

# Perspectives of Pediatric Providers on Patients With Complex Chronic Conditions: A Mixed-Methods Sequential Explanatory Study

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**BACKGROUND** Children with complex chronic conditions present unique challenges to the pediatric intensive care unit, including prolonged length of stay, complex medical regimens, and complicated family dynamics. **OBJECTIVES** To examine perspectives of pediatric intensive care unit health care providers regarding pediatric patients with complex chronic conditions, and to explore potential opportunities to improve these patients' care. **METHODS** A prospective mixed-methods sequential explanatory study was conducted in a tertiary medical-surgical pediatric intensive care unit using surveys performed with REDCap (Research Electronic Data Capture) followed by semistructured interviews. **RESULTS** The survey response rate was 70.6% (77 of 109). Perspectives of health care providers did not vary with duration of work experience. Ten semistructured interviews were conducted. Eight overarching themes emerged from the interviews: (1) the desire for increased formal education specific to pediatric complex chronic care patients; (2) designation of a primary intensivist; (3) modifying delivery of care to include a discrete location for care provision; (4) establishing daily, short-term, and long-term goals; (5) monitoring and documenting care milestones; (6) strengthening patient and family communications with the health care team; (7) optimizing discharge coordination and planning; and (8) integrating families into care responsibilities. **CONCLUSIONS** Pediatric intensive care unit health care providers' perspectives of pediatric patients with complex chronic conditions indicated opportunities to refine the care provided by establishing daily goals, coordinating discharge planning, and creating occasions for close communication between patients, families, and providers. (*Critical Care Nurse*. 2020;40[5]:e10-e17)

**P**ediatric complex chronic care patients (PCCPs) have been defined as children and adolescents “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition” and/or those “who require health and related services of a type or amount beyond that required by children generally.”<sup>1(p117)</sup> Although PCCPs make up only 10% to 17% of pediatric hospital admissions,<sup>2-5</sup> they account for more than 50% of pediatric intensive care unit (PICU) admissions

and use more than 75% of PICU resources.<sup>6</sup> In addition to the increasing<sup>3</sup> and disproportionate resource allocation<sup>6,7</sup> to PCCPs, previous studies have indicated higher rates of unplanned readmissions,<sup>8</sup> higher rates of in-hospital mortality,<sup>7,9</sup> prolonged hospitalizations, greater severity of illnesses, complex treatment plans, multiple health care teams,<sup>10</sup> and inconsistent care.<sup>11</sup>

To date, much of the literature concerning PCCPs has portrayed an unfavorable view of these patients by health care providers and identified complicated family dynamics.<sup>10-14</sup> As an example of this negative perception, engagement by physicians was reported to diminish with medically complex, “difficult” patients, with tensions attributable to medical and psychosocial variables.<sup>10</sup> Furthermore, conflicts were reported between health care providers and parents during discussions about the goals of treatment.<sup>12</sup> These factors can influence providers’ attitudes toward their patients and affect the quality of care provided.<sup>13,14</sup>

Previous research on experiences in the PICU has identified 7 major themes regarding the attitudes, opinions, and perspectives of parents of children with severe disabilities: “(1) know my child’s baseline; (2) integrate and bridge multiple services; (3) disconnect between role of parent at home versus parent in the PICU; (4) a PICU admission does not equate with respite; (5) high-stakes learning environment; (6) heterogeneity within group; and (7) lack of fit within the acute care model.”<sup>15(p2068)</sup> On the other hand, few studies have explored the perspectives of health care providers who care for PCCPs. Understanding of such perspectives could help bridge gaps between providers and families with regard

to care priorities. Therefore, we conducted a mixed-methods study designed to capture the attitudes and perspectives of health care providers working in a Canadian medical-surgical PICU. The study was also intended to explore opportunities to improve the care provided to PCCPs in the PICU.

## Methods

### Study Design and Setting

This prospective mixed-methods sequential explanatory study was conducted by administering surveys, followed by semistructured interviews. The University of Saskatchewan Research Ethics Board and Saskatchewan Health Authority granted approval for the study.

The study participants worked as health care providers in a 10-bed integrated medical-surgical PICU at the Royal University Hospital in Saskatoon. The PICU admits more than 550 critically ill children (newborn to 17 years) per year from a geographically vast province with a population of 1.1 million. Most PICU admissions require retrieval from its transport team, including the PCCPs who live in remote communities. Pediatric complex chronic care patients account for 42% of PICU admissions, which is comparable to the 50% reported in the literature.<sup>6</sup>

### Quantitative Survey Development

The 7 major themes identified by Graham et al<sup>15</sup> were used to guide the development of this study’s survey questions. The survey, which included multiple choice, Likert-scale, and short-answer questions, was piloted by 7 health care providers and modified to mitigate leading questions

and ensure face validity, ease of completion, and clarity. Sur-

Engagement by physicians has been reported to diminish with medically complex, “difficult” patients, with tensions attributable to medical and psychosocial variables.

vey respondents had to be PICU health care providers including administrators, intensivists, nurses, respiratory therapists, social workers, dietitians, pharmacists, and rehabilitation therapists who had been in their position for at least 6 months (Table 1).

Surveys were sent to 109 health care providers through REDCap (Research Electronic Data Capture), a secure, HIPAA (Health Insurance Portability and Accountability Act)–compliant web application for building, managing, and distributing online research that ensures secure web

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**Table 1** Demographic characteristics of survey respondents<sup>a</sup>

Characteristic	No. (%)
Type of PICU provider	
Registered nurse	49 (64)
Respiratory therapist	12 (16)
Pharmacist	5 (7)
Physician	4 (5)
Other	6 (8)
Length of PICU experience	
6-12 mo	6 (8)
1-5 y	35 (46)
6-10 y	15 (20)
> 10 y	20 (26)
Current clinical practice	
PICU only	26 (34)
PICU and pediatric EM	25 (33)
PICU and ward pediatrics	10 (13)
PICU and neonatal ICU	10 (13)
PICU and adult medicine	5 (7)

Abbreviations: EM, emergency medicine; ICU, intensive care unit; PICU, pediatric intensive care unit.

<sup>a</sup> Participants total 76 because 1 of the participants chose not to answer all questions.

authentication, secure layer encryption, and anonymous participant responses.<sup>16</sup> Reminder emails were sent to nonrespondents at 4-day intervals. No incentives were provided. Likert-scale questions evaluated attitudes related to caring for PCCPs and non-PCCPs. The Kruskal-Wallis test was used to compare responses on the basis of caring for PCCPs versus non-PCCPs and length of time in practice (< 1 year, 1-5 years, or > 5 years).

### Qualitative Interview Question Development

Results from the initial survey were used to guide development of the qualitative interview questions.

The semistructured interviews consisted of open-ended questions. Interviewees were PICU administrators and health care providers who had previously completed the survey. After consent was obtained from the participants, we conducted 10 in-person discrete interviews with 2 intensivists, 2 respiratory therapists, 4 nurses, 1 rehabilitation specialist, and 1 dietitian. Interview times ranged from 30 minutes to 1 hour. The interviews were transcribed, and the anonymized transcripts were analyzed through inductive thematic analysis.<sup>17</sup> This process resulted in the emergence of multiple themes, which were subsequently coded and organized into categories. In an effort to ensure interrater reliability, discrepancies were resolved through an iterative process of dialogue and reevaluation until a consensus was achieved among the researchers.

### Results

The response rate of the initial quantitative survey was 70.6% (77 of 109). Length of time in practice in the PICU did not have a statistically significant impact on attitudes and perspectives. Statistically significant differences in Likert-scale scoring were found between providers' perspectives regarding PCCPs versus non-PCCPs (Table 2).

Specific themes associated with discrete PICU health care professions emerged from the survey's short-answer questions. Occupational and physical therapist themes included repetitiveness of work, importance of the PCCP's family members in providing care, and time management barriers. Nursing themes involved ethical and/or moral challenges associated with PCCP care, desire for consistent care goals, importance of family education, and need for frequent rounding and family meetings. Finally,

**Table 2** Statistically significant differences between providers' perspectives regarding PCCPs versus non-PCCPs

Survey item	P
Families of PCCPs understand their child's caregiving goals.	<.001
PICU health care providers experience feelings of decreased work satisfaction when working with PCCPs.	<.001
A designated primary intensivist improves continuity of care and work satisfaction related to managing PCCPs.	<.001
Parents of PCCPs are integrated into delivery of medical care.	<.001
Families of PCCPs are asked more frequently about their expectations regarding involvement of care provision during their child's stay.	<.001
Families of PCCPs help to facilitate care.	<.001
PCCP families are essential to determine their child's baseline.	.08

Abbreviations: PCCP, pediatric complex chronic care patient; PICU, pediatric intensive care unit.

**Table 3** Themes emerging from semistructured interviews

Theme	Respondents identifying theme, No. (%)
Desire for increased formal education	7 (70)
Designation of a primary intensivist	9 (90)
Modifying delivery of care to include a discrete location for care provision	9 (90)
Establishing daily, short-term, and long-term goals	6 (60)
Monitoring and documenting care milestones	5 (50)
Strengthening patient/family communication with the health care team	7 (70)
Optimizing discharge coordination and planning	10 (100)
Integrating families into care responsibilities	8 (80)

intensivist themes entailed refocusing goals and accepting the slower progress with PCCPs.

Eight overarching themes emerged from the semistructured interviews (Table 3), revealing potential opportunities to enhance the care of PCCPs in the PICU.

### Theme 1: Desire for Increased Formal Education Specific to PCCPs

Many comments revealed the need for increased formal education specific to PCCPs. As one respondent remarked, “That will affect our job satisfaction, and our morale, and our understanding of how to incorporate all the things that we need to incorporate for the chronic care patients, the families, [and their] care.” In both the survey and the interviews, participants noted that current guidelines for the care of PCCPs are limited and resources are insufficient. This perspective is consistent with previous literature indicating that many communities do not have sufficient human resources or appropriate infrastructure to provide optimal care for PCCPs.<sup>18</sup> It has been reported that health care providers who received education on disabilities performed significantly better on attitude assessments toward these children.<sup>13</sup> Furthermore, education specific to patients with complex chronic conditions has the potential to affect the quality of care provided.<sup>13</sup>

Our results demonstrate no statistically significant differences between health care provider attitudes and perspectives toward PCCPs based on duration of practice. Considering length of time in practice as a proxy for timing of education, this finding may indicate that

education on patients with chronic complex conditions has not changed. Our findings suggest that education regarding PCCPs is inadequate. Improvement of such education may enhance work satisfaction and quality of care by increasing provider engagement.

### Theme 2: Designation of a Primary Intensivist

The need to designate a primary intensivist to promote continuity of care and provide consistent messaging emerged as a vital theme. In the words of one respondent,

The biggest complaint I hear from families is every week or twice a week our physicians change. So, the families just find that they have a plan for the whole week, and it takes a couple of days to get the plan going. And they have a couple of the days of the plan actually running and then all of a sudden, a new physician comes on. . . . So, yeah, it just puts parents in a bad spot too, because I think it forces them to be the continuous person in the room. And often they just have a lot of stress trying to remember everything that’s been said and everything that’s been done. So, I think if there was just one continuous physician, there would be one plan of care for that child.

A primary intensivist allows for one physician to build a relationship and rapport with a PCCP and their family. As a result, the family is likely to experience increased comfort with and trust in their care provider. As previously reported,<sup>15</sup> this improved relationship may attenuate parents’ feelings of unease when their chronically ill child deteriorates from their baseline and is admitted to the PICU.

Our results indicate that allocating a primary intensivist has the potential to increase work satisfaction for both the intensivist and other members of the health care team. As expressed by one respondent, “I currently act as primary care physician for a patient in the unit right now and it certainly changes the level of satisfaction I have for caring for that type of patient.” Potential drawbacks may include scheduling challenges, particularly if the primary intensivist is absent for a period of time. These scheduling challenges may be mitigated by having the primary intensivist round with the on-service team at preestablished intervals.

### Theme 3: Modifying Delivery of Care to Include a Discrete Location for Care Provision

Both survey and interview participants reported that PCCPs do not fit into the typical acute PICU model of care. The consensus was that a modified version of a “step-down” or “high-dependency” unit would be a better place to provide care to PCCPs:

I think it would be a space that has proximity to the traditional PICU environment but that is physically distinct and separate. . . . I think incorporating not just physical space, but in the model of care somewhere we need to make sure that we have a strong emphasis in terms of family involvement and then how to incorporate families in daily care, because that’s something we already support and do in the intensive care unit, but I think it needs to be perhaps explicit in terms of outlining that type of a unit.

These findings support the Canadian Association of Paediatric Health Centres (CAHPC) recommendation to “build capacity within the healthcare system to deliver coordinated care that is holistic, comprehensive and family-centred to all children with medical complexity, closer to home.”<sup>19(p10)</sup>

Previous research found no association between having an intermediate care, or step-down, unit and most measures of PICU efficiency (eg, length of stay, readmissions).<sup>20</sup> However, little has been reported on the overall experiences of PICU health care providers or families working in such a unit. We found support for a distinct space with proximity to a traditional PICU focusing on the care required by PCCPs. Pertinent aspects of care included flexible or customized sleep/wake schedules, an emphasis on increased family involvement, and a space that feels more like a home environment, with flexibility to accommodate rehabilitation health care providers. A pediatric medical complex disease unit recently opened in Madrid, Spain, to meet the needs of the growing population of children with complex medical conditions in Spain. The unit in Madrid focuses on coordination of subspecialty care, establishment of discharge criteria, and delivery of care by specially trained pediatricians.<sup>18</sup> Establishment of this unit resulted in decreases in mean length of stay and estimated overall costs per patient.<sup>18</sup> It is unclear whether

this unit incorporated the other factors (eg, increased family involvement, flexible or customized sleep/wake schedule, homelike environment) that were identified in our study. Therefore, an iterative process of discussion, development, and assessment would be imperative before establishment of such a unit in other centers.

### Theme 4: Establishing Daily, Short-term, and Long-term Goals

Pediatric complex chronic care patients do not always fit into the expected recovery patterns of acutely ill children. Long-term goals can seem overwhelming or even unachievable with the slower rates of progress common with PCCPs. The creation of intermediate goals can enhance communication regarding consistent goals among members of the care team and decrease feelings of stress related to lack of goal clarity. As expressed by one respondent:

If a patient spends 1 extra hour of the day on lower level of breathing support . . . they may not seem in a traditional sort of PICU environment like you’re making any strides, but I think refocusing and recognizing that the goal is a month away, or 3 months away, or 6 weeks away, as opposed to 6 days away. So, I just think it’s refocusing of goals.

Furthermore, if goals are visible (ie, written on a board in the patient’s room), this serves as another form of communication, which enhances consistent messaging between families and health care providers.

### Theme 5: Monitoring and Documenting Care Milestones

The concept of regularly evaluating care milestones is consistent with and supplements the theme of establishing daily, short-term, and long-term goals. Monitoring and documenting care milestones in nursing care plans allows the health care team to objectively monitor progress. Pediatric chronic complex care patients often do not have the same recovery expectations as acutely ill children in the PICU. Thus, discharge plans may be months in the future, and the goals for discharge can seem overwhelming or even impossible to achieve. Thus, monitoring and documenting care milestones provides the opportunity to objectively document care progress, visualize goal progressions, increase care provider

satisfaction, and increase communication between the care team and families. In the words of one provider, “For these complex care kids and their families, it’s sometimes very small changes or very small progressions . . . and marking those milestones to see that there is a progression happening.” Another provider remarked,

Being able to see how satisfied a family is with the care that they’re getting and the fact that they’re sensing that their child is “doing better,” that’s huge. And so, yeah, those are the moments or little snippets where I get a lot out of providing for those patients.

This theme also supports the CAPHC recommendation to “develop and maintain a shared single care plan with common language and clear ownership for children with medical complexity that is accessible and updated in a timely manner.”<sup>19(p10)</sup> Placing visible whiteboards in patients’ rooms is a feasible strategy for enhancing patient- and family-centered communication.<sup>21</sup> Whiteboards allow for visualization of objective progress, which has the potential to increase families’ satisfaction with the care being provided and may also contribute to increased work satisfaction among health care providers working with PCCPs. Previous research has documented parents’ frustration and anger with inadequate communications and occasionally receiving different or conflicting information from care providers.<sup>11</sup> Documentation of care milestones can be encouraging to families, allowing them to visualize progress, and serves as a consistent source of information about care-related goals. Evaluating the association between documenting care milestones and provider satisfaction would be worthwhile.

### Theme 6: Strengthening Patient and Family Communication With the Health Care Team

Although communication with patients and families is always an important aspect of care, communication is especially important with PCCPs, because families are often the primary health care providers at home. In the PICU environment, PCCPs’ care may be triaged behind that of higher-acuity patients. Although the needs of PCCPs may be subacute, the implementation of consistent assessments and plans is critical for the family as well as for the PCCP’s long-term outcome. As one provider commented,

Regular communication [between patients, families, and the team] of what those care goals are and reiterating what our goals are because I think sometimes you can get a disconnect of what the team’s vision, the goals for the patient are, versus what the family’s goals are.

Additional communication can be accomplished by increased scheduled communications with families (eg, 2-3 times per week) and more family meetings (eg, once a month). This increased communication may provide more opportunities to address any potential concerns of families and to establish the daily, short-term, and long-term goals. Such improvements in communication align with families’ desires as described in previous literature.<sup>15</sup>

### Theme 7: Optimizing Discharge Coordination and Planning

Discharge planning is an integral part of caring for PCCPs. In the words of one provider,

As a bedside nurse, just knowing that my patient is supposed to be going home in 3 weeks helps you gauge the situation and see what the parents need to learn, what they need to be taught, what they have questions about . . . that they’re nervous about in going home.

Discharge planning requires formulating follow-up appointments, coordinating necessary supports for home (eg, home oxygen, home care), and ensuring that all members of the care team are prepared for discharge. Family education and discussions regarding activities of daily living and challenges are critical for a successful transition into the home environment. It has been reported that the presence of a discharge coordinator improves health care outcomes, decreases length of stay, promotes continuity of care, and increases patient and family satisfaction with the discharge process through feelings of preparedness.<sup>22</sup> Increased support for discharge coordination not only helps to organize and manage the necessary steps for discharge but also provides motivation to achieve those steps.<sup>22</sup>

**Pediatric complex chronic care patients do not always fit into the expected recovery patterns of acutely ill children.**

## Theme 8: Integrating Families Into Care Responsibilities

Routine integration into care provision is essential to ensure that families feel comfortable providing care for their child once they go home. One provider noted, “A lot of the time with chronic kids we kind of let the family direct the care, which is great because the family is very knowledgeable . . . because they’ve been with them from the start.” Another remarked, “I think some of the problem comes with families not feeling understood . . . or us not being clear on the expectations of their role.”

Integration of families into care responsibilities corresponds with the concept of a “high-stakes learning environment,” in which parents want to be included in care planning and use the PICU care as a means of improving their own skills and preparing for discharge.<sup>15</sup> Thus, when caring for PCCP patients, the PICU health care provider may have to modify their daily focus to account for the families’ learning needs. Mutual respect between the provider and the family regarding knowledge and roles may lead to shared learning and empowerment. This integration of families into the provision of care aligns with the CAPHC’s recommendation to “empower families by proactively supporting them to develop skills, competency and confidence to comprehensively care for their child and to advocate on behalf of their child.”<sup>19(p10)</sup> Like any paradigm, an integrated model of care for PCCPs may contain its own pragmatic challenges, but these barriers do not negate its utility.

## Discussion

Our study begins to bridge the gap between the perspectives of health care providers and those of PCCPs’ parents in the PICU, which was previously studied by Graham et al.<sup>15</sup> On the basis of the findings of our study, a number of modifications were made to the delivery of care to PCCPs in the PICU at the Royal University Hospital, including allocation of a primary intensivist, marking goals of care, celebrating care milestones, and recruitment of a PCCP discharge coordinator. Evaluating the effects of this changing paradigm for PCCPs in the PICU will be a valuable endeavor; however, thoughtful examination of the broad impacts on the family, health care providers, and institutions is critical. One of our study participants said it best:

We need to do a better job of informing our communities, our administrators, our politicians, about the fact that chronic complex care is going to become that much more common with the passage of time. Twenty years ago, many of the children that are now requiring a complex care, didn’t survive . . . so this is not a problem that’s going to be solved by technology and advances in medical care. Advances in medical care and technology are going to result in more children with complex medical illnesses. We have to face the reality that our achievements in medicine have consequences . . . we have to accept that reality and start planning and allocating resources to deal with that reality. Twenty years ago, 30 years ago, the PICU here was for critical care of the acutely ill. Now the predominant issue in here is the critical care of the chronically ill. And that is not going to change. . . . We’d better start facing that reality and plan accordingly.

## Limitations

Our study had several limitations. The findings were confined to a single center and may not be generalizable to other PICUs. In addition, Canada’s publicly funded health care system may limit generalizability to other systems. Future research in a non–publicly funded system would add to the body of knowledge. Despite a 70.6% survey response rate and 10 comprehensive semi-structured interviews, the responses may not reflect the perspectives of all of the PICU health care providers.

Some phrasing discrepancies between Likert-scale questions regarding PCCPs versus non-PCCPs may have affected the differences identified. It is impossible to be certain whether all respondents interpreted the definition of PCCPs as we intended. The use of a pilot survey and sufficient time to ask for clarification were used to mitigate these concerns. Further, it is possible that health care providers were not fully candid with their responses because of apprehension about presenting oneself in an unfavorable manner or concern about perceived repercussions of voicing negative opinions. However, every effort was made to diminish participants’ concerns, including anonymous survey responses, anonymized interview transcripts, and having a researcher not affiliated with the PICU perform the interviews.

## Conclusions

This study addresses a significant gap in the literature. However, additional research is needed to gain a better understanding of how PCCPs fit into the current culture of care, both inside and outside of the PICU. The PCCP's experience with health care providers is not limited to the PICU but transcends many acute and chronic care services, including most subspecialties. Evaluating perspectives regarding PCCP patients across all health care domains may allow for greater understanding and provide an opportunity to optimize the care provided in all realms. [CCN](http://www.ccnonline.org)

### Financial Disclosures

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## See also

To learn more about caring for pediatric patients, read "Improving Collaborative Decision-making in the Pediatric Setting" by Small in *AACN Advanced Critical Care*, 2019;30(2):189-192. Available at [www.aacnconline.org](http://www.aacnconline.org).

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