (IVH >gr 2), BPD, Surgical NEC, Anemia, GERD.

Other Morbidities _____

Diagnosis /reason for
monitor _____

Caffeine at discharge _____ (Y/N)
Length of Stay _____ Gestation at discharge _____ Weight at discharge

Lag Time (Time between Last Gavage feed WITH stable temp. and Discharge)

_____ Cause of Lag time >48 hours _____
Readmissions (Y/N) _____ Cause _____

Length of Monitor Use as outpatient _____
Number of Downloads Obtained _____
Number of outpatient visits related to monitors _____

APPENDIX B: TELEPHONE SCRIPT

Hello,

My name is _____. I am a research assistant in the Neonatal intensive care unit at The University of Kansas Hospital. We are conducting a survey on caregivers whose infants were discharged home with an apnea monitor and have currently completed their use. The survey consists of 5 short questions about your experience with the monitor. None of this information will become part of your child's medical record or affect your child's ongoing medical care. We will follow the HIPAA laws about privacy. If you decide to participate, we shall also mail you the consent form for obtaining your permission to abstract specific information about your child's medical history during the overall NICU stay.

Would you be willing to share your experience with us?

Would you verify your address with us?

APPENDIX C: APNEA MONITORING RETROSPECTIVE PARENT SURVEY

1. How would you describe the current health status of your baby?
 - a. Excellent
 - b. Good
 - c. Fair
 - d. Poor
2. Did you use the monitor every night, most nights, once or twice a week, or rarely?

3. How often did you experience false alarms with the monitor?
 - a. Almost always
 - b. Often
 - c. Seldom
 - d. Never
4. Did the monitor make you feel more secure?
Yes/No
5. Did using the monitor make you feel more anxious?
Yes/No

Anything about the monitor use you would like to share: