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Family Experiences and Perspectives on Infection Prevention in Pediatric Long-Term Care

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Abstract

Purpose—Residents of pediatric long-term care facilities (pLTCF) are particularly vulnerable to healthcare-associated infections. The aims of this qualitative study were to (a) explore perspectives on infection prevention among families visiting children in pLTCF and (b) identify facilitators of and barriers to optimal hand hygiene.

Design and Methods—Semistructured, in-depth interviews with 10 family members visiting two New York City metropolitan area facilities were analyzed to identify themes.

Findings—“Everyone follows the rules” and “infections are inevitable” were primary themes. Participants reported “common sense” as a facilitator and “distraction” as a major barrier to prevention practices.

Conclusion—Current education for visitors may be inadequate to improve infection prevention behaviors.

Clinical Relevance—Nurse-led education strategies for infection prevention should be tested and modified for families visiting pLTCF.

Keywords

Pediatric long-term care; infection control; hand hygiene; public health

Introduction

Healthcare-associated infections (HAIs) are an urgent public health threat, causing substantial suffering, morbidity and mortality, and economic burden worldwide (U.S. Centers for Disease Control and Prevention, 2015; World Health Organization, 2011). Hand hygiene is widely accepted as the most effective method of preventing HAI, but adherence to guidelines by healthcare workers and visitors is suboptimal (Ellingson et al., 2014). Accordingly, research and interventions designed to improve hand hygiene and infection prevention (IP) practices have proliferated in numerous healthcare settings, including adult

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and pediatric acute care and adult long-term care, and among laypeople in their homes (Birnbach et al., 2012; Chan, Homa, & Kirkland, 2013; Fakhry, Hanna, Anderson, Holmes, & Nathwani, 2012; Hong et al., 2015; Sax, Uçkay, Richet, Allegranzi, & Pittet, 2007; Uchida, Pogorzelska-Maziarz, Smith, & Larson, 2013). A burgeoning body of evidence is mixed on the relative success of these interventions in other populations and settings, but an important subgroup has been overlooked (Abdolahi, Fisher, Aquino, & Beydoun, 2012; Gould, Moralejo, Drey, & Chudleigh, 2010; Mauger et al., 2014).

Until recently, little work has been done to address the IP needs of medically fragile children and adolescents with an array of neurodevelopmental disorders and complex medical conditions living in pediatric long-term or sub-acute care facilities (pLTCH). This understudied population is growing as medical technology extends the lives of these children who previously died at younger ages (Murray et al., 2015). pLTCH provide medical care and rehabilitation, and on-site social, academic, recreational, and therapeutic activities. Children are particularly vulnerable to antibiotic-resistant HAI such as methicillin-resistant *Staphylococcus aureus* and vancomycin-resistant enterococcus, for two reasons. First, the interactive nature of many of these activities and room sharing brings residents together in close proximity, allowing for transmission of infections from child to child. Also contributing to children's susceptibility is the complexity of their conditions, immature immune systems, and presence of multiple indwelling devices (Buet et al., 2013). These infections cause preventable suffering and illness and may lead to serious injury and death among pLTCH residents. Moreover, this problem transcends the boundaries of pLTCH into the acute care and public health realms. Prabaker and colleagues (2012) documented high rates of microbial transmission from long-term care to acute care settings through the transfer of long-term care patients.

Our research to date in pLTCH, funded by the Agency for Healthcare Research and Quality (R01HS021470), has focused primarily on outbreak surveillance and control, antimicrobial stewardship programs, and hand hygiene knowledge, attitudes, and practices/behavioral observations among staff (Buet et al., 2013; Løyland, Wilmont, Cohen, & Larson, 2016; Løyland, Wilmont, Hessels, & Larson, 2016; Murray et al., 2015; Neu, Plaskett, Hutcheon et al., 2012). Unlike research on visitors and family members in adult long-term care and pediatric acute care, families of pLTCH residents are underrepresented in the literature (Abdolahi et al., 2012). This study therefore aimed to add to the literature by addressing the following research questions: (a) What are the experiences of family members visiting children in pLTCH, and (b) what are their perceptions of the role of IP in their children's well-being?

Methods

As proposed by Thorne and colleagues (1997), Interpretive Description is a naturalistic research method influenced by commonly used qualitative methods such as ethnography, phenomenology, and grounded theory and is dedicated to meeting the epistemological traditions and practical demands of nurse researchers working to more fully understand specific human experiences in healthcare. This method was selected for this study for two reasons. The first is the acknowledgment that results of qualitative interviews with members

of such a small, unique, and under-recognized population would not yield generalizable results. Instead, the purpose of this inquiry is to use participants' own words to describe their perspectives and, from them, identify common themes.

The second reason is our intent to build on existing knowledge in this area to guide development of more meaningful IP education and training interventions for families who have children living in pLTC (Forman, Creswell, Damschroder, Kowalsi, & Krein, 2008). This intent differentiates Interpretive Description from its traditional qualitative descriptive counterparts, as described by Thorne and colleagues (2004) as assuming "nurse investigators are rarely satisfied with description alone and are always exploring the meanings and explanations that may yield application implications" (p. 6).

Design

This study employed semistructured, one-on-one in-depth interviews to ensure participants' confidentiality and privacy. The rationale was that deidentification of data would increase participants' comfort level to openly discuss this topic and their knowledge and behavior. This would have been impossible to do in a group setting, as participants affiliated with a particular facility would not only recognize each other but may avoid revealing personal beliefs, criticism, and/or offering socially undesirable responses. This may be especially true if they know or learn that their attitudes and/or practices may put other participants' children at risk for infection.

Setting, Sample, and Recruitment

The two study facilities had 54 and 137 beds, respectively. Overall, residents' lengths of stay ranged from 1 day to 21 years, with averages from several weeks to several years. Most children had feeding tubes, almost half had tracheostomies, and fewer than 10% were ventilator dependent and/or had central venous catheters. Both facilities included on-site schools.

After approval from the Columbia University Medical Center Institutional Review Board, we coordinated with pLTC facility leadership to schedule on-site recruitment. Eligible participants included English-speaking adults (18 years or older), parents, siblings, grandparents, and aunts/uncles who visit at least monthly. With visitation characteristically low at these facilities, this sample was representative of a family member who is relatively involved in the resident's care at the facility. The researchers employed purposive sampling to recruit family members while they were on site visiting their child or a relative. At both sites, data were collected primarily during the evening and after work hours and Sunday afternoons when visitors were most common. Approximately 20 eligible subjects were invited to participate, and our final sample included 10 informants. Identifying demographic information was not collected.

Participants were offered a modest incentive for their cooperation, a "2015 Flu Season Survival Kit," which included personal-sized bottles of hand sanitizer, hand lotion, tissues, and alcohol wipes. They were asked to read an "Interview Introduction" sheet and were informed that their voluntary participation in an interview implied informed consent but that they could withdraw at any time, for any reason.

Data Collection

An interview/topic guide based on a guide used in a previous study of healthcare workers' IP perspectives was adapted to elicit candid responses from participants during private conversations (Appendix). It was vetted by and rehearsed with an interdisciplinary team of researchers and nursing faculty independent of this study, piloted with members of the research team familiar with the subject matter and study setting, and revised accordingly.

Interview topics focused on (a) participants' experiences during a typical visit, (b) the resident's history of infections, (c) participants' general understanding of various IP methods and the role of hand hygiene, (d) participants' assessment of their own and staff performance of such methods, (e) their sense of the nature and usefulness of IP education and training offered by their respective facilities, and (f) suggestions for improving IP education.

Audio recordings of the interviews were transcribed by members of the research team, some verbatim and some comprising only relevant text extracted from discussions. The format of transcripts was determined by the individual analyst's preference. Simultaneous collection and preliminary analysis of data facilitated an iterative process in which participants' feedback added new discussion topics to those selected a priori. This improves the quality of interviews as they happen, and as noted by Oliver (2012), Interpretive Description "replicates clinical reasoning as the researcher compares individual instances with each other and with their context and alternates between asking 'what is going on?' and 'how does this relate to what else is known?'" (p. 412). Data collection continued until thematic saturation was reached at 10 participants.

Data Analysis

Using a three-tiered, iterative analytic process described by Auerbach and Silverstein (2003), we identified common themes through an evolution of raw text coding and content categorization aligned with Interpretive Description methodology. Transcripts of the interview audio recordings were reviewed and searched for relevant text and content germane to the research question. Text was examined for pattern, theme, and content analysis. We then coded for repeating ideas, thoughts, or statements that emerged from all or nearly all participants. The most common repeating ideas were organized into themes.

Rigor

In the field, the interviewer was familiar with the social context known to facility leadership and bracketed all assumptions prior to interviews with participants. With participants' verbal consent, conversations were audio recorded to ensure accuracy of data capture and to facilitate analysis. The interviewer, a master's level nursing student with experience in qualitative research, was trained and supervised by senior researchers and faculty. A second researcher accompanied the interviewer on three of six site visits to provide back-up audio recording and debrief following each interview.

Throughout the study period, reflexivity was fostered in several ways. First, the interviewer kept a journal documenting reflections on sources of potential bias, study limitations, ethical issues, and challenges to objectivity to avoid skewing the results and analysis with

preconceived assumptions about the participants. This was useful in the iterative process used to continuously evaluate our methods and to develop probative questions and dialogue. Second, notes taken during the interviews allowed for triangulation of multiple analysts' insights and to ensure all verbal and nonverbal details of the interviews were captured accurately. They were also used to generate ideas for inquiry to be incorporated into interviews as they continued and to facilitate analysis by documenting audio time codes of key responses and respondents' nonverbal communication relevant to their comments. Notes were not included per se in the analysis.

Three researchers independently listened to the audio recordings and/or read the transcripts. Peer debriefing among the research team allowed for an exchange of individual analyses and interpretations, and discussions continued until consensus was reached regarding relevant text, themes, and representative excerpts from the interviews.

Results

Private interviews lasting 5–30 minutes were conducted with seven mothers, one father, a grandmother, and a brother of a resident in two pLTCFs between October 28 and December 12, 2015. The shortest interview was held with a mother who was unaware that her bus was scheduled to leave within a few minutes of sitting down with us, so she spent the time she had. All but one participant stated that their child had had an infection at some point during their stay in the facility. Most described their children as being nonverbal or unable to express their needs and voiced their own frustration with being unable to communicate with them, particularly about how they felt. Participants described a wide range of activities associated with a typical visit, including going outside for a stroll, watching videos, playing with toys, and even going to the mall. Most mentioned using visits to get updates of their child's status from clinical or administrative staff. Some of the participants said they performed routine care such as bathing, dressing, and feeding their children during their visits; one described that as “what you're supposed to do as a parent.”

All respondents listed IP methods such as wearing gloves and hand hygiene as activities performed during a typical visit. Most described meticulous attention to hand washing and the constant use of alcohol-based hand sanitizer. Aware that they were being observed as well as interviewed, some acted out movements associated with each of these activities, even while behaving in a manner entirely disconnected from the IP process. For example, one mother had her second child, a healthy infant, on her lap during an interview in which she described her confidence with her own and the facility staff's IP competence. Nevertheless, she laid a pacifier on a changing table just used to change the infant's diaper, “cleaning” the pacifier in her own mouth before returning it to the infant, and neglecting to perform any hand hygiene whatsoever before, during, or after the process.

When asked about the type of IP education they received from staff and which staff member delivered it, there was scarce mention of any kind of formal instruction or training. Instead, they described an appreciation of the ongoing, frequent communications with staff—primarily nurses—providing them with infection status updates, whether their child or roommates were under quarantine or if isolation precautions were in place. All responded

that a wide range of staff—nurses, nurses' aides, physicians, social workers, and even security guards—offered verbal reminders and encouragement at every opportunity. All respondents perceived themselves and the staff as doing everything humanly possible to protect their children from HAIs.

Thematic Analysis

Participants' comments revealed two main themes. First, "Everyone Follows the Rules," which reflected their assessment that they and the staff were doing everything possible to prevent HAI in the facility. Second, "Infections Are Inevitable," which revealed a fatalistic attitude that, despite everyone following the rules, the children get infections because they are extremely susceptible to germs.

Theme 1: Everyone Follows the Rules

Subtheme 1: Staff is competent—Informants generally reported satisfaction with the care their child was receiving; they also reported that nearly all of the children had had infections at one time. They appreciated the cleanliness of the facilities, described a high comfort level with having their child in a controlled residential environment, and were confident in their assessment that the staff were doing all in their power to prevent HAIs. All but one had no complaints about staff members' adherence to IP protocols, including hand hygiene and standard and isolation precautions. As one mother stated,

[Mother, S2] This place is fantastic a zillion percent. I think they're trying the most, most, most, most. I don't think it can get better...if there's an infection, I wouldn't blame the hospital for even a minute... I think it's the child that...first of all, it's probably not even possible to be 100,000 percent. People are people and germs are all over. It's in the air. We talk. We breathe. From [the facility] side, I think they can't be better. They are the best.

Another mother expressed the perceived inevitability of HAI,

[Mother, E3] I guess no matter where you are, it's a normal reaction. Infections can happen with anyone. So as long as they take care of her...

This sense of inevitability appeared to be related to a general thankfulness that they were relieved of the burden of caring for their child at home, where safety and suffering were constant problems, in contrast to the safer setting of the pLTCF where around-the-clock medical care often kept their child out of the emergency department or hospital. As one mother put it, she felt better having her daughter in residential care:

[Mother, S1] ...even if something [is] going on with her here, I have doctors, I have the qualified nurses, so they can do it very quickly to check her, to find out what's going on with her.

Participants were generous in complimenting staff on following protocols designed to prevent outbreaks when one or more children had infections in the facility. There was consensus that the exertion of physical controls on the environment and visitors were necessary to keep the residents safe. They didn't mind, for example, being told to stay home if they were ill or keeping other children out of their child's room during a visit. In fact,

when asked about their perceptions of the value of various isolation precautions and the use of personal protective equipment, participants agreed that they were happy to comply with whatever protocols were necessary and felt confident that staff was compliant at all times.

In two cases, however, participants said they were more likely to just stay home instead of having to contend with personal protective equipment because it acts as a barrier between them and their child. One mother compared a mask and gown to “a gate between me and [my child].”

Subtheme 2: Visitors are vigilant—Invariably, participants reported performing hand hygiene constantly, attributing the behavior to “common sense” or “habit” and that the same was true for facility staff and other visitors. During the interviews, this concept appeared to be obvious to the participants, judging by their body language and facial expressions. They pointed to the ubiquity of wall-mounted hand sanitizer dispensers as a facilitator of hand hygiene. They use hand sanitizer so much, they said, that the constant use of alcohol has damaged their hands. As one participant showed the interviewers the dry skin on her hands,

[Mother, E6] As soon as you walk through the doors, it's right there. From the time you come in until the time you leave, hand-washing all day. There's no sense in using lotion, because this is how it is all day.

One participant captured the sense that family members and staff are motivated to perform hand hygiene for a single reason:

[Mother, E7] I just do it for my sake, for my child. My concern here is for my child. That's it. I'm not here for nobody else's child...I just do what I do as a mom.

Another participant had a different perception:

[Grandmother, S3] I'm always thinking about these workers. Do they have children? They don't need to get sick and take it home to their children. I never used to think about what happens after you go home, but now I do.

In identifying possible barriers to hand hygiene performance and IP behavior, participants denied that there were any barriers, that the availability of hand sanitizer made it routine. One participant, when asked if there were times when he found it difficult to clean his hands, stated,

[Father, E2]No. It's just “boomboom”...it's very accessible.

Another felt nothing gets in the way of hand hygiene, shrugging as she said,

[Mother, E1] ...when I come to touch my boy I know I use hand sanitizer because I am coming in from the outside. Not really difficult.

Others reported, however, that barriers to hand hygiene do exist in certain situations. For example, one participant squirmed in her chair while stating that, if she is asked to do something by a staff member, she will forego cleaning her hands. Another grimaced while stating that she might forget to clean her hands when she faces competing priorities:

[Mother, S2] I m trying to do it, but if I m around with [my new baby from home], sometimes she is screaming and wants something from me, so I m running between them and sometimes I forget to use it.

Theme 2: Infections Are Inevitable

Subtheme 1: Germs are everywhere—There was a general sense among informants that the “dirty” outside world should be kept out of the “clean” facility environment. One mother had what she termed “cootie phobia,” and that it was ingrained in her from her work as a nurses’ aide. All participants stated that they unfailingly used hand sanitizer upon entering the facility to keep germs from the community out and used it upon exiting to prevent germs from inside the facility from coming home with them. One participant noted that this was common among her peers:

[Mother, E2] When everyone comes in I do notice the sanitizer right there. I notice it’s the first thing people do...and I do it myself, too. I sign the paper, then I use the sanitizer. Every time I walk through and see one, I just use it.

Subtheme 2: Children are susceptible—Again, participants invariably mentioned the ubiquity of germs in the community and the typical group interactions among pLTC residents as the main reasons that keeping children infection-free is virtually impossible. Their comments suggested a “kids will be kids” explanation for their assertion that no matter what IP measures are taken and despite their confidence that such measures are done adequately, HAIs are inevitable in the pLTC setting. This belief was bolstered by participants’ keen awareness of residents’ susceptibility to infections. Those whose children had infections reacted emotionally when asked about their experience:

[Mother, S1] Oh my goodness. I have like a red blinking light in my head when she’s catching infection because it’s so dangerous for her because of the seizure disorder. So when she’s catching the infection, the seizures are out of control so sometimes it’s very difficult to stop them. So, it’s terrible. [Mother, E6] It was the worst. The first time she got [a urinary tract infection] when she was here, it was so bad that it turned into a [sludge].

When asked what they believed were the causes of their child’s infections, participants offered little in the way of possible explanations but were confident that it was not the result of staff or visitor behavior. According to one mother, her child’s condition was the culprit:

[Mother, S2] It’s a lot about the child herself...the doctors told me they still can’t figure out why or how she gets sick. This is what she is...she needs attention. She likes to get sick. She likes when everybody’s busy with her. That’s the joke in the family.

Another participant had a similar view, saying:

[Grandmother, S3] His immune system is not that strong and he was quite sick. It was respiratory, I felt it was very compromising because he has a trach. He had rhinovirus and maybe parainfluenza virus. Before he was in [another facility], he was hospitalized there for parainfluenza and also had coxsackievirus.”

Discussion and Conclusions

Previous observations by this research team of pLTCF staff behavior and their feedback related to IP yielded insights about existing facilitators of and barriers to optimal adherence to hand hygiene and other key IP practices (Løyland, Wilmont, Cohen, et al., 2016; Løyland, Wilmont, Hessels, et al., 2016). During these observations of staff behaviors, two observers witnessed inadequate IP practices among family members and other visitors at residents' bedsides and during their movements around the facilities. This experience inspired the current study, which aimed to add to the literature by eliciting similar insights from visiting family members, who, like staff, play key roles in preventing infections in pLTCF (Ciofi degli Atti et al., 2011).

We asked, "what are the experiences of family members visiting children in pLTC" and "what are their perceptions of the role IP plays in their children's well-being?" The themes that emerged reveal a common perception among family members that IP is a priority in pLTC and that staff and visitors perform various IP methods adequately and often. This perception exists, despite respondents' acknowledgements that virtually all their children experienced at least one infection during their residency at the facility. They attribute this to the inevitability of infections and their children's vulnerability to them. These insights will inform the development of interventions and education targeting family members and visitors to improve their understanding of their roles in IP and ways they might improve their adherence to accepted guidelines.

Assuring Rigor, Credibility, and Confirmability

To gain confidence in the trustworthiness of our study, we sought to establish credibility and confirmability of our findings through the use of established techniques in qualitative research evaluation. We established credibility—confidence in the truth of our findings—using prolonged engagement, thick description, and peer debriefing. We established confirmability—the degree of neutrality and extent the findings are shaped by respondents, not researcher bias—using researcher reflexivity and analyst triangulation (Malterud, 2001, 2012; Lincoln & Guba, 1985).

The researchers spent many hours over the course of several weeks in the field cultivating relationships with study site staff and administrators and learning about the culture coloring participants' perspectives. This "prolonged engagement" allowed the research team sufficient access to plan study logistics with real-time efficiency. It provided adequate face time with both staff and family members to develop rapport and trust, which facilitated recruitment, informed consent, and candor of participants. We provided "thick description," a detailed account of the settings, participants, and field observations to reveal nonverbal data and provide context for the findings. "Peer debriefing" involved weekly meetings in which the field researchers and other members of the research team discussed interim analyses relevant to the iterative data collection process. This enhanced the internal validity of the discussion topics and questioning as the interviews were conducted.

Multiple verbatim excerpts paint a picture of participants' experiences in their own words, adding transparency to the content analysis. By keeping a reflexive journal and taking

copious field notes capturing nonverbal communication and observations, the interviewer minimized the potential for her own biases to creep into data collection and analysis. Similarly, the interdisciplinary research team met regularly to discuss individual perspectives and experiential biases to mitigate their impact.

Limitations

Despite frequent site visits and the attainment of data saturation, the characteristically low rate of family visitation made it difficult to find eligible informants. Those willing and available to participate may represent the most engaged family members who are more involved in their child's care and IP efforts than those not visiting. They also would likely have more up-to-date HAI and IP knowledge, based on the common report that "education" about hand hygiene and isolation precautions is delivered in-person, on the spot, and informally. We were only able to conduct the interviews in English, so our data lacked the perspectives of non-English speakers. Another potential bias may have resulted from participants' uneasiness in criticizing staff or admitting to undesirable behaviors.

Implications for Practice and Future Research

According to the family members interviewed in this study, nothing more can be done than is already being done to prevent HAI in the pLTCF where their children reside. In reality, however, infections are common, and outbreaks occur frequently. We learned that IP challenges are unique in this setting and that guidelines adopted in the adult long-term care and rehabilitation and pediatric acute care areas are ill-suited to pLTCF. However, it is still worthwhile to explore the utility of adapting them to meet the unique challenges of pLTCF providers and families (Løyland, Wilmont, Cohen, et al., 2016; Løyland, Wilmont, Hessels, et al., 2016; Uchida et al., 2013). Family members may benefit from training *specifically tailored to their needs* to be more comfortable and skillful in IP practices. More forethought considering their feedback should be put into planning educational activities and materials. As clinicians responsible for patient and family education, nurses should encourage and empower family members to play significant roles in optimizing IP efforts (Davis, Savvopoulou, Shergill, Shergill, & Schwappach, 2014).

To learn more specific details about their health literacy and education preferences, a quantitative knowledge, attitudes, and practices survey may be warranted. Results, when cross-referenced with the results presented in this paper, may generate actionable data to guide the development and evaluation of novel IP interventions. Finally, our previous research findings suggest that pLTC providers and families may have more in common by dint of their unique needs than they do by dint of their location or the demographics of their community. Nevertheless, a more far reaching multisite study across different parts of the country may yield insights that improve care of this underserved population.

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Appendix

Family and Visitor Feedback Interview Guide

Open

- Thank you for participating; we will limit our conversation to 10–15 minutes, tops.
- You are part of the care team here, so your point of view is important to include when any kind of educational programs are developed; otherwise, they won't be effective. So, we really want to hear what you have to say.
- You are safe to be candid (private, confidential, staff/administration unaware) because what is said here stays between you and the Columbia research team

- We would like your permission to audio record conversation to make sure we accurately capture your thoughts. Is it ok?

Conversation

- So, what comes to mind when you hear the term “infection prevention”?
- During an average visit, what makes you think about it?
- (If not addressed yet) Where do you think hand hygiene fits into the general concept of infection prevention?
- Give me an idea of the various situations in which you practice hand hygiene (Like, how do you decide to use soap and water versus alcohol rub? Other methods?)
- Do you feel there are any barriers to practicing hand hygiene? Like, what would some reasons be to not clean hands?
- What is your sense of other family members'/visitors' hand hygiene practices?
- What do you think is the most helpful way to teach family members/visitors about infection prevention?
- Any suggestions for new methods, materials, timing, etc.?

Close

- What should we have asked you that we didn't?
- Thanks so much for your help!
- We plan to summarize our findings and prepare a report of what we learned that we [will use as a foundation of future family/visitor education programs].
- Again, be assured that no individuals will be identified.

Key Practice Points

- Healthcare-associated infections are a particularly dangerous threat to children with complex medical conditions living in residential pediatric long-term care and rehabilitation facilities.
- Suboptimal performance of hand hygiene by visiting family members thwarts infection prevention efforts and puts vulnerable children at risk.
- Visiting family members are unaware that they lack the knowledge and skills to improve their infection prevention practices and are disconnected from the process/protocol.
- If provided the appropriate resources, pediatric rehabilitation nurses can empower visiting family members to build the skills and confidence necessary to optimize infection prevention efforts.