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ORIGINAL ARTICLE

Impact of care coordination on service utilisation for children with medically complex cerebral palsy

Adrienne Harvey [1,2] Daisy Shepherd,[1,2] Susan Gibb,[2,3] Gordon Baikie,[1,3] Anita D'Aprano [1,2,3] Dinah Reddihough,[1,2] Rose Babic,[1] Frances Hunter,[1] Gretta Jealous[1] and Christine Imms[1,2,3]

[1]Neurodisability and Rehabilitation, Murdoch Children's Research Institute, [2]Department of Paediatrics, University of Melbourne and [3]Neurodevelopment and Disability, The Royal Children's Hospital, Melbourne, Victoria, Australia

Aim: Complex care programmes for children with medically complex cerebral palsy (CP) exist; however, evidence for their impact is limited. This study (i) explored the impact of The Royal Children's Hospital Complex Care Hub (CCH) on hospital service utilisation rates over a 3-year period for children with medically complex CP compared with those eligible but received routine care, and (ii) compared health, disability and socio-demographic characteristics of children and their families in both groups.

Methods: Electronic medical record data from 78 children (mean age 9.43 years, females $n = 37$) with medically complex CP who accessed CCH services, and 92 (mean age 10.86 years, females, $n = 39$) who received routine care were included. Multivariable regression was used to analyse service utilisation: number of emergency department (ED) presentations, length/number of inpatient and intensive care unit admissions and number/type of hospital appointments. Critical health-care needs, functioning/disability profile and child/family demographics for each group were compared.

Results: More children in the CCH group had a mixed motor type (73.1% vs. 15.2%), were classified within Gross Motor Function Classification System level V (76.9% vs. 34.8%), had respiratory, nutrition and social support needs and epilepsy. Children receiving CCH services had higher service utilisation rates; ED presentations (rate ratio (RR) = 1.81, 95% confidence interval (CI): 1.09–3.01), inpatient admissions (RR = 2.77, 95% CI: 2.01–3.83), outpatient encounters (RR = 1.69, 95% CI: 1.31–2.18) and telephone encounters (RR = 6.05, 95% CI: 4.56–8.02).

Conclusions: Children with medically complex CP accessing a complex care service have higher service utilisation rates yet have more complex clinical presentations and higher support needs.

Key words: care coordination; cerebral palsy; chronic conditions; medical complexity.

What is already known on this topic

1 Children with medically complex cerebral palsy (CP) have high health care needs and resource requirements from many different specialties.
2 The field of complex care is emerging, however most evidence originates from North America, with few high-quality studies available, and conflicting results.
3 Further evidence is needed to guide complex care programs, particularly for children with medically complex CP in the Australian setting.

What this paper adds

1 Children with medically complex CP who receive support from a complex care service have higher rates of respiratory and nutritional support needs, epilepsy, severe gross motor function limitations and a mixed motor type presentation.
2 Children with medically complex CP who receive support from a complex care service tend to have higher service utilisation rates.
3 More research is required to examine whether higher service use translates to a better experience for children and their families.

Correspondence: Associate Professor Adrienne Harvey, Neurodevelopment and Disability, Murdoch Children's Research Institute, 50 Flemington Road, Parkville, Vic. 3052, Australia. Fax: +61 (3) 8341 6212; email: adrienne.harvey@mcri.edu.au

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Cerebral palsy (CP) is an umbrella term that describes a group of conditions associated with an early, static brain lesion, occurring through maldevelopment or injury, resulting in abnormal body movements or postures.[1] Children with medically complex CP have severe functional limitations and multiple medical comorbidities associated with high health-care needs and resource requirements.[2] Most will require support from many medical and allied health specialties. Families with a medically fragile child, and potentially other family complexity, find navigating the health-care system difficult and can experience barriers to children receiving optimal health care.[3]

The emerging field of complex care is focused on holistic medical and social care requiring specific expertise in care coordination and communication both with children and families, and health-care providers.[4] The aim is to shift the focus from a reactive and crisis driven approach to one that is proactive and preventive.[5] Research on complex care is emerging; however, there is limited evidence to guide service design, evaluation and implementation.[6] Most evidence originates from North America, with few high-quality studies available, and conflicting results.[7–10] Recent studies conducted within Australia have investigated the lived experiences of children with medical complexity[11] and established integrated models of care coordination for children and young people living with medical complexity.[12]

Further evidence is needed to guide complex care programmes, particularly for children with medically complex CP in the Australian setting. The Royal Children's Hospital (RCH), Melbourne, has a well-established Complex Care Hub (CCH) with a multidisciplinary team that partners with families and community providers to deliver proactive, coordinated care for children with medical complexity across Victoria.[3] The CCH provides an enhancement to existing medical services, by providing a single point of contact (nursing or social work) for routine clinical advice, care coordination, provision of support services and a conduit to more direct interaction with other clinical team members.

This study aimed to (i) explore the impact on hospital service utilisation over 36 months for children receiving support from the CCH compared to those who were eligible but not enrolled in the CCH; and (ii) describe and compare differences in health, disability and socio-demographic characteristics of children and their families who were supported by the CCH with those who received routine care without CCH support, to understand which characteristics may be predictive of referral to the CCH.

Table 1 Criteria for Complex Care Hub (CCH) eligibility, used to define medically complex cerebral palsy (CP) in this study

	Criteria	Eligible if…
1	Chronicity	Condition is expected to last 12 months or more; indicated by diagnosis of CP or like condition (e.g. perinatal stroke).
2	Complexity	*Medical complexity* More than 10 medical appointments in 12 months; 3 or more specialty teams dealing with different organ systems AND/OR *Psychosocial complexity* Significant difficulties in areas of carers health, geographical isolation or disability that impact attendance and care
3	Instability	More than one emergency department admission in 12 months (actual or predicted). To accommodate the difficulty of identifying 'potential instability' we will also include those classified at GMFCS Levels IV or V, and those in any GMFCS level and comorbid epilepsy.
4	Functional limitation	Condition impacts on child's participation in independent age-appropriate activities: assumed as yes, with a diagnosis of CP.

GMFCS, Gross Motor Function Classification System.

Methods

Study design and setting

This study was the first phase in a multiple-method, three-phase, observational project aiming to gain an in-depth understanding of the care coordination needs of children with medically complex CP and their families. This first phase examined existing electronic medical record (EMR) data from the RCH between 1 January 2019 and 31 December 2021. Ethical approval was obtained from the RCH Human Research Ethics Committee (HREC/87242/RCHM-2022). The parents/guardians of all eligible children were invited to participate via mail and provide informed consent through an opt-out process.

Ethics approval

The authors confirm that all methods were carried out in accordance with relevant guidelines and regulations as outlined in the Declaration of Helsinki. Ethics approval was gained by The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC/87242/RCHM-2022). The parent/legal guardian and, where deemed competent and mature to provide informed consent, the children/adolescents involved provided informed consent. The following consenting options were provided: (i) no-response – assumed informed consent for access and use of data from the EMR; (ii) opt-out – active decision to not allow access and use of data from the EMR; and (iii) active informed consent for access and use of data.

Participants and recruitment

Participants were ascertained from the EMR and eligible if they had a diagnosis of CP and medical complexity based on: (i) chronicity; (ii) complexity (number/diversity of medical appointments and/or psychosocial needs); (iii) instability; and (iv) functional limitation (see Table 1). The CCH group consisted of children who were receiving CCH services on 1 January 2019; the comparator group was those who met CCH eligibility who had never received CCH services and received routine hospital care. There were no exclusion criteria. During the study period children may have stopped receiving CCH support due to (i) age transition (18 years); (ii) graduation due to reduced medical complexity and no longer eligible; or (iii) death.

Intervention and comparator group details

Intervention group

The CCH provides a range of services with different levels (tiers) of support provided depending on the medical care needs of the child. Tiers 1–3 correspond to the highest to lowest level of support. The model is based on a partnership between families and providers and delivers care coordination via a key contact, 24-h access to clinical advice (tier 1), proactive care planning, psychosocial support and for the most fragile and intense patients, in home health-care support. It is a hospital-based programme

providing a single point of contact for children and families who are referred to the service by their treating physician. Twenty-four-hour access to clinical advice is available to children in tiers 1 and 2, while home health-care support is only available to those in tier 1. Other services are provided across all tiers.

Comparator group

Usual care consisted of hospital appointments and admissions without a dedicated service for care coordination and clinical advice.

Outcomes and data extraction

The primary outcome, service utilisation, was measured by: (i) number of emergency department (ED) presentations; (ii) number of inpatient admissions; (iii) length of inpatient admissions; (iv) number/length of intensive care unit (ICU) admissions; (v) number and type of hospital appointments (telephone, telemedicine, onsite); and (vi) date of any subsequent referral to CCH of the comparison group. Only services utilised at the RCH were examined.

Secondary outcomes were as follows:

1 CCH critical health-care needs, measured by: (i) number/profile of critical health-care needs (respiratory, nutrition, neurological, skin, psychological); (ii) number/profile of additional care needs related to medication, communication, mobility, continence and renal needs; (iii) number/profile of complexity factors (language, carer health, housing/isolation, recent adverse events); and (iv) course over the period: entrance to, or exit from, CCH supports. The individual items under (i)–(iii) can be combined to form three composite scores representing the total critical care needs, additional care needs and the complexity factors, respectively. Complexity factors were obtained through the EMR. Recent adverse events were defined as something significant in the previous 6 months that impacted family capacity to provide care: for example, death of a family member, major financial impact, new serious medical condition.
2 CP functioning/disability profile: (i) movement disorder and topography[13]; (ii) Gross Motor Function Classification System level (GMFCS)[14]; (iii) Manual Ability Classification System level (MACS)[15]; (iv) Communication Function Classification System level (CFCS)[16]; and (v) Eating and Drinking Classification System level (EDACS).[17] The GMFCS, MACS, CFCS and EDACS are internationally recognised classification systems to describe a child's mobility, hand, communication and eating and drinking function and range from I (mild functional limitations) to V (severe functional limitations).
3 Child and family socio-demographic profile: (i) child age/biological sex; (ii) family location; (iii) Socio-Economic Indexes for Areas (SEIFA) advantage-disadvantage score; and (iv) presence of social supports markers.

Table 2 Child and family socio-demographic profile of participants in the Complex Care Hub (CCH) group and comparator group

	CCH group		Comparator group	
	Missing, *n* (%)	*n* = 78	Missing, *n* (%)	*n* = 92
Age: years (as of 1 January 2019)	0 (0)		0 (0)	
Mean (SD)		9.43 (4.95)		10.86 (5.29)
Median (IQR)		9.69 (5.00–13.47)		11.30 (6.32–15.28)
Sex at birth: Female, *n* (%)	0 (0)	37 (47.4)	0 (0)	39 (42.4)
Address: State, *n* (%)	0 (0)		0 (0)	
Victoria		75 (96.2)		91 (98.9)
New South Wales		2 (2.6)		0 (0.0)
Queensland		1 (1.3)		0 (0.0)
Western Australia		0 (0.0)		1 (1.1)
Geographical location, *n* (%)	0 (0)		10 (10.9)	
Major cities of Australia		67 (85.9)		63 (76.8)
Inner regional Australia		10 (12.8)		16 (19.5)
Outer regional Australia		1 (1.3)		3 (3.7)
SEIFA disadvantage score, mean (SD)	0 (0)	993.33 (84.9)	1 (1.1)	981.43 (103.5)
Family structure, *n* (%)	0 (0)		0 (0)	
Two parent household		62 (79.5)		69 (75.0)
Single parent household		16 (20.5)		14 (15.2)
Lives with extended family		0 (0.0)		7 (7.6)
Other		0 (0.0)		2 (2.2)
Presence of social support, *n* (%)	0 (0)		0 (0)	
Use of interpreters		14 (17.9)		5 (5.4)
Engagement with social work services		78 (100.0)		5 (5.4)
Involvement of child protection		23 (29.5)		1 (1.1)
Vulnerable child flag		23 (29.5)		1 (1.1)
Legal flag		4 (5.1)		0 (0.0)

IQR, interquartile range; SD, standard deviation; SEIFA, Socio-Economic Indexes for Areas.

Outcome data for all included children were extracted from the EMR by two researchers using a customised data extraction template.

Table 3 Trajectories of participants during the 36-month study period and details about the Complex Care Hub (CCH) service utilisation

	CCH group ($n = 78$)	Comparator group ($n = 92$)
Deceased, *n* (%)	13 (16.7)	3 (3.3)
Transitioned out of RCH services, *n* (%)	9 (11.5)	15 (16.3)
Still receiving RCH support (when 19 years of age), *n* (%)	0 (0)	3 (3.3)
Length of time active in RCH services		
Duration, mean (SD) (years)	2.6 (0.7)	2.7 (0.7)
All 36 months (study period), *n* (%)	57 (73.1)	74 (80.4)
CCH services		
Graduated, *n* (%)	24 (30.8)	—
Graduated (but now re-referred), *n* (%)	2 (2.6)	—
Continued to receive support throughout follow-up period, *n* (%)	30 (38.5)	—
Time receiving support prior to follow-up period		
Enrolled since clinic established (1 July 2017), *n* (%)	46 (59.0)	—
Duration, mean (SD) (years)	1.2 (0.5)	—

Tier of support at start of study period, *n* (%)	Received	Eligible for
Tier 1 (highest level of support)	50 (64.1)	14 (15.2)
Tier 2	4 (5.1)	8 (8.7)
Tier 3	24 (30.8)	70 (78.1)

Data analysis

Supporting information for analyses and results is provided in the Supplementary material. For service utilisation, the target trial framework[18] and causal diagrams[19] were used to guide analyses and identify potential bias (Fig. S1, Table S1). Confounders included child age at start of study, sex, SEIFA, GMFCS level and critical care needs score.

For outcomes relating to number of events, the causal effect of interest was the rate of events if all children were receiving support from the CCH compared to the rate of events if none of them were (rate ratio). Rate ratios were estimated using negative binomial regression, with each event type analysed as a separate outcome (Table S2). The zero-inflated analogue was used when the proportion of zero events was large. Regression models included the exposure and confounders as main effects. An offset term was included in all models for the varying follow-up durations of participants.

Length of ICU admissions/inpatient admissions were combined into one total length of admission (bed utilisation; recorded in days) as movement between the ward and ICU is dependent on many factors (i.e. respiratory support, bed availability). The causal effect of interest was the difference in median admission length when receiving CCH services versus not receiving CCH services, due to the skewed distribution of admission lengths.[20] Estimation used a linear quantile mixed regression model, including a random intercept to account for repeated outcome measures for the same individual.

For the primary aim, a subgroup analysis looked at each 12-month calendar period individually, to separate the potential effect of COVID-19 on hospital service use. Due to a low prevalence of ICU admissions and no time log of outpatient encounters, these outcomes were excluded from the subgroup analysis.

Health, disability and socio-demographic characteristics were summarised for each group. Analyses were conducted in R version 4.3.1.[21] on available cases, with any missing data reported.

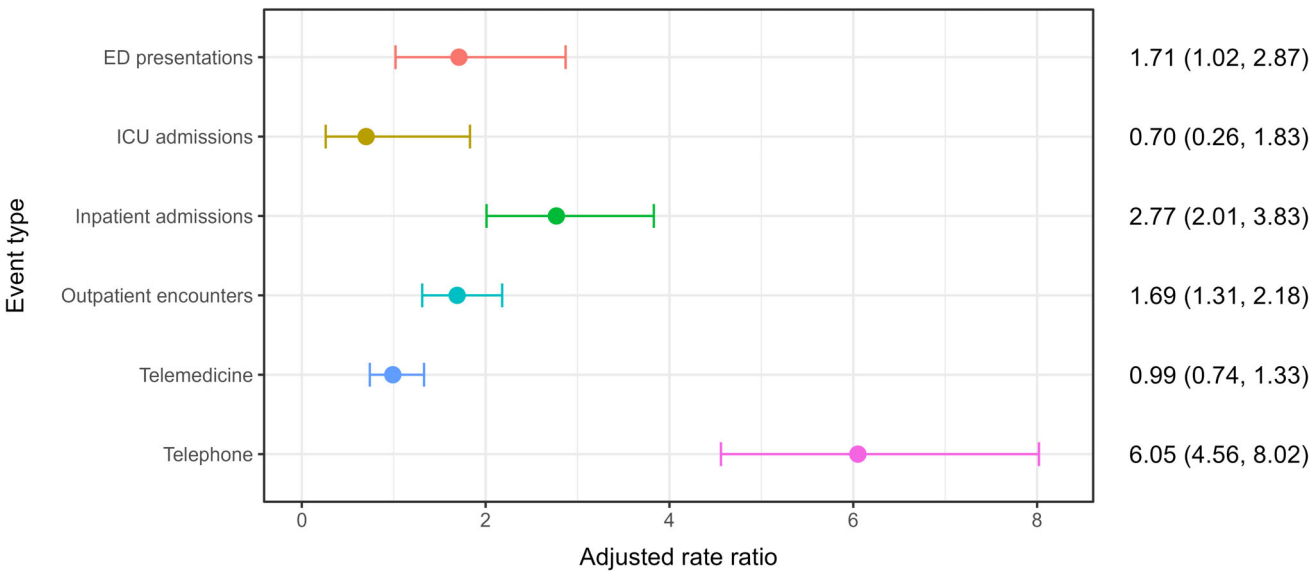

Fig. 1 Estimated adjusted rate ratios for service utilisation comparing if received support from the Complex Care Hub (CCH) versus not received support from the CCH.

Table 4 Impact of receiving support from the Complex Care Hub (CCH) on service utilisation

	Causal effect estimates (CCH vs. not CCH)	
	Rate ratio	95% CI
Emergency department presentations	1.71	(1.02, 2.87)
Inpatient admissions	2.77	(2.01, 3.83)
ICU admissions	0.70	(0.26, 1.83)
RCH outpatient		
Outpatient encounters	1.69	(1.31, 2.18)
Telephone	6.05	(4.56, 8.02)
Telemedicine	0.99	(0.74, 1.33)
	Difference in medians	95% CI
Length of admission (ICU, inpatient) (days)	1.99	(−0.20, 4.19)

Estimates are adjusted for child's sex at birth, child's age, Socio-Economic Indexes for Areas, GMFCS level and critical care needs score. CI, confidence interval; ICU, intensive care unit; RCH, Royal Children's Hospital.

Results

Study participants

Data extraction identified 78 individuals with medically complex CP who received CCH services (CCH group), and a comparator group of 92 who met eligibility criteria yet were not enrolled in CCH services. The distribution of sex, geographic location and SEIFA scores was similar between the two groups (Table 2). The presence of social support was more prevalent in the CCH group. Of those receiving CCH services at the start of the study period, 46 (59%) had been receiving services since CCH inception in June 2017 (duration approximately 1.5 years; Table 3). For others, enrolment in CCH services ranged from 5 days to 1.4 years before the study period (CCH group mean 1.2 (standard deviation: 0.5) years). Most individuals were receiving tier 1 support ($n = 50$, 64.1%).

Trajectories during study period

Across the 36-month study period, 16 children died (13 CCH, three comparator group), and 24 transitioned to adult services (nine CCH, 15 comparator group; Table 2). Within the CCH group, 26 individuals graduated, two of which were re-referred during the study period. No one in the comparator group was referred to the CCH. The mean time active in the service (RCH) was similar between the CCH and comparator groups (2.6 years vs. 2.7 years; Table 3), with most individuals active for the whole study period (73.1% and 80.4%; Table 3).

Service utilisation

The rate of service utilisation tended to be higher for children in the CCH group; the magnitude of the difference varying over outcomes (Fig. 1, Table 4; sample characteristics in Table S3). The estimated rates for individuals receiving support from the CCH were higher compared to those who did not for (i) ED presentations (RR = 1.71, 95% confidence interval (CI): 1.02–2.87) and inpatient admissions (RR = 2.77, 95% CI: 2.01–3.83). The rate of ICU admissions was similar in both groups (RR = 0.70, 95% CI: 0.26–1.83). However, the frequency of ICU admissions over the 36-month period was low in both groups (16 admissions each for CCH and comparator). The median length of stay was approximately 2 days higher for children receiving CCH support (causal difference in medians = 1.99, 95% CI: −0.20, 4.19; Table 4).

The rate of outpatient encounters was higher (RR = 1.69, 95% CI: 1.31–2.18) when receiving CCH support versus not, as were telephone encounters (RR = 6.05, 95% CI: 4.56–8.02; service provided as part of the 24-h access to clinical advice). However,

Table 5 Impact of receiving support from the Complex Care Hub (CCH) on service utilisation broken down by year (subgroup analysis)

	Causal effect estimates (CCH vs. comparator group)					
	2019		2020		2021	
	Rate ratio	95% CI	Rate ratio	95% CI	Rate ratio	95% CI
Emergency department presentations	1.64	(0.94, 2.87)	1.49	(0.80, 2.78)	1.84	(0.97, 3.58)
Inpatient admissions	2.38	(1.63, 3.49)	2.35	(1.45, 3.83)	3.93	(2.42, 6.46)
	Difference in medians	95% CI	Difference in medians	95% CI	Difference in medians	95% CI
Length of admission (ICU, inpatient) (days)	1.49	(−0.99, 3.96)	2.56	(3.47, 8.58)	0.49	(−0.85, 1.84)

Estimates are adjusted for child's sex at birth, child's age, Socio-Economic Indexes for Areas, GMFCS level and critical care needs score. Sample sizes for each subgroup analysis are presented in Table S4. CI, confidence interval.

Table 6 Critical health-care needs information of participants in the Complex Care Hub (CCH) group and comparator group

	CCH group		Comparator group	
	Missing, *n* (%)	*n* = 78	Missing, *n* (%)	*n* = 92
Critical care needs				
Total score (range: 0–40)	0 (0)		2 (2.2)	
Mean (SD)		10.51 (7.82)		9.53 (6.08)
Median (IQR)		13.0 (0–16.0)		8.00 (6.0–12.0)
Respiratory support, *n* (%)	0 (0)		0 (0)	
None		31 (39.7)		42 (45.7)
Low		2 (2.6)		23 (25.0)
Moderate		24 (30.8)		15 (16.3)
High		17 (21.8)		12 (13.0)
Severe		4 (5.1)		0 (0.0)
Nutrition support, *n* (%)	0 (0)		0 (0)	
None		25 (32.1)		39 (42.4)
Low		4 (5.1)		21 (22.8)
Moderate		32 (41.0)		29 (31.5)
High		17 (21.8)		3 (3.3)
Severe		0 (0.0)		0 (0.0)
Neurology support, *n* (%)	0 (0)		0 (0)	
None		40 (51.3)		37 (40.2)
Low		27 (34.6)		36 (39.1)
Moderate		7 (9.0)		4 (4.3)
High		2 (2.6)		7 (7.6)
Severe		2 (2.6)		8 (8.7)
Skin support, *n* (%)				
None		24 (30.8)		26 (28.3)
Low		33 (42.3)		55 (59.8)
Moderate		18 (23.1)		9 (9.8)
High		3 (3.8)		0 (0.0)
Severe		0 (0.0)		2 (2.2)
Psychology support, *n* (%)	0 (0)		2 (2.2)	
None		49 (62.8)		41 (45.6)
Low		18 (23.1)		26 (28.9)
Moderate		10 (12.8)		17 (18.9)
High		1 (1.3)		5 (5.6)
Severe		0 (0.0)		1 (1.1)
Additional care needs				
Total score (range: 0–12)	0 (0)		2 (2.2)	
Mean (SD)		10.36 (3.15)		7.47 (3.26)
Median (IQR)		12.0 (9.3, 12.0)		7.5 (5.0, 10.0)
Medication, *n* (%)	0 (0)		1 (1.1)	
None		2 (2.6)		4 (4.4)
Low needs		45 (57.7)		42 (46.2)
Moderate needs		26 (33.3)		32 (35.2)
High needs		4 (5.1)		10 (11.0)
Severe needs		1 (1.3)		3 (3.3)
Communication, *n* (%)	0 (0)		1 (1.1)	
None		3 (3.8)		17 (18.7)
Low needs		2 (2.6)		6 (6.6)
Moderate needs		10 (12.8)		34 (37.4)
High needs		10 (12.8)		17 (18.7)
Severe needs		53 (67.9)		17 (18.7)
Mobility, *n* (%)	0 (0)		2 (2.2)	
None		4 (5.1)		12 (13.3)
Low needs		6 (7.7)		14 (15.6)
Moderate needs		7 (9.0)		16 (17.8)

(*Continues*)

Table 6 (Continued)

	CCH group		Comparator group	
	Missing, *n* (%)	*n* = 78	Missing, *n* (%)	*n* = 92
High needs		17 (21.8)		22 (24.4)
Severe needs		44 (56.4)		26 (28.9)
Continence/renal, *n* (%)	0 (0)		1 (1.1)	
None		14 (17.9)		47 (51.6)
Low needs		3 (3.8)		2 (2.2)
Moderate needs		2 (2.6)		4 (4.4)
High needs		59 (75.6)		37 (40.7)
Severe needs		0 (0.0)		1 (1.1)
Complexity factors				
Total score (range: 0–7)	0 (0)		1 (1.1)	
Mean (SD)		2.40 (1.78)		0.95 (1.21)
Median (IQR)		2.00 (2–4.0)		1.0 (0–1.0)
Language, *n* (%)	0 (0)		1 (1.1)	
None		51 (65.4)		85 (93.4)
Low		24 (30.8)		3 (3.3)
High		3 (3.8)		3 (3.3)
Carer health, *n* (%)	0 (0)		1 (1.1)	
None		31 (39.7)		74 (81.3)
Low		26 (33.3)		15 (16.5)
High		21 (26.9)		2 (2.2)
Housing, *n* (%)	0 (0)		1 (1.1)	
None		29 (37.2)		51 (56.0)
Low		34 (43.6)		37 (40.7)
High		15 (19.2)		3 (3.3)
Adverse life events: Yes, *n* (%)	0 (0)	25 (32.1)	1 (1.1)	15 (16.5)

IQR, interquartile range; SD, standard deviation.

the rate of telemedicine encounters was similar (RR = 0.99, 95% CI: 0.74–1.33).

Subgroup analysis indicated the rate ratio of ED presentations was consistent across each year, while the rate ratio of inpatient admissions was higher in 2021 indicating a higher rate of admissions when receiving support from the CCH (RR = 2.42, 95% CI: 2.42–6.46; Table 5. See Table S4 for participant frequencies). While the median length of stay was higher for those receiving CCH support overall, the difference was lower in 2021 (causal difference in medians = 0.49, 95% CI: −0.85, 1.84) compared to the previous 2 years.

Comparison of group characteristics

The critical health-care needs score was similar between the groups (Table 6); however, more children in the CCH group had moderate to high respiratory and nutritional support needs than those in the comparator group. The CCH group had higher scores related to complexity factors and additional care needs than those in the comparator group, with more children with severe communication (67.9% vs. 18.7%) and mobility (56.4% vs. 28.9%) impairments and high complexity for carer health (26.9% vs. 2.2%), housing (19.2% vs. 3.3%) and adverse life events (32.1% vs. 16.5%). There was a higher proportion of children with epilepsy in the CCH group (84.6% vs. 62.0%). The CP functional and disability profile data (Table 7) showed a higher proportion of children with a mixed motor type (73.1% vs. 15.2%) and classified within GMFCS level V (76.9% vs. 34.8%) in the CCH group. There was a large amount of missing data in the manual ability, communication, and eating and drinking classifications which precluded meaningful comparisons.

Discussion

Children with medically complex CP who received CCH support tended to have higher service utilisation rates, particularly for inpatient admissions, telephone encounters and length of stay, compared with those eligible but not enrolled. The high rate of telephone encounters for the CCH group was expected as this is a core component of the service. While children in both groups were eligible for CCH, children who received CCH support had higher rates of respiratory and nutritional support needs, epilepsy, severe gross motor function limitations and a mixed motor type presentation. Additionally, more children in the CCH group had engaged with social work; an expected result given social work input is an integral part of the service.

The higher social support needs and high complexity of the children who accessed the CCH, and their higher chance of

Table 7 Cerebral palsy functioning/disability profile of participants in the Complex Care Hub (CCH) group and comparator group

	CCH group		Non-CCH group	
	Missing, *n* (%)	*n* = 78	Missing, *n* (%)	*n* = 92
Movement disorder and topography, *n* (%)	0 (0)		39 (42.4)	
Spasticity		11 (14.1)		27 (29.3)
Dyskinesia		4 (5.13)		10 (10.9)
Mixed presentation		57 (73.1)		14 (15.2)
Other		6 (7.7)		2 (2.2)
Movement disorder and topography, *n* (%)	1 (1.3)		45 (48.9)	
Bilateral		74 (96.1)		39 (83.0)
Unilateral – left		2 (2.6)		4 (8.5)
Unilateral – right		1 (1.3)		4 (8.5)
Gross motor function classification system: GMFCS, *n* (%)	0 (0)		0 (0)	
I		0 (0.0)		2 (2.2)
II		7 (9.0)		13 (14.1)
III		1 (1.3)		9 (9.8)
IV		10 (12.8)		36 (39.1)
V		60 (76.9)		32 (34.8)
Manual ability classification system: MACS, *n* (%)	46 (59.0)		35 (38.0)	
I		0 (0.0)		7 (12.3)
II		3 (11.5)		5 (8.8)
III		1 (3.8)		4 (7.0)
IV		4 (15.4)		12 (21.1)
V		24 (92.3)		29 (50.9)
Communication function classification system: CMFCS, *n* (%)	56 (71.8)		38 (41.3)	
I		1 (4.5)		11 (20.4)
II		1 (4.5)		4 (7.4)
III		2 (9.1)		6 (11.1)
IV		2 (9.1)		11 (20.4)
V		16 (72.7)		22 (40.7)
Eating and drinking classification system: EDACS, *n* (%)	62 (79.5)		56 (60.9)	
I		1 (6.3)		13 (36.1)
II		1 (6.3)		3 (8.3)
III		1 (6.3)		7 (19.4)
IV		2 (12.5)		4 (11.1)
V		11 (68.8)		9 (25.0)
Epilepsy: Yes, *n* (%)	0 (0)	66 (84.6)	0 (0)	57 (62.0)

referral to CCH, are the likely drivers of the differences in service utilisation between the groups. The higher complexity and additional care needs for those in the CCH group include more health issues for carers, less stable housing and more social support needs due to child protection issues and vulnerable child flags. A 'vulnerable child flag' is an alert in the EMR and usually added when there are protective concerns and a report to child protection has been made. When recognised, these factors are likely to result in clinician referral to the CCH. The majority of those in the comparator group were less complex, and thus resulting in lower likelihood of referral, especially if the families appear to be, or are, managing adequately.

It has been suggested that improving aspects of health-care delivery for children with medical complexity reduces unnecessary health-care encounters, improves the quality of care children receive, improves health- and quality-of-life-related outcomes for children and their families and reduces health-care-related expenditure.[22] The few randomised controlled trials conducted have reported conflicting results for the impact of comprehensive care on health-care utilisation compared to usual care for children with medical complexity. Two studies found no differences in number of ED visits or number of hospitalised days,[7,10] whereas another reported reduced ED visits and hospitalised days.[9] Our study results differ by suggesting an increase in service utilisation and health-care encounters. However, we focused specifically on children with CP, with those in the CCH group requiring more respiratory and nutritional support, having epilepsy, greater functional limitations and complex movement disorders. These markers of severity of CP might explain the difference.

No previous studies have specifically described or compared the socio-demographic characteristics of children with medically complex CP and their family who access complex care services versus those who do not. Our study found no differences between the groups for sex, geographic location, family structure and socio-economic advantage-disadvantage according to SEIFA. However, social support needs were higher in those receiving services from the CCH, including greater involvement of child protection and presence of vulnerable child and legal flags.

This study provides preliminary evidence as to which children with medically complex CP access a complex care service and the relationship between CCH referral and service utilisation. The CCH has been resourced to provide dedicated social work support to all families with high social needs. The integral role of the social work team enhances emotional support and assists coordination of external services including with the National Disability Insurance Scheme, Housing, Education and Child Protection. It is important to recognise this need alongside the medical complexity when designing services. Although children accessing the CCH appear to have higher support needs and more complex medical conditions, children in the comparator group also had critical care and other needs and are also likely to benefit from care coordination. Future research should examine quality of services delivered, child and family satisfaction, impact on quality of life of children and their parents and costs to the family and health-care system.

This study has some limitations. The study was designed to capture the clinical reality of providing services to children with medically complex CP in one centre only. Consequently, the sample size for the study was limited by the number of children who accessed services at a particular point in time and services accessed outside the RCH were not captured. Using existing data in the EMR meant some data on child functioning/disability profiles and child/family socio-demographics were limited or missing. Despite this, we feel that the risk of significant missing information is low. The observational study design is a further

limitation. Although a randomised controlled trial would potentially provide stronger evidence, this is neither appropriate nor feasible. We aimed to minimise the potential confounding bias through careful statistical design and analyses. However, we acknowledge the potential for residual bias remains high due to restrictions on sample size and the size of adjustment set, and thus results need to be interpreted considering this. In addition, the approach to adjustment assumes a constant causal effect across confounder substrata, which may not be a realistic assumption.

Conclusions

In conclusion, preliminary evidence suggests that children with medically complex CP who are supported by a complex care service have higher service utilisation rates; however, they have more complex clinical presentations and higher social support needs than those eligible but not enrolled. Future research should examine whether higher service use translates to a better experience for children and their families.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Supporting information for primary analysis and results.
Figure S1. Causal diagram illustrating the assumed causal structure underpinning our causal question.

Table S1. Target trial and emulation strategy used to answer the causal question estimating the impact of receiving support from the CCH on service utilisation over a 36-month period for individuals with medically complex CP.

Table S2. Justification for the regression model selected to estimate the causal effect (rate ratios) for each outcome within the primary analysis aim.

Table S3. Characteristics of analytic sample used for the primary analysis exploring the impact of receiving support on service utilisation. Analysis was performed on available cases (three individuals in the comparator group were excluded).

Table S4. Counts of participants included in the subgroup analysis, noting available cases formed the analytic sample.