

11-1-2014

An Emerging Population: The Chronically Critically Ill

Philip Jurasinski

Marquette University, philip.jurasinski@marquette.edu

Christine A. Schindler

Marquette University, christine.schindler@marquette.edu

Accepted version. *Journal of Pediatric Health Care*, Vol. 28, No. 6 (November/December 2014):
550-554. DOI. © 2014 Elsevier. Used with permission.

NOTICE: this is the author's version of a work that was accepted for publication in *Journal of Pediatric Health Care*. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in *Journal of Pediatric Health Care*, VOL 28, ISSUE 6, November/December 2014, DOI.

An Emerging Population: The Chronically Critically Ill

Philip Jurasinski

*College of Nursing, Marquette University
Milwaukee, WI*

Christine A. Schindler

*Acute Care Pediatric Nurse Practitioner,
Division of Critical Care, Medical College of Wisconsin
College of Nursing, Marquette University
Milwaukee, WI*

Key Words: Chronic critical illness; care conferences; family support

Case Presentation

A 15-year-old medically fragile adolescent presented to the emergency department with a 2-day history of rapid, shallow respirations, weak cough, and an inability to expectorate or clear secretions. Although these findings represented an acute change in respiratory status, the parents reported that during the past year the patient had increased difficulty managing secretions.

History

The patient was born at 27 weeks gestational age and sustained hypoxic ischemic encephalopathy. The adolescent's history was significant for multiple medical and surgical interventions associated

[Citation: *Journal/Monograph Title*, Vol. XX, No. X (yyyy): pg. XX-XX. [DOI](#). This article is © [Publisher's Name] and permission has been granted for this version to appear in e-Publications@Marquette. [Publisher] does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from [Publisher].]

with this syndrome. During his neonatal course, he experienced recurrent episodes of necrotizing enterocolitis, which resulted in short gut syndrome and parenteral nutrition dependence. He was nonverbal, with profound visual impairment as a result of a bilateral optic nerve atrophy, and had a seizure disorder, severe dysautonomia, and global developmental delays. His more recent history was significant for multiple episodes of gram-negative bacterial and fungal sepsis. He had chronic lung disease and during the past year prior to this illness experienced a significant decline in overall health status, requiring monthly admissions to the pediatric intensive care unit (PICU).

Review of Systems

When the provider interviewed the family, the mother and father expressed distress that their son's health status was declining. They noted faster, shallower breathing, a weak cough, and an inability to clear secretions. He had recent weight loss, increased fatigue, and increased abdominal distension. The family denied rhinorrhea, fever, change in level of consciousness, bleeding, or increase in tone. He had approximately three 2-minute generalized tonic-clonic seizures per day, which was consistent with baseline.

Physical Examination

The patient appeared ill but nontoxic. He was awake, alert, and tracked with his eyes but was nonverbal. All growth parameters measured less than the 3rd percentile. Current vital signs included heart rate, 95 beats per minute; blood pressure, 115/75 mmHg; respiratory rate, 42 breaths per minute; and oxygen saturation, 88% on room air. In addition, he was afebrile. Nasal flaring, subcostal retractions, and a weak, nonproductive cough were observed. Secretions were pooling in the posterior pharynx, and a weak gag reflex was noted. Upon auscultation, diminished breath sounds were heard in the lung bases bilaterally with scattered coarse rhonchi. The remainder of the examination was unremarkable.

Diagnostic Testing

A chest radiograph, capillary blood gas value, and viral nasopharyngeal swabs were obtained to evaluate for pneumonia and other sources of viral illness.

Clinical Course

The patient was subsequently diagnosed with influenza A (H1N1) virus and was admitted to the PICU. His PICU course was complicated by a significant decline in neuromuscular strength and prolonged intubation as the result of a secondary bacterial pneumonia. Given his chronic lung disease and baseline impaired airway clearance, the care team recommended a tracheostomy to facilitate weaning from the ventilator and transition of care to rehabilitation services.

The pediatric nurse practitioner (PNP) recognized that the family was overwhelmed by the decisions they had to make, such as whether a tracheostomy was the right intervention given their son's airway compromise, and that they were unsure whether the tracheostomy would improve the quality of their son's life or prolong his suffering.

The PNP organized a care conference that elucidated issues and facilitated discussions, which allowed the family to make informed decisions. Some considerations included a tracheostomy, noninvasive positive pressure ventilation, an altered cardiopulmonary resuscitation (code) status, and increased home care support/home nursing. Subsequently, the family made the decision to forego a tracheostomy and agreed to a move into a more palliative mode of therapy with the full support of the multidisciplinary team.

Case Study Questions

1. How is a patient classified as chronically critically ill?
2. What strategies can a PNP use to address the family's needs?
3. How can PNPs support families who are making decisions about chronically critically ill children?
4. What factors influence the ways in which these discussions happen?

5. What is the role of PNs in the care of chronically critically ill children and their families?

Case Study Answers

Chronically Classically Ill Classification

1. How is a patient classified as chronically critically ill?

Chronic critical illness is an emerging concept, as children are living longer with complex chronic illnesses, resulting in prolonged PICU stays, fluctuations in care needs, and frequent exacerbations of their illness that require frequent PICU admissions ([MacIntyre, 2012](#)). Patients with complex chronic illness who survive an acute critical illness may subsequently experience chronic critical illness, which is characterized by protein depletion, ongoing catabolism, and neuromuscular weakness ([Kalb & Lorin, 2002](#)). These patients tend to be more susceptible to nosocomial, antibiotic-resistant infection. Patients may or may not have tracheostomies and be mechanically ventilated ([White, 2012](#)). Although experts disagree on the length of time that a chronic care device needs to be in place for the patient to be considered chronically critically ill, the range of cited length of mechanical ventilation is as little as 2 days to as long as 15 years, with an average time cited as 21 days ([Boniatti et al., 2011](#), [González-Cortés et al., 2011](#), [King, 2012](#) and [Nelson et al., 2010](#)). Researchers cite a range of 16 to 40 days after tracheostomy placement and intensive care length of stay anywhere from 7 to 51 days as the criteria to be considered chronically critically ill ([Carson, 2012](#)).

Unfortunately, most chronic critical illness literature focuses on adults, with little exclusive information on pediatric chronically critically ill patients. However, differences exist in pediatric patients, such as smaller airways, lower cardiac reserve, and increased numbers of comorbidities compared with their adult counterparts ([Peterson-Carmichael & Cheifetz, 2012](#)). The estimated prevalence of these children is six to seven per 100,000. Similar to adults, the majority of chronically critically ill pediatric patients are treated for underlying respiratory issues ([Peterson-Carmichael & Cheifetz, 2012](#)).

This medically fragile adolescent acutely presented with influenza in addition to his chronic respiratory insufficiency. He was at high risk to become a chronically critically ill adolescent given his numerous comorbidities. This family needed additional support and counseling when making complex care decisions that accompany chronic critical illness. These decisions included a need for tracheostomy, possible dependence on mechanical ventilation, aggressive use of antimicrobial agents, and the need for rehabilitation services, hospice, or palliative care.

Strategies to Address the Family's Needs

2. What strategies can a PNP use to address the family's needs?

PNPs can use a variety of strategies to deal with the family's needs. In addition to providing support at the bedside, PNPs can use care conferences to help guide decision making. Facilitating care conferences can be challenging, but three mnemonics can guide the PNP when facilitating open discussions with children and their families (see the [Table](#)).

In addition to providing support at the bedside, PNPs can use care conferences to help guide decision making.

Table. Mnemonics for facilitating care conferences

| Mnemonic | Approach |
|--|--|
| ABCDE | Advance preparation |
| | Building a therapeutic relationship |
| | Communicating well |
| | Dealing with the patient's and family's reactions |
| | Encouraging/validating emotions |
| SPIKES | Setting up the conference |
| | Perception assessment |
| | Information disclosure preferences |
| | Knowledge and information presentation to the patient/family |
| VALUE | Empathic responses |
| | Strategy and summary |
| Valuing and appreciating what family members say | |

Mnemonic

Approach

Acknowledging family emotions

Listening

Understanding who the patient is as a person

Eliciting questions from the family members

Note. Data from Lautrette, A., Ciroldi, M., Ksibi, H., & Azoulay, E. (2007). End-of-life family conferences: Rooted in the evidence. *Critical Care Medicine*, 34(11), S364–S372 and Sharma, R., & Dy, S. (2011). Cross-cultural communication and use of the family meeting in palliative care. *American Journal of Hospice & Palliative Medicine*, 28(6), 437–444.

When possible, advanced care planning, such as advanced directives and altered code status determinations, may help families set limits around care and have frank discussions with the care team about care goals. Families of children who are hospitalized for prolonged periods as a result of chronic critical illness face a high degree of stress and uncertainty. Given poor outcomes for many patients and high costs and burdens of treatment, effective communication between the family and members of the multidisciplinary team is essential. Institutional resources, including chaplains, social workers, hospital ethics committees, and palliative care providers, may support families.

How PNs Can Support Families

3. How can PNs support families who are making decisions about chronically critically ill children?

PNs can coordinate and facilitate care conferences for both the family and the interdisciplinary team. PNs can recognize which members of the care team are necessary for the best outcomes for the care conference, such as the critical care team, the palliative care team, the pulmonary care team, chaplains, respiratory therapists, and social workers.

In addition to facilitating the exchange of information and the decision-making process, care conferences also offer the unique opportunity to provide psychosocial support to families and staff beyond the support that can be provided by a single clinician. The PNP can build a therapeutic relationship with the family through care

[Citation: *Journal/Monograph Title*, Vol. XX, No. X (yyyy): pg. XX-XX. DOI. This article is © [Publisher's Name] and permission has been granted for this version to appear in e-Publications@Marquette. [Publisher] does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from [Publisher].]

conferences by acknowledging the family's emotions of grief and loss. Families are often in an emotionally fragile state before the care conference takes place and are at high risk for heightened anxiety, posttraumatic stress disorder, and depression (Hickman, Daly, Douglas, & Clochesy, 2010.) The care conference allows the interdisciplinary team to provide an environment of trust for the family. Families of institutionalized members of the chronically critically ill adult population face higher rates of depression and life restrictions compared with patients who live at home (Choi et al., 2011 and Douglas et al., 2010). This problem also prevails among parents of chronically critically ill children, because these parents are socioeconomically and psychologically challenged (Peterson-Carmichael & Cheifetz, 2012). The care conference also recognizes the role that the family has in the treatment of the child and allows the family to feel that the interdisciplinary team is actively providing care for the child and is a partner in care planning and care decisions.

Factors Influencing the Discussions

4. What factors influence the ways in which these discussions happen?

Facilitating an environment of trust is essential for influencing the way that key discussions take place; however, establishing an environment of trust is not enough for a successful care conference. The care conference allows the opportunity to discuss potentially bad news, and the way in which clinicians deliver the information to the family is as important as the information itself. Therapeutic communication techniques that clinicians can use to better provide support to the family include allowing for periods of silence, acknowledging strong emotions, and repeating what family members have said to better facilitate communication, care, and understanding. Clinicians should focus on speaking less and listening more (Truog, Meyer, & Burns, 2006). Additional therapeutic communication techniques include the acknowledgment of appreciation and hope, support of family beliefs, and providing accessibility and continuity of care to patients and their families.

The care conference allows the opportunity to discuss potentially bad news, and the way in which clinicians deliver the information to the family is as important as the information itself.

PNPs and other clinicians can also use specific words and techniques to provide psychosocial support for families. Avoiding the word "but" and instead using the word "and" can shift the tone of the conference toward feelings of mutual exploration. Providing one viewpoint and then an alternate viewpoint can also be useful for mutual exploration. Holistic assessments of the family's needs, including physical, spiritual, and mental health needs, can facilitate stronger interdisciplinary psychosocial support. Nonverbal communication, including head nodding, therapeutic touch, and attentive body language, can also provide support (Fineberg, Cohen, Kawashima, & Asch, 2011). These techniques enable clinicians to gain a better perspective of a child's life and increase familial comfort during care conferences.

Role of PNPs

5. What is the role of PNPs in the care of chronically critically ill children and their families?

PNPs can effectively lead care conferences by implementing both nonverbal and verbal therapeutic communication techniques. In addition, their prior experience as bedside nurses allows PNPs to use their emotional knowledge and thinking to further facilitate better outcomes for pediatric patients by preparing the family for difficult and emotionally charged conversations (Cypress, 2011). PNPs also have the opportunity to provide guidance for bedside nurses, who can in turn prompt families to ask questions and serve to guide the efforts of the interdisciplinary team because bedside nurses are present for multiple provider visits (Gay, Pronovost, Bassett, & Nelson, 2009).

PNPs can facilitate the coordination of care for pediatric patients in two important ways. First, they can ease the transition from hospital to home. Transition from hospital to home can increase the quality of life in the chronically critically ill patient because the home environment fosters normalization of the child's life. Home health care

personnel play a vital role in the care of the chronically critically ill patient because they support not only the patient's transition home but also the family and the difficulties they might face, such as lack of resources and financial burden. PNs have the unique opportunity to meet with both hospital and home care nurses to ensure the quality of the emotional support in both environments. Second, PNs can coordinate the efforts of the palliative care team, chaplains, and social workers to serve the needs of the family. It is also recommended that clinicians receive training in palliative care to understand the goals and needs of patients and families assuming this care trajectory (Truog et al., 2006).

Summary

Using these approaches, the team was able to describe various options for the best care of this chronically critically ill adolescent. When care conferences are well facilitated, they can be a powerful tool to provide essential support to families during very challenging points along the continuum of care.

Acknowledgements

We thank the fabulous Children's Hospital of Wisconsin Chronic Critical Illness Committee for all their hard work to improve the care we provide to complex chronically critically ill patients.

References

- Boniatti et al., 2011. M. Boniatti, G. Friedman, R. Castilho, S. Viera, L. Fialkow. Characteristics of chronically critically ill patients: Comparing two definitions. **Clinics**, 6 (4) (2011), pp. 701–704
- Carson, 2012. S.S. Carson. Definitions and epidemiology of the chronically critically ill. The chronically critically ill patient. *Respiratory Care*, 57 (6) (2012), pp. 848–856
- Choi et al., 2011. J. Choi, M.P. Donahoe, T.G. Zullo, L.A. Hoffman. Caregivers of the chronically critically ill after discharge from the intensive care unit: Six months' experience. *American Journal of Critical Care*, 20 (1) (2011), pp. 12–23
- Cypress, 2011. B.S. Cypress. Family conference in the intensive care unit: A systematic review. *Dimensions of Critical Care Nursing*, 30 (5) (2011), pp. 246–255

- Douglas et al., 2010. S.L. Douglas, B.J. Daly, E. O'Toole, R. Hickman. Depression among Caucasian and non-Caucasian caregivers of the chronically critically ill. *Journal of Critical Care*, 25 (2) (2010), pp. 364.e11–364.e19
- Fineberg et al., 2011. I.C. Fineberg, M. Kawashima, S.M. Asch. Communication with families facing life-threatening illness: A research-based model for family conferences. *Journal of Palliative Medicine*, 14 (4) (2011), pp. 421–427
- Gay et al., 2009. E.B. Gay, P.J. Pronovost, R.D. Bassett, J.E. Nelson. The intensive care unit family meeting: Making it happen. *Journal of Critical Care*, 24 (4) (2009), pp. 629.e1–629.e12
- González-Cortés et al., 2011. R. González-Cortés, J. López-Herce-Cid, A. García-Figueruelo, G. Tesorero-Carcedo, M. Botrán-Prieto, A. Carrillo-Álvarez. Prolonged stay in pediatric intensive care units: Mortality and healthcare resource consumption. *Medicina Intensiva*, 35 (7) (2011), pp. 417–423
- Hickman et al., 2010. R.L. Hickman, B. Daly, S.L. Douglas, J. Clochesy. Informational coping style and depressive symptoms in family decision makers. *American Journal of Critical Care*, 19 (5) (2010), pp. 410–420
- Kalb and Lorin, 2002. T.H. Kalb, S. Lorin. Infection in the chronically critically ill: Unique risk profile in a newly defined population. *Critical Care Clinics*, 18 (2002), pp. 529–552
- King, 2012. A.C. King. Long-term home mechanical ventilation in the United States: The chronically critically ill patient. *Respiratory Care*, 57 (6) (2012), pp. 921–932
- MacIntyre, 2012. N.R. MacIntyre. Chronic critical illness: The growing challenge to health: The chronically critically ill patient. *Respiratory Care*, 57 (6) (2012), pp. 1021–1027
- Nelson et al., 2010. J.E. Nelson, C.E. Cox, A.A. Hope, S.S. Carson. Chronic critical illness: Concise clinical review. *American Journal of Respiratory Critical Care Medicine*, 182 (2010), pp. 446–454
- Peterson-Carmichael and Cheifetz, 2012. S. Peterson-Carmichael, I. Cheifetz. The chronically critically ill patient: Pediatric considerations. *Respiratory Care*, 57 (6) (2012), pp. 993–1003
- Truog et al., 2006. R.D. Truog, E.C. Meyer, J.P. Burns. Toward interventions to improve end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 34 (11) (2006), pp. S373–S379
- White, 2012. A.C. White. Long-term mechanical ventilation: Management strategies. *Respiratory Care*, 57 (6) (2012), pp. 889–899

Conflicts of interest: None to report.

Correspondence: Christine A. Schindler, PhD, RN, CPNP-AC,
Marquette University College of Nursing, 9000 W Wisconsin Ave, MS
681, Milwaukee, WI 53201.

Vitae

Philip Jurasinski, Graduate Nursing Student, Marquette University
College of Nursing, Milwaukee, WI.

Christine A. Schindler, Acute Care Pediatric Nurse Practitioner, Division
of Critical Care, Medical College of Wisconsin, Milwaukee, WI,
and Coordinator, Pediatric Acute Care Graduate Option,
Marquette University College of Nursing, Milwaukee, WI.