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Readmission drivers for children with medical complexity: Home nursing shortages cause health crises

Sarah A. Sobotka, MD, MSc[1], **Emma Lynch, MPH**[1], **Monica E. Peek, MD, MPH, MSc**[2], **Robert J. Graham, MD**[3]

[1]Section of Developmental and Behavioral Pediatrics, Department of Pediatrics, The University of Chicago, Chicago, IL

[2]Section of General Internal Medicine, Department of Pediatrics, The University of Chicago, Chicago, IL

[3]Division of Critical Care Medicine, Department of Anesthesiology, Critical Care and Pain Medicine, Boston Children's Hospital, Boston, Massachusetts

Abstract

Objective: Children with medical technology dependence (MTD) are frequently readmitted to the hospital. However, due to their medical fragility, it is often difficult to untangle the root causes for readmissions to identify the most effective preventive approaches. We sought to explore environmental and family factors driving hospital readmissions for children with MTD.

Design: Semi-structured, in-person interviews were conducted with state-wide care coordinators for children with MTD in Illinois with at least 1 year of experience. Interview topics related to children with MTD transitioning from hospital-to-home, essential supports for living in the community, and factors which influenced and prevented hospital readmission. The interview guide served as an initial codebook which was iteratively modified as themes emerged.

Results: Fifteen care coordinators with on average 6.6 years of experience were interviewed. They described that lack of home nursing was one of the primary drivers of readmissions due to parental exhaustion and lack of medical expertize in the home. Unavoidable medical admissions, a lack of a plan for emergencies, and home environmental factors also contributed to readmissions.

Conclusion: Hospital readmission is an expected occurrence for children with MTD, yet still may be substantially reduced through consistent, quality home health nursing to bolster family capacity and allow for respite from constant caregiving. Improved incentives for the home health workforce to increase manpower would be ultimately offset by reduced hospitalizations for children with MTD. Additionally, more research is needed to understand which home nursing structures and skills optimally support families in the reality of manpower scarcity.

Correspondence: Sarah A. Sobotka, MD MSc, Section of Developmental and Behavioral Pediatrics, Department of Pediatrics, The University of Chicago, 950 East 61st Street, Suite 207, Chicago, IL 60637. ssobotka@peds.bsd.uchicago.edu.

CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interests.

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Keywords

bronchopulmonary dysplasia; children with medical complexity; home healthcare; mechanical ventilation; noninvasive ventilation; private duty nursing; readmissions

1 | INTRODUCTION

Children with medical technology dependence (MTD) require both a medical device to compensate for the loss of a vital body function and home nursing care to minimize further morbidity and, potentially, avert mortality.[1–3] Representing survivors of extreme prematurity, and a variety of underlying complex conditions, including genetic, cardiac, pulmonary, and neurological disorders,[4–6] the children, historically, required long-term placement, or remained in acute care hospitals. Home technologies and home nursing, however, have expanded in capacity and scope for the past 35 years, enabling many of these children to transition to community and family settings.[7–9] Yet, these children, remain vulnerable and are frequently readmitted for intermittent care.[10–14] The reasons for frequent readmissions have been attributed to their extreme medical fragility and inevitable nature of their complex diseases, such as pulmonary or tracheotomy-related complications.[13,15] However, contextual social reasons have also been hypothesized to contribute to readmissions.

Most studies of hospital readmissions rely on administrative data to determine the reasons for readmissions. Certainly, a child with chronic respiratory failure in the community and baseline need for a ventilator would be identified as having “respiratory distress” or “respiratory failure” upon readmission to the hospital. The root causes for presentation, however, might be unrelated to, or only indirectly related to, the respiratory support needs. To unravel the complex factors, which contribute to readmissions for medically fragile patients, we designed a qualitative study which utilized in-person, semi-structured interviews with care coordinators, working throughout the state of Illinois, for children with MTD. The study objective was to examine, from the perspective of care coordinators, the root causes of readmissions for children with MTD, and to detangle medical from social factors. Care coordinators represent one of the key stakeholder groups not well represented in the literature; their perspectives are invaluable as their charge is to direct and coordinate home health care for families of children with HMV.

2 | METHODS

Semi-structured interviews were conducted with care coordinators for children who require home health services and medical technologies. The study was approved by the University of Chicago Institutional Review Board and informed consent was obtained from all participants. Themes relating to readmissions were analyzed for this paper.

2.1 | Background

In 1937, the division of specialized care for children (DSCC) was established in Illinois as a result of a department of health and human services waiver[8] to support children with MTD

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living in the community. DSCC is funded by a Health Resources and Services Administration Title V program to improve resources for children with disabilities through care coordination services. This program assigns care coordinators to families, facilitating access to vital resources, including transportation assistance, medical care services, early intervention and rehabilitation therapies, home care nursing and durable medical equipment (DME). In addition to connecting families to services, these providers serve as liaisons and help families communicate with specialists, and learn to navigate the complicated healthcare services landscape.

2.2 | Medically fragile/technology dependent children waiver

Children in the State of Illinois can qualify for home nursing services though the Medically Fragile Technology Dependent (MFTD) waiver if they "because of the severity of their physical illness or disability would require the level of care appropriate to a hospital or skilled nursing facility without the support of the services provided under this waiver.[16] An assessment tool determines the nursing allocation per case, but the rubric for this determination is not publically available. In the state of Illinois LPNs or RNs are potential home health providers, depending on the medical technology required by the child.

2.3 | Participant recruitment and study methods

Eligible participants were care coordinators working with the DSCC Home Care program for at least 1 year; a total of 24 participants were eligible based on these criteria. DSCC supervisors screened employee rosters for eligibility, and the primary investigator invited them to participate in the study. Care coordinators participated in a semi-structured, in-person interview. The overall interview guide included topics of: the process of hospital-to-home discharge, essential supports for families living at home with a child with MTD (eg, nursing care, DME), and factors which influence hospital readmission for children with technology dependency.[17] Interviews were audiotaped and field notes were captured, and later reviewed to calibrate importance of given quotes and themes. Data were deidentified and transcribed verbatim. Care coordinators provided demographic information via online survey after their interview.

2.4 | Analytic strategy

Using the interview guide as an initial codebook as part of a modified template approach,[18] all interviews were coded independently by two reviewers (SS and EL). To resolve differences coders discussed to agreement to ensure inter-coder reliability. The analyses presented in this paper are limited to the themes relating to readmissions.

3 | RESULTS

3.1 | Participant characteristics

Participants were enrolled between December 2016 and June 2017. The interviews lasted a mean duration (range) of 77 (51–122) minutes. The average age of care coordinators was 45.2 years old with6.6 years of work experience as a care coordinator (Table 1). The majority of participants (93%) were women; approximately half of respondents (52%) had a master's degree in social work, counseling, or psychology.

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3.2 | Emergent themes

The following themes were categorized. More detailed quotes for each theme can be found in Table 2.

3.3 | Major theme 1: reasons for acute care presentation are often unrelated to chronic illness

Care coordinators reflected upon both specific case examples as well as general drivers for patients' need to return to the hospital. Frequent readmission reasons were *unavoidable medical reasons* (*Theme IA*), and often related to the children's baseline neurological and respiratory vulnerabilities: "Fever, vomiting, seizures." "A lot of times it's respiratory." "Infections, like a UTI." Care coordinators also described a seasonality to readmissions, "RSV season" and "in the wintertime, a lot of kids go back in when they have trachs."

Participants also described that families returned to the hospital at times which, if they had more immediate remote access to a medical expert, might have had been avoided: *potentially avoidable medical readmissions* (*Theme IB*): one caregiver described, "I had a situation once with a patient who also had asthma component in addition to his compromised airway. And he started wheezing. His sats were going down. And the family, instead of getting in touch with the doctor, they rushed the child to the emergency room, while the situation wasn't that dramatic yet. And later on, it was specified that if the family contacted the doctor, if the steroid was ordered and administered at home, it would probably be preventable….panic situation on family's side." Another care coordinator described rushed discharges which resulted in readmissions, "Sometimes, not often, but every once in a while, they're discharging the kid too quickly, and then the kid's right back in. So, don't change anything in their routine for at least a week before you discharge."

A third subtheme emerged describing that parental discomfort or ill preparation for homecare led to readmissions (*parental reasons: comfort/preparedness [Theme IC]).* Parent experience and expertize influenced the frequency of hospital readmissions, and tended to dissipate with time and experience. Some care coordinators described parental experience in terms of age of the child, with less experienced parents of younger parents returning to the hospital more often. "I think just out of being scared, they would just rush to the emergency room if they just don't know what's wrong with their kid." "Sometimes at the beginning, it may be the fear that something is terribly wrong. After a while, they'll discover that this is how the child would react to too much mucus in their airway that could have been easily suctioned."

Other *environmental factors* (*Theme ID*) included critical issues in the home environment itself (electricity, sanitation, homelessness) which influenced the safety of a child living in the home. "If power's out…definitely it's not turned on, you need to head to the hospital." "I have a family who had a mice infestation in their apartment… the nurses—they weren't going to work there, and nursing stopped. And then mom has three other kids. There's a dad, but he works all the time… eventually the child was hospitalized because it was just too much. No nursing, mice running around, just mom." Care coordinators also referred to

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caregivers' inability to access respite care if urgently required. "[Parents are] wanting to go out of town and they don't have the backup or the support."

3.4 | Major theme II: need for emergency care plans to avoid readmissions

Care coordinators clearly described the care team's mission to reduce readmissions through carefully crafted care plans for emergencies (*Theme IIA*). They described both their role and roles of the primary physician team in emphasizing this care plan: "I'm continuously educating them not to use the ER. "We're going to call your pediatrician. These are going to be your first steps… You're not going to go to the ER for a sore throat." "I have a mom—she's very good at troubleshooting. Her and her doctor have a protocol." "If I can troubleshoot and solve something for the families…occasionally, without my intervention… the child could be hospitalized."

Home nurses also play a critical role in supporting emergency care plans, thus avoiding readmissions *(Theme IIB)*. "The nurse is going to be there to handle some of those crisis situations." "I have a case that the nurses are really, really good…they do PICU stuff in the home [and] keep him out of the hospital." "A really good, strong, strong nurse, that's what keeps the kids out."

3.5 | Major theme III: lack of home care nursing leads to increased hospital utilization

While the interview guide was designed to probe on various home care topics separately, the intertwined relationship between home care nursing and readmissions emerged organically in conversations with care coordinators and in data analysis. Care coordinators consistently linked the ubiquitous home care shortage to increased hospitalizations through the root causes of parental exhaustion (*subtheme IIIA*) and lack of ready access to medical expertize (*subtheme IIIB*).

Care coordinators described how exhausted parents find themselves turning to the emergency room as a last resort out of desperation. "Families may end up at the emergency room just because … the nurse didn't show up… They may be tired. Child may be running a fever, so they anticipated something may go wrong… they kind of act in advance, knowing that they don't have the support." "(She) didn't have any nursing, so she took him to (the hospital) and they had to admit him. Because the nurse was off or sick or what have you, and the foster mom said, "I just can't do this.""

Care coordinators described that readmissions are prompted at times not only the lack of back-up caregiving in the form of home nursing, but the lack of medical expertize in the home. They described that parent caregivers, although trained extensively over weeks and months in the hospital for the skilled care of their child, still benefit from nursing expertize to continue their education in the home setting and to respond to emergencies. When homecare is unavailable and/or unskilled, families lack this critical resource: "After two, 3 days, or a week or two without nursing support, they physically are unable to do it at the required level. Or they are not medical professionals, so they may not be able to recognize—even though they are experts in their child's care—but if some new symptoms start to show they may not be able to pick up early enough, and then …the child has to be rushed to an emergency room."

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3.6 | Major theme IV: families attitudes towards and negative impact of readmissions

Parents were perceived as *overall hesitant to return to the hospital* (*Theme IVA*). “The families try to keep them home longer than a … normal family would. They’ll do the Diastat. They’re not running to the hospital.” “At least my families…they don’t go to the emergency right away.” This hesitancy may have been because of the anxiety that readmission would be perceived as a family failure “Because they think that they didn’t do a good job.”

Perhaps families aim to avoid readmissions in part because hospitalization has an overall *negative impact on the family* (*Theme IVB*). Despite the uniform lack of formal respite provision, parents wished to avoid returning to the hospital for practical and emotional reasons: “I think it really broke her heart to be separated from her daughter…to have to put her in the hospital and just come visit.” “Trips to the emergency room, if it’s in the middle of the night, everybody’s got to be up…it’s such a disruption.” This theme was in contradiction to the common misconception that returning to the hospital represents a respite period for families.

4 | DISCUSSION

State care coordinators for children with MTD, poised at the helm of both health care logistics and intimate family dynamics, are uniquely positioned to understand the complex factors driving hospital readmission for children with medical complexity and technology dependence. Care coordinators described medical fragility as a root cause for some admissions, but not all. Instead our thematic analysis highlighted insufficient availability of the home health nursing workforce as the core driver of readmissions.

Extracted themes also suggested that although rehospitalization is pursued when parents are desperate for a break from caregiving, in reality it does not represent respite for families. The disruption to the family unit is significant, separating siblings and forcing parents to decide with which children to prioritize spending time. Additionally, families are conscious that it may appear to their healthcare teams that they have failed to appropriately care for their child if read-mitted, hinting that they may feel scrutinized during the inpatient training period as well.

However, a lack of consistent home caregiving support can leave caregivers with few other options other than intermittent readmissions. Other qualitative studies have described that parents do not find that PICU admissions provide needed respite, but rather are chosen out of desperation when no other option exists.[19] Our study also shines positive light on family capability and motivation. Care coordinators noted that, beyond the initial transition period, families generally manage a high level of care in the home setting when fully supported. Care coordinators did not describe mishaps and poor care management by families in the community, nor did they describe a need for additional training to prepare families adequately. Perhaps, there is a greater imperative to support families with more home nursing during the initial weeks at home before they are fully accustomed to independent care in the community. It may be that current assessment tools for calculating nursing needs overly focus on medical severity and would better serve families if they allowed for

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increased flexibility based on various contextual factors which impact on family capacity. Expectations for family work inside the home need to be valued and protected in line with safety standards in other health care settings; parents cannot be the default to deliver 24/7 nursing care to their children with MTD.[20,21]

While this study provides insight into the complex reasons behind hospital readmission, conclusions should be interpreted within this study's limitations. Our small participant cohort, while typical for qualitative analyses, represents input from a single state. In addition, the stories that the care coordinators told are of families that have successfully launched into home care. These families do not fully represent the entire population of children with MTD, many of whom remain in the hospital awaiting home care nursing and others who are cared for in foster or group home settings.

We note that care coordinators did not mention inadequate *quality and/or training* of the home care nurses, especially as a potential cause of readmissions, but we acknowledge that inadequate staff training may be a potential contributor to hospital readmissions for this population. We also acknowledge that care coordinator perspectives are not synonymous with family perspectives, whose voice is essential to understanding effective models for quality community-based care of complex children. Prior qualitative prior work has engaged family and nursing perspectives,[22–25] and found that parents over time gain confidence in caring for their child and even training professionals who have had less ventilator experience, although navigating the complex relationships between nurses and parents is complicated for both parties.

Further, care coordinators interpret these stories and core readmission drivers from the lens of their prior training, which, for a majority of providers, was a nonmedical social work background. Other readmission drivers pertain to other stakeholders. Perhaps the critical role of quality Complex Care Programs which provide prioritized access to complex care professionals by phone or appointment, and have been demonstrated to reduce readmissions and costs in complex pediatric populations,[26,27] was not top of mind for these providers, but might have offered solutions to many family home care challenges. However, Medicaid comprises the primary payer for block nursing in pediatrics throughout the US, thus findings from this single-state program are likely generalizable for the broader population of children with MTD.

5 | SUMMARY AND CONCLUSION

Overall, care coordinators endorsed that families of children with MTD are highly motivated to care for their children safely in their home environment, and nearly always make efforts to do so with sacrifices to financial, personal, and family well-being. However, chronic gaps in home nursing support[21] without help on the horizon leads to readmission in situations of desperation and severe caregiver and family stress.

Alternative care models should be considered which allow for greater stability and continuity between acute and home care settings. For example, acute care hospitals could

partner with home care agencies to augment the size and quality of the home care workforce (eg, "job-sharing").[28]

While care coordinators did not report specific incidences of clear insufficient parental preparation for homecare, the trend of readmissions either shortly after discharge due to family preparedness or generally trending toward younger children/parents new to home care suggests missed opportunities to optimize training for families and community health providers. Perhaps universal application of simulation lab training would better prepare families to respond in these emergent situations.[29,30] Likewise, home health nurses may also benefit from access to simulation training, which in pediatric training has the capacity to familiarize learners to rare events.[31,32]

In conclusion, hospital readmissions, although a common event for children with MTD, may be reduced through augmented home health nursing which functions to bolster family capacity and bring medical expertize to the community bedside. Although some hospital readmissions are expected, other readmissions may represent failures in community health capacity. Healthcare policies which focus on maximizing quality outcomes and cost efficiency across settings must focus on strategies for augmenting the home health workforce to benefit the healthcare system as a whole. If readmission rates are utilized for program quality measures or patient outcomes assessment, it is essential to understand the drivers. Our findings suggest that infrastructure is a contributing factor. Low Medicaid reimbursement rates have been a cited cause for difficulties staffing home care cases.[33] However, other studies may be needed to fully explore the supports needed to sustain the home nursing workforce, which is critical for families of children with medical technologies living at home.

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TABLE 1

Demographic characteristics of DSCC care coordinators (N = 15)

Characteristic	N (%)
Age, y, mean (range)	45.2 (28–57)
Female	14 (93)
Race/ethnicity	
Non-Hispanic White	7(47)
Non-Hispanic Black	6 (40)
Hispanic	2 (13)
Total household income	
50–99 K	11 (79)
100–150 K	3 (21)
Marital status	
Non-married	4(27)
Married/living as married	11 (73)
Years in care coordinator role, mean (range)	6.6 (1–27)
Educational background	
Registered nurse	5 (33)
Masters in social work or counseling	8 (52)
Physical therapy/occupational therapy	2 (13)

Abbreviation: DSCC, division of specialized care for children.

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TABLE 2

Detailed quotes for readmission themes from interviews with care coordinators for children with medical technology dependency (N = 15)

Theme I: Reasons for acute care presentation are often unrelated to chronic illness

I. A. Unavoidable medical reasons

"Fever, vomiting, seizures. Seizures is probably one of our big ones."

"Some come back [to the hospital if] the child's gotten sick. Urinary tract infection. G-tube out. Some, the condition has gotten worse, so they need to go back into the hospital, And some have had to stay a little longer, because they had to change their care. Some trachs may need to be changed…in the wintertime, a lot of kids go back in when they have trachs…because of the weather."

"Usually in the beginning, sometimes it's just RSV season."

"I have a child today who's having [a planned] surgery."

I. B. Potentially avoidable medical reasons

"Sometimes, not often, but every once in a while, they're discharging the kid too quickly, and then the kid's right back in. So don't change anything in their routine for at least a week before you discharge."

"This mom takes her kid to the ER all the time. She took him into the ER for pink eye. I mean, not the best use of resources…I'm like, "You really should just call the pediatrician, and get him in right away there.…[her response], "I just, I wanted him seen that night.""

"I had a situation that the child was sent to the emergency room. It was like miscommunication between parents and the physician over the phone…I think mom understood that she should take the child to the emergency room, while it wasn't really what the doctor meant."

I. C. Parental reasons: comfort/preparedness

"I think just out of being scared, that they would just rush to the emergency room if they just don't know what's wrong with their kid. Just depends on the age, I think, too…Smaller kids, I think they run. Bigger kids, I think they wait that time, maybe 24 h, to see if things are going to improve."

"Sometimes at the very beginning, it may be the fear that something is terribly wrong. After a while, they'll discover that this is how the child would react to either too much mucus in their airway, that could have been easily suctioned, and the family maybe didn't have a good technique of suctioning. You know, the saturation levels will decrease. Alarms will beep, and family may panic. So at the very beginning, it may be just simple lack of knowing what's the norm."

A: "We've had quite a few occasions that the child is taken to emergency room for G-tube malfunction—falling out. So this is something that maybe shouldn't be happening that often.

Q: Shouldn't be happening meaning the family should learn how to…?

A: How to reinsert it, yeah…Be more comfortable at least, with it."

I. D. Environmental factors

"if there's some sort of power outage.…If power's out, the electric company, the gas company—they get letters letting them know there is this family in your area that needs to be attended to first. But if definitely it's not turned on, you need to head to the hospital."

"I have a family who had a mice infestation in their apartment… the nurses—they weren't going to work there, and nursing stopped. And then mom has three other kids. There's a dad, but he works all the time. So it's just her. And her three younger kids are all under four, so it's just toddlers and everything. And eventually the child was hospitalized because it was just too much. No nursing, mice running around, just mom."

Theme II: Need for emergency care plans to avoid readmissions

II. A. Care plan for emergencies

"I have a mom—she's very good at troubleshooting. Her and her doctor have a protocol. Because sometimes the nurse will say, "Let's go to the ER." And mom says, "Nope, we've got to follow the steps." And she has been able to for three years now—it's just more recently he has had to go to the ER and then been hospitalized. But for three years and following the protocol, she's been able to…avoid ER and hospitalization."

"I'm continuously educating them not to use the ER. "We're going to call your pediatrician. These are going to be your first steps. You're going to work with the nursing agency…You're going to follow the pediatrician's advice. You're not going to go to the ER for a sore throat." Or, "You are going to go if you're alone and the G-tube comes out." "You're going to know an emergency protocol to call 9-1-1." We help set up all of that, before they go home. But then it's also reinforced by the nursing agency, and also the hospital."

"if I can troubleshoot and solve something for those families, and occasionally. …without my intervention, the child could be either hospitalized or we wouldn't know where to go or what to do. So this is really rewarding."

II. B. Home nurses support emergency care plans

"The nurse is going to be there to handle some of those crisis situations."

"I have a case that the nurses are really, really good. I mean, and they do PICU stuff in the home…Like keep them out of the hospital…It was just one of those conditions that—it's an incurable disease. But like they would just do IVs at home. They'd do everything. Blood, everything, at home… they would have to really, really, really, really sick for them to have to be admitted."

"That's where those strong nurses coming in at, is just, "This is what we're going to do. We're going to give these nebulizer treatments around the clock, for 24 h, for ten days. Whatever. We're just going to keep this kid out of the hospital." And that's where the dedicated nurses come in."

Theme III: Lack of home care nursing leads to increased hospital utilization

III. A. Rehospitalization due to parental exhaustion

"If you don't have the nursing, then the parents are up. If the parents are up, then they're tired. If they're tired, then mistakes can happen. Then what happens? Then the child has to go back into the hospital. …if you don't have help, you can't do it all. You can't do 24/7. I mean, I have parents that try. But you know what? And then they become ill. And then I'm always like, "If you don't take care of yourself, who's going to take care of this child?""

"Unfortunately sometimes when we see those cases that it's so hard to find nursing coverage for, we know that the families are stressed physically and emotionally. And sometimes we see increased number of medical complications and even hospitalizations or ER visits, that possibly could have been avoided if there was better nursing support for the parents."

"didn't have any nursing, so she took him to [the hospital], and they had to admit him. Because the nurse was off or sick or what have you, and the foster mom said, "I just can't do this."

III. B. Rehospitalization due to lack of medical expertize at home

"They do go to the emergency room, because when their child gets sick…There's no nursing in the home. So a lot of these parents obviously although they're quote unquote experts with their child, they're still not medical professionals. So if they do see that their child is experiencing something that's beyond their skill level, they know that it's time to go to the emergency room and not take any chances. So unfortunately sometimes when we see those cases that it's so hard to find nursing coverage for, we know that the families are stressed physically and emotionally. And sometimes we see increased number of medical complications and even hospitalizations or ER visits, that possibly could have been avoided if there was better nursing support."

"families may end up at the emergency room just because … the nurse didn't show up… They may be tired. Child may be running a fever, so they anticipated something may go wrong… they kind of act in advance, knowing that they don't have the support."

Theme IV: Families attitudes towards and negative impact of readmissions

IV. A. Overall hesitant to return to the hospital

"I would say if anything the families try to keep them home longer than a … normal family would. They'll do the Diastat. They're not running to the hospital anymore with these kids."

"Their G-tube comes dislodged, and…they tried to reinsert it. These parents—they're amazing. they really are. They're better trained than I—when I was on the floor, I wouldn't know how to put a G-tube back in…they don't want to be back in that hospital."

"at least my families—I can only speak for mine—they don't readily go to the emergency right away. The only way they'll do it is if they really see—like right now, one of my moms, she says, "We kind of know her symptoms. So we try to just work with it, to keep her from going." So they've learned how to."

IV. B. Negative impact on the family

"I think it really broke her heart to even be separated from her daughter within that time… she has to be at home with her other children. So I think sometimes we forget that being disconnected from your child…—she can't not only see her mom every day like she was prior, but her siblings."

"Trips to the emergency room…if it's in the middle of the night, everybody's got to be up. And everybody's going to get in the car and go… it's such a disruption."

Q: Do families feel penalized for going back to the hospital if they need to?

A: Because they think that they didn't do a good job or something or keeping them…? Um, I think new ones do…"Oh, I did something wrong."

Abbreviations: ER, emergency room; IV, intravenous therapy; PICU, pediatric intensive care unit; RSV, respiratory syncytial virus.

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