

PROGRAM REPORT

Care management for children with medical complexity:

Patient characteristics, process improvement, and impact on satisfaction

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PROGRAM SUMMARY

BACKGROUND: We created a nurse care management (NCM) program in an academic general pediatrics clinic with the goal of improving communication and increasing satisfaction among caregivers of children with medical complexity. All nurses in the clinic participated in delivering care management services; there was no specific funding for this work. Standard work processes were created for identification of patients, enrollment, creation of a care plan, pre-visit call scripts, and NCM co-visits. Pre- and post-intervention surveys evaluating needs, services provided, and satisfaction were completed by caregivers of 24 patients.

OUTCOMES: Before intervention, 83% of caregivers reported that increased contact with the clinic would be beneficial. Within six months, we showed a 71% increase in the caregivers who reported that at least one nurse in the clinic knew their child's health history. We found a 51% increase in reports of adequate assistance in acquiring special medical equipment. 48% noted that nurses definitely knew important information about their child's care needs and care received from other providers, an increase from 4% initially. Caregiver knowledge of how to contact a nurse when they needed help or had a question increased by 39%.

CONCLUSION: Our NCM model supports improved care coordination and caregiver perceptions of quality of care received.

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INTRODUCTION

According to the 2018 National Survey of Children's Health, children with special health care needs (CSHCN) constitute 18.8% of US children. 86.9% of CSHCN do not receive care in a well-functioning system, and 68% never or only sometimes receive help in coordinating health care.¹ A growing subgroup of CSHCN are children with medical complexity (CMC), defined as children with chronic medical conditions that affect several body systems and who see multiple specialists.² CMC account for 1 of every 4 pediatric acute-care hospitalizations in the US,³ have an average of 7 times more outpatient visits,⁴ may be technology dependent,⁵ and face financial and social stressors.⁶

Formal pediatric care coordination efforts aim to improve quality of care received by connecting the patient and the healthcare system.⁷ Complex care management (CM) relies on specially trained, multidisciplinary teams to perform four essential activities: (1) engage patients at high risk for poor outcomes, (2) perform comprehensive health assessments proactively, (3) coordinate closely with caregivers and providers, and (4) avoid unnecessary services.⁸

Care coordination dually benefits caregivers and care team members. Streamlining services reduces caregiver stress,⁹ emergency department (ED) visits,¹⁰ need for additional subspecialist visits, and prevents delays in treatment.¹¹ A CM framework fills in communication gaps, encourages providers to perform at the "top of their license," and allows for better allocation of resources.¹² However, optimal integration of team members presents a unique challenge in the academic pediatric hospital setting, as primary care focused registered nurses (RNs) are scarce,¹³ and residents and faculty have different levels of training in the care of CMC.¹⁴

We report on the development of a nurse care management (NCM) intervention within our academic primary care clinic. We hypothesized that patients would benefit from more comprehensive, coordinated care among primary and specialty care leading to improved outcomes. Specifically, we sought to describe our experience establishing an interdisciplinary CM program in an academic general pediatrics clinic, and share data about our patients who were eligible for NCM and their characteristics, clinical utilization patterns, and changes in caregiver satisfaction with the intervention.

PROGRAM DESCRIPTION

Our NCM intervention took place at an academic primary care site located within a 154-bed children's hospital in a large metropolitan area in the western United States. A large proportion of children seen in our/this clinic are medically complex. Prior to the onset of this project, patients of two pediatric primary care providers (whose panels contained a relatively large proportion of CMC) routinely received some care management interventions (such as development of care plans, pre-visit planning calls) from a team of two clinic nurses. Prior to the intervention, about 20-30 patients were part of this informal program.

We expanded NCM services across the practice's 12 faculty physicians and 29 resident physicians. We began by forming a clinic committee composed of a physician champion, a nurse champion, and the practice manager to guide and plan the intervention. The committee's physician champion had experience managing medical complex patients and with CM models in other clinic settings. The nurse was one of two clinic RNs who was already providing CM to a subset of clinic patients and who also served as the pediatric

representative on the hospital-wide Primary Care Care Management Committee.

Leadership buy-in and support came from the medical director and division chief.

ADMISSION CRITERIA: The committee provided education via email and in-person clinic huddles to staff (RNs, faculty, residents) regarding the criteria used to determine medical complexity and NCM activities. Patients with diagnoses that affected three body systems or diagnoses that affected two body systems as well as social stressors that could impact care utilization were included.

Physicians also considered the patients' diagnoses, social determinants of health, an EHR-generated admission risk score, and the Pediatric Medical Complexity Algorithm in helping to determine which patients would be referred to CM. The committee created a standardized process for physicians to electronically refer patients to NCM and a standard work document for RNs to follow in contacting their assigned patients. Part of the referral included PCPs' NCM goals for their patients, which provided a starting point for NCM work.

PROGRAM ROLES: Patient referrals were reviewed weekly by the committee's physician and nurse champions as well as

Figure 1: Nurse Care Management Activities in the General Pediatrics Clinic

one additional clinic nurse. The physician champion had a special interest in complex care and did not receive funded FTE to support this work. The physician dedicated approximately 4 hours per week (0.1 FTE) during the start-up phase, and 2 hours per week (0.05 FTE) to this work during the maintenance phase. The nurse champion also had a special interest in systems-based practice and used existing administrative time to support this project (approximately 2 hours per week). The nurse champion managed electronic documentation, including documenting the referral, and placing the name of the Nurse Care Manager as a member of the Care Team in the electronic health record (EHR).

Nurses used a standard format to document outreach to patients, and those outreach notes were shared with the partner nurse

and PCP. Nurses also used an EHR-based tool to track patient outreach and schedule future outreach to families on their NCM panel. Specific components of the NCM intervention included proactive outreach calls prior to scheduled appointments, nurse co-visits to provide education or support, and creating a care plan for each patient to track specialists, referrals, special medical equipment/home health, and current goals. A visual representation of the NCM program and study activities is shown in Figure 1, and details of Epic-based documentation is provided in the Appendix.

	Enrolled patients, n=26; (%)		Enrolled patients, n=26; (%)
Demographics		PMCA score†	
Age at start of study		Low Risk (0 pts)	0 (0)
Infant ≤ 12 months	14 (54)	Medium Risk (1 pt)	0 (0)
13 months-2 years	1 (4)	High Risk (≥ 2 pts)	21 (81)
3-5 years	4 (15)	Not calculated (age<1)	5 (19)
6-11 years	5 (19)	PMCA Systems†	
12-18 years	2 (8)	Cardiac	8 (31)
19-21 years	0 (0)	Craniofacial	3 (11)
Sex		Dermatologic	1 (4)
M	13 (50)	Endocrinological	3 (11)
F	13 (50)	Gastrointestinal	8 (31)
Race		Genetic	7 (27)
White	17 (65)	Genitourinary	1 (4)
Multi-racial	6 (23)	Hematologic	0 (0)
Asian	2 (8)	Immunological	2 (8)
Black	1 (4)	Malignancy not in remission	0 (0)
American Indian	0 (0)	Mental health	12 (46)
Ethnicity		Metabolic	2 (8)
Non-Hispanic	20 (77)	Musculoskeletal	8 (31)
Hispanic	6 (23)	Neurological	18 (69)
Insurance		Ophthalmological	15 (58)
Public Insurance	20 (77)	Otologic	8 (31)
Private Insurance	4 (15)	Pulmonary	6 (23)
Other	2 (8)	Pulmonary/Respiratory	11 (42)
		Renal	5 (19)
		Progressive	15 (58)

† Pediatric Medical Complexity Algorithm (PMCA)

Table 1. Demographics and clinical characteristics of patients newly enrolled in Nurse Care Management intervention, General Pediatrics Clinic (n=26)

PATIENT POPULATION: Twenty-six patients were enrolled in our NCM intervention study over one year; approximately 125 patients are currently enrolled in the NCM program. The majority of the 26 patients were infants ≤ 12 months, white, non-Hispanic, and on public insurance plans (Table 1). 81% of patients were high risk based off the Pediatric

Medical Complexity Algorithm (PMCA) score, with neurological and ophthalmological systems most involved, and most disease states were considered 'progressive'. The majority of patients were given an adjudicated risk score (based on EHR risk score and care team's perception of risk) of 4 (highest level).

OUTCOMES

Patients who received the NCM intervention and were qualified to participate in the study were given surveys at the start of the project and 6-15 months later to assess the effectiveness of NCM services. Surveys were developed via a consensus approach at the start of the study. Patients were eligible to participate if they were English-speaking and if they had not already been receiving NCM. Surveys included the following domains: needs assessment,

satisfaction with NCM, and evaluation of CM services provided by the clinic.

Data analysis was conducted using Microsoft Excel (Redmond, WA) and Stata version 14 (College Station, TX). Surveys were distributed using Qualtrics software (Seattle, WA). We used basic descriptive statistics to describe our data and Fisher's exact test to compare distribution of data within frequency tables. A p-value less than 0.05 was used to denote statistical significance. IRB approval was obtained. There was no funding specific for this project.

Is there at least one nurse in this clinic who knows you or your child well and is familiar with your child's health history?*		
	Pre (n=26) (%)	Post (n=21) (%)
Yes (%)	4 (15)	18 (86)
No (%)	17 (65)	3 (14)
N/A (%)	5 (19)	0 (0)
In the last 12 months, did that nurse/nurses know important information about your child's health and care needs?*, **		
	Pre (n=25)	Post (n=21)
Definitely (%)	1 (4)	10 (48)
Somewhat (%)	1 (4)	9 (43)
No (%)	6 (24)	0 (0)
In the last 12 months, did that nurse/nurses seem informed and up-to-date about the care your child got from other providers?*, **		
	Pre (n=25)	Post (n=21)
Definitely (%)	1 (4)	10 (48)
Somewhat (%)	1 (4)	8 (38)
No (%)	6 (24)	1 (5)
In the last 12 months, did that nurse/nurses support your decisions about what is best for your child's health and treatment?*, **		
	Pre (n=25)	Post (n=21)
Definitely (%)	3 (12)	19 (90)
Somewhat (%)	1 (4)	1 (5)
No (%)	4 (16)	0 (0)
In the last 12 months, did that nurse/nurses help make sure you got your child's special medical equipment?*, **		
	Pre (n=25)	Post (n=21)
Definitely (%)	2 (8)	15 (71)
Somewhat (%)	0 (0)	0 (0)
No (%)	5 (20)	1 (5)
Did you know how to contact a nurse when you needed help or had a question?*, **		
	Pre (n=23)	Post (n=21)
Yes (%)	14 (61)	21 (100)
No (%)	6 (26)	0 (0)
In the last 3 months, did a nurse from our clinic contact you without you getting in touch with them first?*		
	Pre (n=18)	Post (n=21)
Yes (%)	4 (22)	10 (48)
No (%)	11 (61)	11 (52)
Overall, in the last 12 months, how often did you get the help you needed to manage your child's care from a nurse care manager?*, **		
	Pre (n=21)	Post (n=21)
Never (%)	11 (52)	3 (14)
Once in the past 6-12 months (%)	2 (10)	1 (5)
Once every 3-6 months (%)	3 (14)	9 (43)
More frequently than once every 3 months (%)	2 (10)	8 (38)
Has the clinic created a shared care plan for your child?*, **		
	Pre (n=23)	Post (n=21)
Yes (%)	0 (0)	7 (33)
No (%)	21 (91)	14 (67)

*p<0.05

**Responses do not add up to column total at times due to unanswered questions or skip logic of question

In the last 12 months, have the providers or anyone from the clinic talked to you about the progress your child was making toward the goals written in his or her shared care plan?*		
	Pre (n=18)	Post (n=21)
Yes (%)	1 (5)	3 (14)
No (%)	7 (39)	4 (19)
My child's shared care plan does not have written goals (%)	3 (17)	0 (0)
In the last 12 months, when you contacted this provider's office during regular office hours, how often did you get an answer to your medical question the same day?*		
	Pre (n=26)	Post (n=21)
Never (%)	2 (7)	0 (0)
Sometimes (%)	6 (23)	3 (14)
Usually (%)	3 (12)	5 (24)
Always (%)	8 (31)	13 (62)
In the last 12 months, how often did this clinic show respect for what you had to say?*		
	Pre (n=25)	Post (n=21)
Never (%)	1 (4)	0 (0)
Sometimes (%)	2 (8)	0 (0)
Usually (%)	2 (8)	2 (10)
Always (%)	19 (76)	10 (90)
In the last 12 months, how often did this clinic spend enough time with you and your child?*		
	Pre (n=25)	Post (n=21)
Never (%)	0 (0)	0 (0)
Sometimes (%)	0 (0)	1 (5)
Usually (%)	2 (8)	2 (10)
Always (%)	22 (88)	18 (85)
In the last 12 months, how often did the clinic seem informed and up-to-date about the care your child got from specialists?*		
	Pre (n=26)	Post (n=21)
Never (%)	2 (7)	0 (0)
Sometimes (%)	3 (12)	3 (14)
Usually (%)	3 (12)	5 (24)
Always (%)	14 (54)	13 (62)
In the last 12 months, did someone in this office talk with you about specific goals for your child's health?*		
	Pre (n=26)	Post (n=21)
Yes (%)	15 (58)	16 (76)
No (%)	10 (38)	5 (24)
In the last 12 months, did someone in this office ask you if there are things that make it hard for you to take care of your child's health?*		
	Pre (n=26)	Post (n=21)
Yes (%)	9 (34)	11 (52)
No (%)	16 (62)	10 (48)
Overall, how satisfied or dissatisfied were you with help you received in managing your child's care or treatment in the last 12 months?*		
	Pre (n=26)	Post (n=21)
Very satisfied (%)	16 (61)	17 (81)
Somewhat satisfied (%)	7 (27)	4 (19)
Somewhat dissatisfied (%)	0 (0)	0 (0)
Very dissatisfied (%)	1 (4)	0 (0)

Table 2. Pre- and post- study survey results for patients enrolled in Nurse Care Management intervention, General Pediatrics Clinic (n=26)

Caregivers of twenty-four study participants completed an initial needs assessment survey. 25% of caregivers were somewhat satisfied to somewhat dissatisfied with the help received in managing their child's care or treatment. 83% of caregivers felt that increased contact with the clinic would be beneficial. The majority preferred to have a nurse call either before or in-between office visits to check-in. While in clinic for an appointment, the majority of caregivers wanted a nurse to help create a care plan, answer any questions, and review after-visit instructions.

Caregivers completed a study survey prior to NCM intervention and at least 6 months later assessing NCM, with changes statistically significant unless otherwise noted (Table 2). Several patients did not have 12 months of prior experience with our clinic, so some questions were not applicable. The percent of caregivers who felt that there was at least one nurse in the clinic who knew them or their child well increased by 71% within 6 months. Before NCM, 52% reported never receiving the help needed to manage their child's care from a nurse care manager. Within 6 months, the majority of caregivers reported receiving help from a nurse care manager once every 3-6 months or more frequently.

48% noted that nurses definitely knew important information about their child's care needs and care received from other providers, an increase from 4% initially. Before the study, 16% of caregivers felt that nurses did not support their decisions about their child's health and treatment, however none reported feeling that way in the post-survey. 20% of caregivers thought that nurses did not help in acquiring their child's special medical equipment, but within 6 months 71% reported receiving adequate assistance. Caregiver knowledge of how to contact a nurse when they needed help or had a question increased by 39% within 6 months. Caregivers were also asked to rate satisfaction with services provided by the clinic in relation to care management, although these changes were not significant.

A subset of charts (n=8) were reviewed to identify trends in clinic and hospital utilization. This data demonstrated an increase in clinic connection and utilization compared to baseline, with a notable increase in proactive outreach to patients. ED and hospitalization utilization was variable and no firm conclusions could be drawn (data not shown).

DISCUSSION

CMC are a vulnerable population, and delivering high quality care requires strengthening the link between caregivers and the clinic. Innovative and successful complex care coordination programs have been studied, including an enhanced medical home providing comprehensive care,¹⁵ a telemedicine model involving Advanced-Practice Nurses,¹⁶ and a program incorporating care plans available on mobile devices.¹⁷ However, literature reporting outcomes of NCM models among CMC is lacking, and some of the least frequently reported outcomes in published CMC research are family perceptions of support adequacy and unmet need.¹⁸

Our experience shows that a nurse-led care management program promotes components of the quadruple aim by improving patient experience, access, and staff satisfaction. Within the American healthcare system, RNs have been identified as integral members of care coordination teams, with their involvement leading to improved quality of care, reductions in ED visits, and reduced cost.¹⁹ We similarly found improved connection and satisfaction with the medical home after establishing a structured care management

intervention with RN care managers.

Caregivers of patients with medical complexity felt more connected to our clinic and were more satisfied with their care.

Additionally, our preliminary data from the first year of this study shows that patients had increased proactive outreach and interaction with our clinic as caregivers developed more longitudinal and fulfilling relationships with dedicated RNs.

LIMITATIONS AND FUTURE

DIRECTIONS: Although our study participants are representative of CMC based on an analysis of basic demographic information, generalizability of our findings is affected by our academic setting with a predominantly white, English-speaking patient population. Due to the nature of new program initiation, many of our patients were <1 year old, and patients were included based on referral which could contribute to a biased sample. Our intervention was built for our setting, and other institutions seeking to replicate this work may find different results. Multiple individuals were involved in conducting this intervention, contributing to variability. In spite of these limitations, we believe that the demonstration of the processes and outcomes of our program is valuable for

other settings seeking to establish similar initiatives.

More training and infrastructure development are required in order for NCM intervention to be successful long-term. Expanding the care team to include allied health professionals, such as social workers and health maintenance coordinators, would improve efficiency and impact. RN workflows are not always conducive to co-visits and proactive outreach, leading to default downgrading of NCM priorities. Although we collected basic information about nurse work satisfaction with this program, this preliminary data is neither validated nor comprehensive to form conclusions. Integrating complex-care specific work-flow improvements into EHR is therefore a necessary step to measure time utilization and promote standardization. Providing more defined roles within NCM, including guidelines on scope of services for all members of the care team can prevent confusion over responsibilities and expectations. Reaching vulnerable populations, young parents, and patients with specific conditions including autism and asthma should be considered during program expansion. Cost-benefit analysis of

the intervention over time is also required for continued leadership buy-in and assessment feasibility of continued NCM services. Next steps are to formalize the role of other interprofessional team members and build up capacity for increased enrollment.

CONCLUSION

In summary, our experience shows early evidence that a structured NCM intervention can improve caregiver connection with the medical home and satisfaction. Our results show early evidence that utilization metrics may improve under NCM; however, this requires further investigation. Impact on staff workflows and time utilization are future areas of investigation to learn more about balancing measures affecting implementation of care management programs.

ACKNOWLEDGEMENTS

We gratefully acknowledge the contributions of the staff and patients of the General Pediatrics Clinic and the support of Lorraine Koepsell, Nicole Ripsom, Lisa Johnson, Katherine Warden, Hayes Bakken, and Greg Blaschke.

DISCLOSURES/CONFLICTS OF INTEREST: We have no financial interests or potential conflicts of interest

FUNDING: None

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TO CITE: Jacob H, Lindert R, Erspamer K, Hasan R. Care management for children with medical complexity: Patient characteristics, process improvement, and impact on satisfaction. *J Child Fam Stud* 2021; EDITION 2.

Originally published online 1/29/2021. Copyright © 2021 by *J Child Fam Stud*

REFERENCES

1. Child and Adolescent Health Measurement Initiative. 2018 National Survey of Children's Health [cited 2020 April 17]. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available from [www.childhealthdata.org].
2. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Ú^áãæ&.* 2011;127(3):529–538.
3. Berry JG, Ash AS, Cohen E, et al. Contributions of children with multiple chronic conditions to pediatric hospitalizations in the United States: A retrospective cohort analysis. *P[•]Ú^áãæ.* 2017;7(7):365–372.
4. Kuo DZ, Melguizo-Castro M, Goudie A, et al. Variation in child health care utilization by medical complexity. *Matern Child Health J.* 2015;19:40-48.
5. Srivastava R, Stone BL, Murphy NA. Hospitalist care of the medically complex child. *Ú^áãæ&Ó]æ & Á-Á P[!cÓÚ^!ææ* 2005;52(4):1165-1187.
6. Thomson J, Shah SS, Simmons JM, et al. Financial and social hardships in families of children with medical complexity. *V@ÁÚ^áãæ&.* 2016;172:187-193.
7. Antonelli RC, McAllister JW, Popp J. Making care coordination a critical component of the pediatric health system: A multidisciplinary framework. *V@ÁÚ^áãæ&.* 2009.
8. Hong CS, Siegel AL, Ferris TG. Caring for high-need, high-cost patients: What makes for a successful care management program? *V@ÁÚ^áãæ&.* 2014.
9. Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress. *Ó@áÚ^áãæ&Á^æcÓ]æ áÁ^ç^[] { ^} c* 2017;43:323–333.
10. Caskey R, Moran K, Touchette D, et al. Effect of comprehensive care coordination on medicaid expenditures compared with usual care among children and youth with chronic disease: A randomized clinical trial. *ROEÚ^áãæ&.* 2019;2(10):e1912604.
11. Ruggiero K, Pratt P, Antonelli R. Improving outcomes through care coordination: Measuring care coordination of nurse practitioners. *ROEÚ^áãæ&.* 2019;31(8):476-481.
12. Vaz LE, Farnstrom CL, Felder KK, et al. Utilizing a modified care coordination measurement tool to capture value for a pediatric outpatient parenteral and prolonged oral antibiotic therapy program. *Ú^áãæ&Á^æcÁ ÓáÚ] &* 2018;7(2):136–142.
13. Bodenheimer T, Bauer L, Olayiwola JN, Syer S. RN role reimaged: How empowering registered nurses can improve primary care. *ÓáÚ] & Á^æcÁ^Ú] ^} áãæ.* 2015.
14. Bogetz JF, Bogetz AL, Rassbach CE, et al. Caring for children with medical complexity: Challenges and educational opportunities identified by pediatric residents. *ROEÚ^áãæ&.* 2015;15(6):621-625.
15. Mosquera RA, Avritscher EBC, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: A randomized clinical trial. *ROEÚ^áãæ&.* 2014;312(24):2640-8.
16. Looman WS, Antolick M, Cady RG, et al. Effects of telehealthcare coordination intervention on perceptions of healthcare by caregivers of children with medical complexity: A randomized control trial. *Ú^áãæ&Á^æcÁ ÓáÚ].* 2015;29(4):352-63.
17. Ming DY, Jackson GL, Sperling J, et al. Mobile complex care plans to enhance parental engagement for children with medical complexity. *Ó]æ & Ú^áãæ&.* 2019;58(1):34-41.
18. Looman WS, Park YS, Gallagher TT, Weinfurter EV. Outcomes research on children with medical complexity: A scoping review of gaps and opportunities. *Ó@áÚ^áãæ&Á^æcÓ]æ áÁ^ç^[] { ^} c* 2019;46(1):121-131.
19. Camicia M, Chamberlain B, Finnie RR, et al. The value of nursing care coordination: A white paper of the American Nurses Association. *P^!Á^ç^[] { ^} c.* 2013;61(6):490-501.

Tables and Figures:

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Yes (%)	4 (15)	18 (86)
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In the last 12 months, did that nurse/nurses know important information about your child's health and care needs?*, **		
	Pre (n=25)	Post (n=21)
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In the last 12 months, did that nurse/nurses help make sure you got your child's special medical equipment?*, **		
	Pre (n=25)	Post (n=21)
Definitely (%)	2 (8)	15 (71)
Somewhat (%)	0 (0)	0 (0)
No (%)	5 (20)	1 (5)
Did you know how to contact a nurse when you needed help or had a question?*, **		
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In the last 3 months, did a nurse from our clinic contact you without you getting in touch with them first?**, **		
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Yes (%)	4 (22)	10 (48)
No (%)	11 (61)	11 (52)
Overall, in the last 12 months, how often did you get the help you needed to manage your child's care from a nurse care manager?*, **		
	Pre (n=21)	Post (n=21)
Never (%)	11 (52)	3 (14)
Once in the past 6-12 months (%)	2 (10)	1 (5)
Once every 3-6 months (%)	3 (14)	9 (43)
More frequently than once every 3 months (%)	2 (10)	8 (38)
Has the clinic created a shared care plan for your child?*, **		
	Pre (n=23)	Post (n=21)
Yes (%)	0 (0)	7 (33)
No (%)	21 (91)	14 (67)

In the last 12 months, have the providers or anyone from the clinic talked to you about the progress your child was making toward the goals written in his or her shared care plan?***		
	Pre (n=18)	Post (n=21)
Yes (%)	1 (5)	3 (14)
No (%)	7 (39)	4 (19)
My child's shared care plan does not have written goals (%)	3 (17)	0 (0)
In the last 12 months, when you contacted this provider's office during regular office hours, how often did you get an answer to your medical question the same day?***		
	Pre (n=26)	Post (n=21)
Never (%)	2 (7)	0 (0)
Sometimes (%)	6 (23)	3 (14)
Usually (%)	3 (12)	5 (24)
Always (%)	8 (31)	13 (62)
In the last 12 months, how often did this clinic show respect for what you had to say?***		
	Pre (n=25)	Post (n=21)
Never (%)	1 (4)	0 (0)
Sometimes (%)	2 (8)	0 (0)
Usually (%)	2 (8)	2 (10)
Always (%)	19 (76)	10 (90)
In the last 12 months, how often did this clinic spend enough time with you and your child?***		
	Pre (n=25)	Post (n=21)
Never (%)	0 (0)	0 (0)
Sometimes (%)	0 (0)	1 (5)
Usually (%)	2 (8)	2 (10)
Always (%)	22 (88)	18 (85)
In the last 12 months, how often did the clinic seem informed and up-to-date about the care your child got from specialists?***		
	Pre (n=26)	Post (n=21)
Never (%)	2 (7)	0 (0)
Sometimes (%)	3 (12)	3 (14)
Usually (%)	3 (12)	5 (24)
Always (%)	14 (54)	13 (62)
In the last 12 months, did someone in this office talk with you about specific goals for your child's health?***		
	Pre (n=26)	Post (n=21)
Yes (%)	15 (58)	16 (76)
No (%)	10 (38)	5 (24)
In the last 12 months, did someone in this office ask you if there are things that make it hard for you to take care of your child's health?***		
	Pre (n=26)	Post (n=21)
Yes (%)	9 (34)	11 (52)
No (%)	16 (62)	10 (48)
Overall, how satisfied or dissatisfied were you with help you received in managing your child's care or treatment in the last 12 months?***		
	Pre (n=26)	Post (n=21)
Very satisfied (%)	16 (61)	17 (81)
Somewhat satisfied (%)	7 (27)	4 (19)
Somewhat dissatisfied (%)	0 (0)	0 (0)
Very dissatisfied (%)	1 (4)	0 (0)

, r > 0.27"

, , Tgur qpugu'f q'pqv'cf f 'wr 'q'eqnwo p'qvcrlcv'vko gu'f wg'v'wpcpuy gtgf 's wgunkqpu'qt'unkr 'mqi ke'qh' s wgunkqp

Appendix: Documentation and Standard Work for Nurse Care Management, using Epic SmartPhrases"

"

Tghgttcn\q'Ectg'O cpci go gpv'

??

Tghgttcn\hqt'Nqpi /vgtO 'TP 'ectg'o cpci go gpv'qh'c'o gf lecm{ 'eqo r ngz 'ej kf '*cpvlekr cvgf '@8'o qpvj u+'"

Tgcuqp'hqt'tghgttcn\O clp'eqpegtpu\ qy "{ qw'ugg'TP u'j gr lpi <*r ngcug'dg'cu'f gvckrgf 'cu'r quukng+'"

, , , "

Ur gekhle'i qcm"{ qw'j cxg'hqt'vj ku'r cvkpv<"

, , , "

"

Gptqmo gpv'

??

Ectg'O cpci go gpv'TghgttcnTgur qpug"

C'tghgttcn\y cu'r nregf 'v'j g'I gp'Rgf u'Ectg'O cpci go gpv'Vgco <*eqr { lr cvg'tghgttcn"

"

Vj g'Rgf kvtle'Eqo r ngz'Ectg'Eqmxdqtcvkg'j cu'f gvgtO kpgf 'vj g'hqmqy lpi 'f kur qukkqp<"

, , , Ceegr vgf 'lpvq'Nqpi /vgtO 'ectg'o cpci go gpv<"

Cuuki pgf 'TP 'ectg'o cpci gt<, , , "

, , , F gplgf 'f wg'v'pqv'o ggvlpi 'etkgtlc'hqt'ectg'o cpci go gpv<, , , "

Pgzv'tvgr u<, , , "

"

"

"

Ectg'Ræp"

??

Ncuw'rf cvgf "qp"B VFB "d{ "B OGB "

Wf cvgf <B VFB ""B PQY B "

""

K gpvHlec vqp<'

Pco g<B P CO GB "

FQD<B F QDB "

Ugz<B UGZB "

Rcvlppv)u'i qcnu+'qHlect g<, , "

Rcvlppv)u'eqo r ngvf 'i qcnu<, , "

J gcnj 'lgo 'i qcnu<, , "

Cevlpp'tæp<, , "

""

J qo gIDceni tqwpf <'

/'O qo lf cf li wctf kcp'pco g*u+<, , "

/'Ngi cni wctf kcp<, , "

/'J gcnj 'Ectg'Rqy gt'qh'CWqtpg{ '*O gf kcnlF gekukqp'O cngt+<, , "

Jrngcug'cum'vq'dt kpi 'kp'f qewo gpw vqp'vq'uecp'kpvq'qwt't geqtf _"

/'Go gti gpe{ 'eqpcev'pco gu'cpf '%u<, , "

/'Rtghgttgf'æpi wci g<, , "

/'Y j q'hxgu'cvj qo g<, , "

/'Y j q'ku'o quw'ikng'vq'eqo g'vq'crr vulnpqy 'y j cvku'i qkpi 'qp'*o qo 'qt'f cf.'i tcpf o c'ge+<, , "

""

UqeknlF gygt o kcpwulDctt lgtu'vq'Ectg<'

/F qgu'cp{ y j pi 'pggf "v'dg'cxqkf gf 'y j kg'lp"y j g'qhlegA', , , "

/"Qy j gt 'pggf u<', , , "

""

J qo g'Uwr r qt w<'

/"J qo g'pwtulpi *j qy 'o cp{ 'j qwtu'r gt'f c{ +<', , , "

/"Ur gekn'igs wr o gpv*pggf 'hjt "grgevkv{ ltgpgy cnf cvg'pggf gf . 'j qur "dggf . "grgevk"y j ggnej ckt+<', , , "

""

O gf lecrJ kwqt { <'

/Rcvlqpvhco kn { 'pcttcvkg'upcr uj qv< , , , "

""

Cngt i lgu<'

B CNNGTI [B "

""

Ur gekrkwuleqpwev' %i<'

P gwtqmi { "

P gwtquwi gt { "

Rwv qpqmi { "

GP V"

Ectf kqmi { "

Gpf qetkqmi { "

I cutqpvgtqmi { "

Rgf kvtkle"Uwi gt { "

Qr j yj cm qmi { "

Kphgevkwa'F kugcug"

P gwtqf gxnqr o gpvni'

Ur ggej 'vj gtr { "

Urgr 'F kuqtf gt'O gf kelpg"

F lgvklcp"

I gpgvku"

F gpvni'

""

Vj gtr kvuE qo o wplv 'Ugt xleguleqpvcev%u'

JGzco rrgu<f qo g'f gcnj . 'QV.'RV.'ur ggej 'vj gtr { . 'o gpvni'f gcnj 'ugt xlegu.'Gctrf 'Kpvt.xgpvkap.'EcEqqp.'UUK'FF "
ugt xlegu.'gve0", , , "

Uej qqrncpco g"cpf "eqpvcevIKR< , , , "

"

FOG'Rtqxlf gtu'

, , , "

""

Ego o wplecvkp<'

/"Unkmulr tghgtgpeg"xgtdcnlpqpxgtdcnlqj gt+< , , , "

/"F gxlegu'hqt"ego o wplecvkp< , , , "

/"Y j cv\q"fq'y j gp'cpzkwulvugungf lweqo hqtvdrg< , , , "

"

CFNu'

/"Ugrh'qt'y kj "cuukwpeg< , , , "

/"Gs wkr o gpv'pbgf gf "hqt'CF Nu< , , , "

/"Co dwevkap'ucwuw< , , , "

/"Rukvklpki "eqpukf gtcvkvpu< , , , "

/"Cevkxkf 't gutk v k pu< , , "

""

Cee gu<] N k n' r q t u . ' r k e u ' g v e _ "

""

T g u r k t c v t { ' t q v e q n < ' "

/"X g p v h t c e j < , , "

/"U g e t g v k p ' o c p c i g o g p v < , , "

"

P w t k k p ' t q v e q n < ' "

/"I ' w d g < , , "

/"V w d g ' h g g f u < , , "

/"P R Q ' l v c w u < , , "

/"F l g v c t { ' t g u t k v k p u < , , "

""

U e n i f c { ' t q v e q n < ' "

/"H g x g t < , , "

/"U g k t w t g < , , "

/"Q v j g t ' u { o r v q o u l k u u g u ' j c v ' p g g f ' u r g e k r i c w g p v k p * g n g x c v g f ' i n w e q u g . d n q f ' r t g u u w t g ' e j c p i g u . g v e + < , , "

"

""

R t g / x l k s / E c n i ' "

??"

R t q x k f g t < , , "

F c v g " c p f " k o g ' q h ' x k u k s < , , "

Y j q ' r t q x k f g f ' l p h q t o c v k p ' t q o ' e c m O Q O I F C F l q v j g t A ' "

P gy 'Rc\lgpvA'}[GUIP Q-572366; "

J cxg'r t gxlquw'tgeqtf u'dggp'tgs wguv g' A'}[GUP Q'P IC'XCTKCDNG-38932; "

*kpenmf g'RER'cf f tguu.'r j qpg.'hcz%'ku'y g'TQKeqo r r g'v g' A'

'''

30Y j cv'tg'"{ qw'vqr 'eqpegt puli qcnukqr leu'yj cv' {qw'y qwf 'hkn g'vq'cf f tguu'cv' {qw'tpgzv'xkukw' A', , , "

40Ctg'"{qw'eqpegtpgf' "{qw'o c{ 'pqv'dg'cdng'vq'i gv'vq' "{qw'cr r qkpvo gpvA' *gi "t'cpur qt'v'v'kp.'ej krf ectg+'
}[GUIP Q-32424; "

50J cu' {qw't'ej krf 'dggp'vq'yj g'GT'ukpeg' "{qw't'ruv'xkukw' A'Y j {A'} [GU'Y J GT'G'P Q-594382; "

60J cu' {qw't'ej krf 'dggp'lp'yj g'j qur kcn'ukpeg' "{qw't'ruv'xkukw' A'Y j gtg'ly j gp'ly j {A', , , "

70J cxg' "{qw'dggp'cdng'vq'c'wpgf' "{qw't'urdur gekerkuv'cr r qkpvo gpvu' A'"} [GUIP Q-572366; "

" J cxg'yj gtg'dggp'cp' { 'ej cpi gu'o cf g'vq' "{qw't'ej krf }u'ectg'r rcp' A', , , "

80J cu' {qw't'ej krf 'j cf 'cp' { 'dnqf 'y qtn'qt'ko ci lpi " *uwej "cu'ztc {u'qt'uecpu+'f qpg'qwukf g'qh'QJ UWA'
}[GUIP Q-572366; "

" Y j gp'ly j gtg' A', , , "

" k'fhqto cv'v'kp'lp'yj g'ej ctv' A', , , "

90Ctg'yj gtg'cp' { 'hqto u'qt'rgwgtu' {qw'p'ggf 'wu'vq' hkn'qwa' A'} [GUIP Q-32424; "

: 0J cxg'yj gtg'dggp'cp' { 'o gf lecv'v'kp'ej cpi gu'ukpeg' "{qw't'ruv'cr r qkpvo gpv'j gtg' A'"} [GUIP Q-32424; "

; 0Ecp'y g'i q'q'xgt'yj g'o gf lecv'v'kp'u' {qw't'ej krf 'ku'v'cn'lp' A' *O gf lecv'v'kp't'geqpekn'cv'v'kp+', , , "

320F q' "{qw'p'ggf 'cp' { 'o gf lecv'v'kp't'ghkmu' A', , , "

; 0Ctg'yj gtg'cp' { 't'guqwt'egu'yj cv'y qwf 'dg'j gr hwn'lp'ectkpi 'hqt' "{qw't'ej krf . 'qt' 't'guqwt'egu' "{qw't'g'j cxkpi 't'qwdng'
ceegu'kpi A', , , "

'''

UqekciF g'vgt'o kpcpw' "

30Ukpeg'yj g'ruv'v'ko g'y g'ucy' "{qw't'ej krf . 'j cu'cp' { yj lpi 't'gcm' { 'u'ect { 'qt' 'wr ug'v'kpi 'j cr r gpgf 'vq' "{qw't'ej krf "qt'cp' { qpg'lp'
yj g'hc'o kn' A', , , "

40Ukpeg'yj g'ruv'v'ko g'y g'ucy' "{qw'y j cv'j cxg' "{qw'o quv'gplq' { gf 'f'qkpi 'vqi g'v'j gt'cu'c'hc'o kn' A', , , "



Complex Care Journal

Care management for children with medical complexity: Patient characteristics, process improvement, and impact on satisfaction

Jacob H, Lindert R, Erspamer K, Hasan R

Complex Care Journal 2021; EDITION 2;

Originally published online Jan 29th 2021;

The online version of this article with any updates is located:

complexcarejournal.org/2021/01/29/care-management-for-children-with-medical-complexity/

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