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PEDIATRIC REHABILITATION MEDICINE (A HOUTROW AND M FUENTES, SECTION EDITORS)

Indirect Care Utilization Among Children with Medical Complexity

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Abstract

Purpose of Review Children with medical complexity (CMC) account for 1% of the US pediatric population and 35% of healthcare costs. Comprehensive care for CMC requires high amounts of indirect care time (ICT). We describe the value of ICT for CMC in a mature, consultative, subspecialty complex care program.

Recent Findings Nine hundred five CMC in our Comprehensive Care Program over a 2-year period received an average of 1283 h of ICT and 640 h of direct visit time per year. Provider costs/year were $93,977 for ICT and $62,848 for direct care provision. The odds of incurring hospital costs increased by 43% among CMC who used ICT.

Summary CMC utilize substantial, costly, and unreimbursed amounts of ICT, yet ICT is associated with increased hospital costs. Perhaps ICT might be a proxy indicator of rising clinical acuity and should prompt escalation of ambulatory care plans; further studies are needed.

Keywords Children with medical complexity · Complex care · Healthcare cost · Value

Introduction

Children with medical complexity (CMC) are a growing population of children with complex chronic medical conditions, severe functional limitations, high resource utilization, and technology dependencies [1, 2•, 3, 4]. CMC represent less than 1% of all US children, yet account for 35% of pediatric healthcare costs [5•, 6, 7], totaling over $100 billion annually [8•]. Emergency department and hospital inpatient utilization have been identified as significant contributors to costs [1, 9–11]. In response, complex care programs have been developed for CMC [11, 12]. Pordes et al. have grouped models of care for CMC into 3 main categories: 1) primary care centered models, 2) consultative or co-management centered models, and 3) episode-based models [13••]. The Comprehensive Care Program (CCP) at the University of Utah, Department of Pediatrics and Intermountain Healthcare Primary Children's Hospital (PCH) is a consultative, outpatient, tertiary center-based program for CMC. Our program was established in 2007 to optimize healthcare value for CMC in our region.

The majority of direct costs incurred by CMC relate to hospital costs, which include inpatient hospital services and emergency department utilization [10, 14, 15]. In our subpopulation of CMC with tracheostomy and ventilator dependencies, we found that 33% of emergency department visits were avoidable [16]. Appropriate emergency department utilization and subsequent hospitalization have the potential to significantly improve healthcare value for these children. Complex care programs for CMC that render comprehensive care in a continuously coordinated model can decrease hospital utilization [17, 18•, 19, 20]. The mechanism by which this occurs is not yet clear.

Providers working in complex care programs invest substantial amounts of time in caring for CMC outside of traditional face-to-face clinic visits; we term this as indirect care time (ICT). Hospital and emergency department utilization for CMC might be reduced through the provision of ICT, including care coordination, care consolidation, telephone management of clinical concerns, and collaboration with subspecialists. The elements of ICT have not yet been fully described in the literature. The aims of this project were to detail the ICT provided to a large population of CMC in the context of our CCP, and then to test the hypothesis that increased ICT correlates with decreased hospital utilization.

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Methods

Our CCP is a consultative, specialty outpatient program staffed by pediatric physiatrists and generalists, advanced practice clinicians, and nurse coordinators; with input from social workers, respiratory therapists, and dieticians as needed. Although the program is intended for CMC as defined by having 3 or more specialists involved, technology dependencies, high resource utilization, high medical fragility, and high psychosocial complexity, we provide initial evaluations for all children, regardless of referral source or diagnoses. Study participants included CMC who had at least one CCP visit during 2014–2015, or CMC who had at least 1 instance of ICT within that 2-year period and had at least one CCP visit during the previous 2 years (2012–2013).

We recorded descriptive data, including demographic details, clinic visit dates, duration of enrollment, active problem/diagnosis list, technology use, primary payer, Feudtner Chronic Complex Condition (CCC) scores, and referral sources, for each study participant. The Feudtner CCC score is a validated, commonly used scoring system in which 1 point is given for the presence of a predetermined diagnostic code within a body system that is likely to last for greater than 1 year and is likely to require admission to a tertiary care center [21]. Feudtner CCC scores have been used since 2000 and applied to a variety of research settings such as risk analysis, morbidity and mortality predication, and identification of populations with high healthcare resource utilization.

Provider costs (salary without benefits) were obtained from institutional sources for the various practitioners working in the program, and hospital costs from the Intermountain electronic data warehouse. Hospital costs were defined as the cost to provide care (not the amount billed or collected) in emergency departments, short stay units, and hospital inpatient units at all Intermountain Hospitals, including Primary Children's Hospital (PCH). PCH is the only tertiary care pediatric care hospital in the Intermountain West, and the primary site for admissions for CMC in our CCP. ICT, direct care time, visit preparation time, and charting time were extracted from an integrated module in our electronic medical record that recorded time spent, activity performed, provider type, date, and patient name. We verified the accuracy of this module by manual chart review of 100 patients.

Total ICT over the 2 years was annualized. The ICT was condensed to 3-month periods for each subject. We sorted subjects into 2 groups: those receiving and those not receiving ICT. The odds ratio of incurring hospital costs for each time period was calculated. Because many patients used zero ICT, a zero-inflated gamma generalized linear regression model was utilized to estimate the effect of ICT on cost, while controlling for age, gender, ethnicity, race, insurance provider, distance away from center, and CCC score.

This study was approved by the University of Utah Institutional Review Board.

Results

We enrolled 905 CMC between January 2014 and December 2015 (2 years). Of these, 831 (92%) remained active at the end of the study, 61 (7%) died, and 13 (1%) were discharged from our program. The average age was 6.9 years (SD 0.9, range 0–34 years), and 54% were male. With regard to race, 87% of the participants were white, 4% were Black/African American, 2% were Asian, 2% were Pacific Islander, 1% were Native American/Alaska Native, and 4% were not disclosed; 14% of the participants were identified as Hispanic/Latino (Table 1). By primary payer, 56% had private insurance, 43% had government insurance, and 1% were uninsured. The average distance from enrollee's homes to the center was 56.0 miles (SD 7.1 miles, range 0–691 miles).

Of the 905 patients, 45 (5%) had a CCC score of 0, and 860 (95%) scored ≥ 1. Among the 860 CMC with CCC ≥ 1, the mean CCC score was 4.5 (SD 0.3, range 1–10) with the three most frequent categories being neurological/neuromuscular, cardiovascular, and respiratory conditions. Six hundred

Table 1 Patient population descriptive data

Current Patient Status	*n*	%
Active	662	73%
Deceased	61	7%
Failed to follow up	6	1%
Moved	4	0%
PRN followed	169	19%
Referred out of program	3	0%
Gender	*n*	%
Female	414	46%
Male	491	54%
Ethnicity	*n*	%
Hispanic/Latino	129	14%
Non-Hispanic/Non-Latino	726	80%
Pt Declined	3	0%
Unavailable	20	2%
Unknown to patient	5	1%
Race	*n*	%
Native American/Alaskan Native	9	1%
Asian	16	2%
Black or African American	34	4%
Native Hawaiian/Pacific Islander	18	2%
Unknown/unavailable	8	1%
White	789	87%

eighty-three children (75%) had at least one medical device. Complexity data are summarized in Fig. 1.

An annual average of 640 h of direct face-to-face clinical care time and 1282 h of ICT was accumulated for this CMC sample. ICT included 684 h of non-visit related ICT (53% of total), 247 h of visit preparation time (19% of total), and 352 h of visit follow up time (27% of total). The most (40%) of the ICT was rendered by our nurse coordinators, followed by physicians (38%), advanced practice clinicians (16.5%), medical assistants (2.9%), and social workers (2%). In total, 67% of total care time for these CMC was ICT, whereas 33% was direct, face-to-face care time. Based on hourly salaries for our providers (excluding benefits), the annualized cost of rendering ICT was $93,977 (60% of total) while the cost of direct care provision was $62,848 (40% of total).

In our cohort of CMC, 391 of the 905 participants (43%) had no documented ICT, 514 (57%) had ≥ 1 instance of ICT. Hospital costs were incurred for 387 (43%) of the CMC, none for 518 (57%). Among the 391 CMC without ICT use, 224 (57%) had no hospital costs, whereas 167 (43%) did. Among the 514 CMC who did use ICT, 163 (32%) incurred no hospital costs, whereas 351 (68%) did incur costs. Overall, 43% of CMC without documented ICT incurred hospital costs, contrasting with 68% of those with ICT who incurred hospital costs. This difference is statistically significant ($p < 0.01$).

CMC with no documented ICT had median hospital costs of $0 (range $0–$306, 182) and those with ICT had median hospital costs of $5191 (range $0–$870, 308). Due to the large number of observed zeros, a two-part regression model was used to estimate odds ratios. The odds of an observed hospital cost increased by 43% for every hour of ICT ($p < 0.01$). This effect decreased by 31% for each year of age ($p < 0.01$), decreased by 4% for every mile lived away from PCH ($p < 0.01$), increased by 791% for the presence vs. absence of any CCC ($p < 0.01$), and increased by 32% for public vs. private insurance ($p < 0.01$) (Table 2).

Among the CMC in our study who incurred hospital costs, the expected cost increased by a factor of 1.12 (12% increase) for every additional hour of ICT used ($p < 0.01$), controlling for age, gender, ethnicity, race, payer type, driving distance, and CCC score. This was decreased by 86% for uninsured vs private pay patients ($p < 0.01$) and increased by 416% for those with a CCC condition vs none ($p < 0.01$) (Table 3).

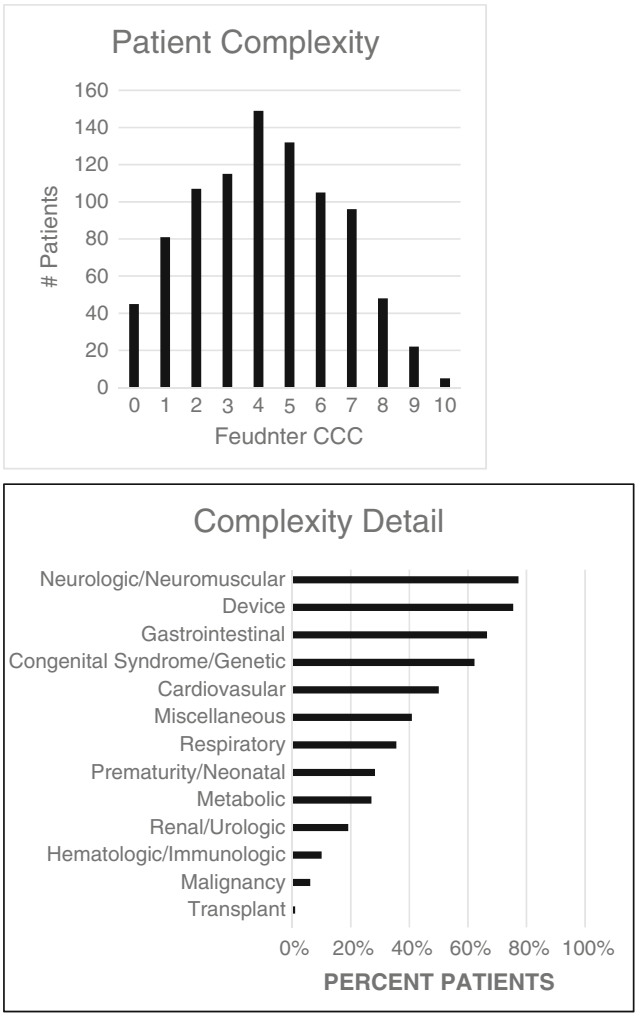

Fig. 1 Distribution of Feudtner complexity scores and diagnostic categories of complexity scores

Discussion

We aimed to quantify the impact of ICT on total healthcare costs for CMC, hypothesizing that ICT would be *inversely* associated with resource utilization and hospital costs. Instead, we found that ICT utilization among CMC was *directly* associated with hospital costs. Although our study design does not allow us to interpret causality, it may be that ICT utilization was driven by rising clinical acuity in CMC, and was therefore a predictor of unplanned escalations in care.

In a carefully controlled intervention, Simon et al. evaluated the impact of comprehensive case management for CMC, including detailed and continuously updated shared plans of care, coordination with subspecialists, acute and chronic condition management [22•]. Their comprehensive case management was an example of high ICT, as defined in this study. The intervention was associated with increases in health care quality and costs, when compared to the control group. In contrast, Gordon showed that a consultative, tertiary hospital-based consultative program for CMC was associated with decreased hospital days, increased clinic visits, and a reduction in tertiary care center charges of $10.7 million for 227 children [18•]. Casey's rural children's hospital-based multidisciplinary primary care clinic for CMC demonstrated decreased inpatient

Table 2 Step 1 Logistic regression: risk of incurring cost by ICT hour spent and impact of covariables

Factor	Odds ratio	Confidence limits		*p*
ICT hours (continuous)	1.43	1.31	1.57	< 0.0001
Age (continuous)	0.69	0.63	0.75	< 0.0001
Gender (male vs female)	104	0.85	1.27	ns
Ethnicity (Hispanic vs non-Hispanic)	1.38	1.05	1.81	ns
Race (white vs non-white)	1.05	0.78	1.42	ns
Insurance (government vs private)	1.32	1.08	1.63	ns
Insurance (uninsured vs private)	0.34	0.09	1.30	ns
Driving distance (continuous)	0.97	0.96	0.99	ns
Any CCC (yes vs no)	7.91	3.48	17.98	< 0.0001

and ED costs, with overall Medicaid cost reductions of $1180 per child per month [23]. In a randomized study of comprehensive care versus usual pediatric primary care, Mosquera too, found that comprehensive care was associated with reductions in ED visits, frequency and length of hospitalizations, pediatric ICU admissions, and total costs; Medicaid payments were reduced by $6250 per child/year [24•]. In our own experience, we demonstrated a $10.5 million cost reduction for nearly 500 CMC in our comprehensive care program (manuscript in review). The evidence for complex care programs for CMC is growing. The key factors that account for value, however, may not be what we have expected. Perhaps it is not care coordination (ICT) but rather the provider-parent-patient relationship and shared decision making of complex care programs that accounts for lower healthcare costs for CMC [25].

This study has several limitations. Providers in our group likely underreported ICT, simply for reasons of competing time demands. Moreover, since the delivery of comprehensive care depends on providers' abilities to move quickly between multiple tasks and also to continually engage with one CMC and family at a time, quantifying units of time can be difficult. Secondly, hospital and emergency department costs were also likely under reported, as visits to non-Intermountain facilities were not included in our data, However, PCH is the only tertiary care pediatric hospital in the Intermountain West (UT, ID, MT, WY, NV), and we believe that most of the emergent and inpatient care was rendered here. Thirdly, we recognize the variability in acute care episodes among CMC, and a 2-year study period might be too short to fully characterize the use and impact of ICT longitudinally. Our descriptive study design does not allow us to compare hospital costs between children who did and did not use ICT. Lastly, our CCP is a dynamic model of care delivery; changes in our program and in the greater healthcare system might have inadvertently influenced our results. Despite these limitations, we believe that this first attempt to measure the provision of ICT for CMC and its associations in hospital costs of care uniquely adds to the growing base of health services literature for CMC.

Conclusions

CMC utilize substantial, costly, and unreimbursed amounts of ICT, and ICT is associated with increased hospital costs in our population. Perhaps ICT might be a proxy indicator of rising clinical acuity and should prompt escalation of ambulatory care plans. To test this hypothesis, further studies are needed.

Table 3 Step 2 Gamma regression: impact on cost per hour ICT and impact of covariables

Factor	Risk factor	Confidence limits		*p*
ICT hours (continuous)	1.12	1.03	1.22	0.0096
Age (continuous)	1.02	0.89	1.16	ns
Gender (male vs female)	0.81	0.63	1.04	ns
Ethnicity (Hispanic vs non-Hispanic)	1.14	0.84	1.54	ns
Race (white vs non-white)	0.93	0.56	1.54	ns
Insurance (government vs private)	0.92	0.72	1.18	ns
Insurance (uninsured vs private)	0.14	0.10	0.20	< 0.0001
Driving distance (continuous)	1.01	1.00	1.03	ns
Any CCC (yes vs no)	4.16	2.00	8.64	0.0001

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Compliance with Ethical Standards

This study was approved by the University of Utah Institutional Review Board.

Conflict of Interest Justin Alvey, Karen Valentine, Jacob Wilkes, Tyler Bardsley, Colleen Marty, Kilby Mann, and Nancy A. Murphy declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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