

Shared Decision Making For Children with Chronic Respiratory Failure- It Takes a Village and a Process

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Abstract

Background and objectives: Shared decision making (SDM) prior to non-urgent tracheostomy in a child with chronic respiratory failure (CRF) is recognized as the standard of care, but has proven challenging to implement in practice. We hypothesize that utilization of the microsystem model for analysis of the complex ecosystem in which SDM occurs will yield insights that enable formation of a reproducible, measurable SDM process. **Methods:** Retrospective chart review of a case series of children with CRF in whom a SDM process was pursued. The process included a palliative care consult, a validated decision aid and 12 key questions designed to elucidate information integral to an informed decision. Investigators reviewed a single hospital admission for each child, focusing on the 3 core elements of a medical microsystem- the patient, the providers, and information. **Results:** 29 patients who met inclusion criteria ranged in age from 0 to 19 years (median 1.7) and remained in the hospital from 10 to 316 days (median 38). Patients were medically complex with multiple and varied respiratory diagnoses, multiple and varied comorbidities, and varying psychosocial environments. 14/29 children received tracheostomies. Each child encountered a mean of 6.2 medical specialties, 1.9 surgical specialties and 8.5 non-physician led services. Answers to 12 key questions were not documented systematically and often not found. **Conclusion:** A unique SDM microsystem is formed around each child but not optimally utilized. Explicit recognition of these microsystems would enable team formation and an SDM process comprised of measurable steps and communication patterns.

Introduction

Children with chronic respiratory failure are a complex and heterogeneous population with varying ages, underlying diagnoses, intellectual abilities, prognoses, and social circumstances.^{1,2} Due to advances in medicine, this resource intensive population has increased. The number of children discharged annually from the hospital on long-term ventilation increased from 5026 to 7812 (55% increase) between 2000 and 2006³. A study of over 140,000 pediatric intensive care unit (PICU) discharges in the United States from 2009 to 2011 found 1.8% of discharged patients received a tracheostomy during their PICU stay and/or were discharged on long-term ventilation². These numbers underestimate the children with chronic respiratory failure (CRF) for whom a decision regarding tracheostomy was made since there are no studies which quantify the number of children for whom tracheostomy or long-term ventilation (LTV) was considered but not pursued.

A recent editorial in *Pediatric Pulmonology* emphasized the both the importance and the challenges of a shared decision making (SDM) approach prior to non-urgent tracheostomy placement in children⁴. Shared decision-making is “a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals and preferences⁵.” SDM is most appropriate in cases where there is more than one reasonable choice. SDM has been increasingly promoted as a part of value based care that offers the potential to both reduce overuse of care not beneficial to the patient, and to center care around the patient⁶. Despite decades of research, there is limited experience with SDM in practice⁷. In general, most studies on SDM focus on how clinicians interact with patients, not on “team, organizational and system factors in which

their interactions are embedded⁸.” Specifically, there are no studies that focus on the complex ecosystems in which the decisions regarding non-urgent tracheostomy placement occur.

In a cohort of children with chronic respiratory failure admitted to a small children’s hospital, this study utilizes a microsystem model⁹ as a lens through which to dissect the complex environment in which decisions regarding tracheostomy placement occurred. Based upon the findings, the authors propose a conceptual model for implementation of SDM in this population that would enable reproducibility, flexibility and measurement.

Methods

Study design

This is a retrospective chart review of a case series, and was determined by the IRB not to be human research.

Participants and procedures

Over a 4-year period starting July 2016, a SDM process (Figure 1) was implemented in routine care of patients with chronic respiratory failure (CRF) who were < 21 years old, admitted to an inpatient pediatric service, and for whom tracheostomy was a consideration. Eligible patients were identified by the investigators as part of usual care, without implementation of a specific screening procedure. Initially two core elements comprised the protocol, the first of which included sharing educational material with the family. This included a patient decision aide called The Child Tracheostomy Decision Guide¹⁰ created by Winnipeg Regional Health Authority, which meets most of the standards set by the International Patient Decision Aid Standards Collaboration¹¹. The second core element was comprised of 12 key questions designed to elucidate medical and psychosocial information which the working group deemed integral to making an informed decision. The SDM protocol was only implemented in one patient during the first year, after which time a third core element was added to the protocol- consultation of the pediatric palliative care team.

Each of the 3 investigators independently performed retrospective chart reviews on 1/3 of the 29 patients deemed evaluable. Data collection focused on the three core elements of a medical microsystem: the patient, the provider and information⁹. After determining in which hospital admission the decision occurred, the investigators extracted data using detailed questions in a REDCap database. Finding much of the data, such as medical diagnoses and information on the SDM process, required the medical expertise and judgement of the investigators, all of whom were fellowship trained pediatric physicians. To address concerns regarding inter-reviewer reliability, a second chart review was performed on each patient by a different investigator, without knowledge of the previous data collection. Investigators then compared the two analyses for congruence and reconciled any discrepancies by consensus re-review of the medical record. During the re-review process, there were two inter-reviewer differences regarding which admission to review, both of which were resolved by consensus opinion.

Measures

Patient data consisted of demographics: age, respiratory diagnoses, comorbidities, admissions in the year preceding the decision, presence of outside services or involvement with governmental agencies, tracheostomy outcome, and mortality data. Length of the stay reflected time continuously spent in an inpatient setting, including those days that patients transiently spent at an outside institution for cardiac procedures not offered at the small children’s hospital.

Health care professionals that collaborated in the care of a patient and documented that interaction in the EMR comprised the ecosystem of health care providers. This ecosystem was divided into three broad categories: 1) physician-led medical services; 2) physician-led surgical services; 3) non-physician led services. Timing of palliative care and pulmonology consults relative to admission and to tracheostomy placement were noted.

Documentation of answers to the 12 key questions comprised the measures of information. If an answer to a question was clearly found at least once in any location in the medical record, the answer was coded as

“present.” 2 of the 12 questions included in the protocol were removed from chart review. One question was eliminated because investigators could find no places in the EMR where health professionals involved in a child’s care were routinely listed. A second question, regarding “any other concerns,” was removed since its answer hinged upon consolidation in one location of the answers to the other 11 questions, a circumstance that almost never occurred. If the answer to any of the remaining 10 questions could not be found, or could only be inferred, the answer was coded as “absent.”

Analysis

Study data were collected and managed using REDCap electronic data capture tools hosted at Stony Brook University Medical Center^{12,13}. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies. Descriptive statistics were used for analysis.

Results

The study population (Table 1)

29 patients met criteria for inclusion in the chart review. They ranged in age from 0 to 19 years, with a median age of 1.7 years. Prior to admission, 16 children lived at home with their families, while 6 lived in a medical residence. 7 children had not yet lived in a place other than the acute care hospital. 9 patients received services from the New York State Office of Persons with Disabilities (OPWDD) and therefore required approval from NY State to limit life sustaining treatment. 10 children received some medical service in the home prior to admission.

Medically, the patients were heterogeneous in terms of underlying respiratory disorders and comorbidities. All were medically complex. Almost all (28/29) had more than one underlying respiratory diagnosis with most (19/29) having restrictive respiratory disease. Most (20/29) had some form of neuromuscular weakness contributing to respiratory dysfunction but only a couple (2/29) had degenerative neuromuscular disease. Common threads in comorbidities included cardiac diagnoses (18/29), genetic diagnoses (13/29) and static encephalopathy (12/29). Almost all (27/29) had swallowing dysfunction and most (22/29) had a gastrostomy and/or jejunostomy tube. Most (20/29) patients in this cohort were admitted at least once in the year prior to the admission reviewed; over a quarter (8/29) were admitted 3 or more times in that period.

Length of stay varied from 10 to 316 days with a mean of 76 days and a median of 38 days. The majority of the longer admissions reflected prolonged neonatal ICU stays. A tracheostomy was placed in 48% (14/29). Timing of tracheostomy ranged from 1 to 316 days post hospital admission, with a median of 22.5 days post admission. 25/29 of patients survived until discharge, with 21/29 surviving at least 6 months after admission. Of note, 7/8 of the children who did not survive 6 months after admission did not receive tracheostomies (2-sided $p=0.035$ Fisher’s exact test).

The medical ecosystem (Figure 2)

During the hospitalization reviewed, each patient encountered a mean of 6.2 medical specialties, 1.9 surgical specialties, and 8.5 non-physician specialties. The most frequent medical consult services were pulmonology (25/29), critical care (23/29) and palliative care (22/29). Pediatric surgery was the most consulted surgical service (20/29), followed by otolaryngology, (13/29). Every patient in this cohort received inpatient services from nursing, care management, and respiratory therapy. Other commonly used services included: physical therapy (27/29), chaplaincy (26/29), and Child Life (24/29).

Although pulmonary and palliative care were the most common medical consults, timing of consultation was highly variable. Palliative care consult timing ranged from 0 to 268 days post admission (median 9.5 days). In cases where tracheostomy occurred, palliative care consult timing ranged from 50 days prior to tracheostomy to one day after (median 7 days prior). Similarly, pulmonary consult ranged from 1 to 130 days post admission (median of 3 days) and from 198 days before to 10 days after tracheostomy placement (median 9 days prior).

Information (Table 2)

Some information such as underlying respiratory diagnoses and accompanying comorbidities was always found, often at the beginning of the admission notes. Other information, such as the family's hopes for the child was more difficult to locate in the electronic medical record (EMR) and often not found at all. Informal observations indicated that finding answers to each of the individual questions was time consuming since answers were usually found in different locations in the EMR and documented in variable ways. On only one occasion were the answers to all the questions consolidated in a single note.

Discussion

Our study is the first to systematically analyze the complex ecosystem in which SDM occurred in a cohort of children with chronic respiratory failure. Prior research on this population has addressed interactions among and opinions of stakeholders in SDM. Hebert et al reviewed 19 transcripts of family-physician conferences regarding tracheostomy placement and concluded that physicians emphasized benefits while minimizing risks¹⁴. Nageswaran et al interviewed 56 caregivers of 41 children who received tracheostomies and found that decisional satisfaction was high¹⁵. A study that elicited the informational needs of caregivers from 43 families who had faced a decision regarding tracheostomy placement demonstrated that families wanted comprehensive information, including what life would be like at home with a child with a tracheostomy. It also demonstrated that being presented with the option not to perform a tracheostomy was reasonable¹⁶. Other studies asked physicians to describe how they go about a shared decision making process^{17,18}.

Two articles allude to how systems in place do not serve the needs of the SDM process^{18,19}. In a Lancet editorial Fine-Gould writes: "For children in ICUs, the health-care professionals involved in making decisions about initiating long-term ventilation are usually not involved in ongoing care once children leave the ICU so a dissociation can appear between the short-term goals of discharge from ICU or hospital and the long-term care goals¹⁹." Large teams with frequently changing members were noted to complicate decision making^{18,19}. Most respondents in a survey of neonatal and pediatric ICU physicians agreed that current ICU systems do not meet the needs of chronically critically ill children¹⁸. Fine-Gould recommends reevaluation of the process of initiating long-term ventilation and suggests focusing on the child's care goals and an ethical framework¹⁹.

This current study has several limitations. It is a retrospective chart review with descriptive data. Patients were not screened systematically for the protocol, but rather identified by the members of the working group as they conducted their usual clinical duties. Due to limited available evidence in 2016 when the protocol started, the "12 key questions" were designed by the working group based upon their own clinical experience. Of note, numerous elements of these 12 questions were consistent with recommendations in subsequently published clinical SDM guidelines^{5,20}. Some parts of the protocol may have been accomplished in real time, but not found on chart review and therefore not counted as accomplished.

The patients in this cohort were medically complex, and heterogeneous both medically and psychosocially, which is similar to prior studies of children with CRF. Two prior studies included a greater proportion of patients who received tracheostomy or long-term ventilation^{15,16}. This is attributable to differing methods of patient recruitment. Neither this study nor prior studies prospectively recruited patients from the point where SDM started.

To our knowledge, this is the first study to document the number of services encountered by each child with CRF during a single hospital stay. Our finding that each patient encountered a mean of 17.1 services was striking, but not surprising. Although this number could be overwhelming for any family, counting the number of services grossly underestimates the number of individuals encountered by a patient during a hospital stay. Physician-led services often function in teams comprised of an attending, residents and students, all of whom rotate weekly or monthly. Nurses, respiratory therapists, physicians and other personnel all change shifts at least once per day.

Another striking finding in this study was the challenge of locating documentation of information specific to the needs of SDM. This information was seldom found in one easy to review location, but rather was

documented by different providers at different times in different ways. This point is illustrated by the need to eliminate 2 of the 12 key questions from chart review. Overall, the fragmentation and lack of clarity of the information specific to the SDM process found on chart review paralleled the barriers to clear communication of this information in real time among health care professionals.

Taken together, these findings demonstrate a medically complex heterogeneous population cared for by a large number of health care professionals with no clear or standardized means of communicating with each other regarding the information deemed integral to reaching a decision. Such a complex and important decision clearly requires teamwork and “Communication is the essential foundation of an effective team²¹.” Examination of the PICU through the lens of a microsystem model sheds light on the systems in place which can make it challenging to form an effective SDM team around each child.

A clinical microsystem is defined as “a small group of people (including health professionals and care-receiving patients and families) who work together in a defined setting on a regular basis (or as needed) to create care for discrete subpopulations of patients⁹.” The anatomy and physiology of a microsystem is often described through the 5 Ps: purpose, patients, professionals, processes, and patterns⁹. Figure 3 compares the 5Ps of a typical PICU to those observed in 2 of the cases in this cohort. The pediatric intensive care unit has the broad mission of treating acute, life-threatening problems, in a relatively discrete timeframe. By contrast the shared decision making process has the narrower goal of reaching a single decision, typically in a longitudinal manner. Case 1 and case 2 illustrate the heterogeneity of this cohort psychosocially as well as medically. One child initially had no health insurance and hailed from a single parent, non-English speaking family with an unstable living situation. The other child lived in an economically stable home with two English-speaking parents, and consistent health insurance.

The PICU is staffed by a core multidisciplinary team with clearly defined members and roles. Communication patterns are built into daily routines through patient-centered rounds, structured EMR notes, multidisciplinary rounds and sign-outs with shift changes. This pilot program for SDM was undertaken without any change in roles or work-flow. At the end of the first year, the SDM process had only occurred in one case, a problem the investigators attributed to lack of a team leader. Palliative care was then recruited to shepherd the process with a subsequent increase to an average of 9 patients/year for whom the SDM protocol was pursued. Beyond the informal designation of “quarterback” assigned to the palliative care physician, no specific roles were assigned to the health care professionals participating in the SDM process. The limitations of this approach are evident in the finding that the patient decision aide included in the protocol was only given to 7/29 patients.

A Proposal for Revised Conceptual Model (Figure 4)

Based upon these findings we propose a new conceptual model for SDM in this population, which would unfold in three, sometimes overlapping stages. Stage I, pre-SDM, would include usual care of the child and start well before the point at which a choice is needed. In some cases, such as in children with progressive neuromuscular weakness, the potential future need of a choice regarding tracheostomy placement may be raised in routine clinical encounters.

Stage 2, SDM, would start with screening followed by consultation with pediatric pulmonary and palliative care to determine if a formal SDM process is merited at that time. If so, a team formation process would ensue in which the unique combination of people and information necessary for SDM in each case is gathered. Finally, the team would enter a deliberation process that includes the three core elements cited by the AAP and ATS guidelines: information exchange, deliberation, and decision^{5,20}.

The final stage would be a multi-dimensional evaluation of the SDM process. Patient centered measures such as “CollaboRATE” developed by at the Dartmouth Center for Shared Decision Making²² would evaluate how effective the SDM process was from the family perspective. Breaking down the process into discrete but flexible steps enables measurement of the process. For example, one could measure if and when a SDM team was formed, number of days that the team was in existence and the composition of its members. Formal team formation enables evaluation of the efficiency and efficacy of team functions such as communication.

Health outcomes and health care utilization would also be measured.

Conclusion

Shared decision-making is an essential process that is often impeded by the complexity of our medical system. The proposed model serves to distill the complexity by forming a SDM microsystem around each patient. Such a microsystem would offer continuity by transcending changes in time, personnel and sites of care. The SDM microsystem for each patient could be formed and integrated into the work of acute care microsystems, such as the PICU, as needed. This staged, microsystem approach would allow for the flexibility needed to assemble the unique combination of people and information needed for each child, and would also provide enough structure to promote reproducibility and enable systematic evaluation of the process. Reproducibility and measurement will be essential for developing appropriate value-based payment systems for SDM. Prospective research studies would be needed to determine the feasibility of such an approach as well as to develop and evaluate measures of the quality of the SDM process. This conceptual model could be expanded to other medically complex populations of all ages for whom shared decision making is needed.

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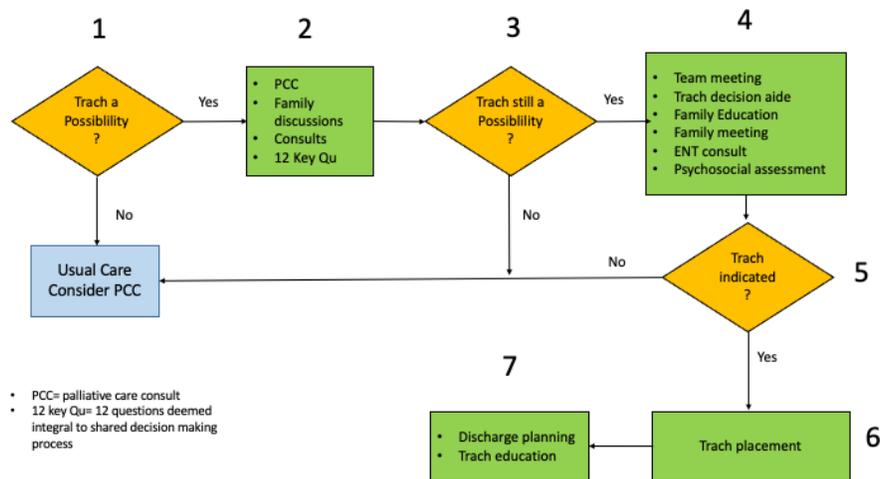
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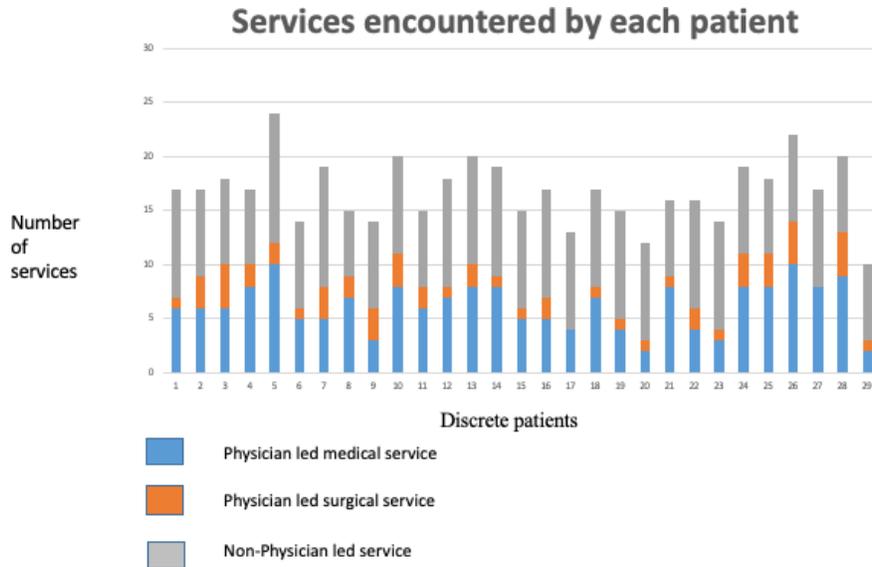
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5 Ps	Typical PICU Microsystem	Shared Decision Making	
		Case 1	Case 2
Purpose	To treat acute, life threatening problems Most often, save lives Triage, stabilize Transition to next level of care or to home Or less often, manage the process of dying	To make a decision that will affect the course of a child's life Possibly prolong life No change in prognosis Transition back to residential facility Or possibly to manage the process of dying	
Patients	All children have acute problems. Some have acute or chronic problems Frequently medical complex Heterogeneous in terms of medical diagnosis, psychosocial circumstances	Acute on chronic problems Highly medically complex and with restrictive lung disease neurocognitive weakness and spastic cerebral palsy Severe global developmental delay History of vascular ring compressing trachea No tracheostomy placed	
Professionals	Core PICU team is multi-disciplinary team with clearly defined members and roles PICU attending clear team leader Consulting services participate when requested by PICU attending PICU attending and attending consultants rotate every week Palliative care attending was a more constant presence Shifts change 2x per day for all core PICU team members	Multi-disciplinary collaboration. However there was often no clear delineation of team members and roles were not well defined. Family viewed palliative care doc as leader Family viewed pulmonary team as leader Consulting services participate when requested by PICU attending PICU attending and attending consultants rotate every week Palliative care attending was a more constant presence Shifts change 2x per day for all core PICU team members	
Processes	Most processes are clearly defined Processes usually start and end in PICU Driven by standardized protocols, usually evidence based, like placing a central line Communication is built into the daily schedule via family centered rounds, daily progress notes, and formal sign-outs at shift changes	Process of SDM is more prolonged. Often without a clear start and end. Started in PICU. Spurred 3 months and 4 admissions. Started on the Inpatient floor. Spurred 2 months and 2 admissions. No evidence based protocols exist Communication occurs ad hoc, rather than on a regular schedule. Communication is often via non-standardized means such as group emails and brief unscheduled conversations. No standardized documentation.	
Patterns of decision making	Often made within minutes or hours, in life-threatening situations Driven by discrete quantifiable data Most decisions regarding routine care are made by medical team. Parental participation is needed for relatively few decisions. SDM is favored when parental input is needed for decisions. Method of implementation is variable.	Often made after deliberations that may take place over days, weeks or months Discrete quantifiable data is necessary, but is often not the main driver of the decision. Parent participation is essential. Parent relied heavily on. Parent participation is essential. Parents did their own research and took medical teams recommendations into account. SDM is favored when parental input is needed for decisions. Method of implementation is variable.	

