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Children with chronic complex medical illnesses: Is inpatient care family-centered?

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Abstract

Background—Families of children with complex chronic medical illnesses (CCMI) benefit from coordinated, family-centered healthcare.

Objective—Compare parental perceptions of inpatient family-centered care for children with CCMI in structured clinical programs (SCPs) with those who are not in SCPs.

Design/Methods—Cross-sectional mail survey of parents of children with CCMIs using the 56-item Measure of Processes of Care (MPOC) to rate perceptions of family-centered healthcare. We compared responses of SCP to non-SCP children.

Results—215 (36.6%) of 588 surveys were returned. Response rates were 40.0% for SCP and 33.8% for non-SCP children. The proportion of favorable (6–7) ratings was higher for the SCP group than for the non-SCP group (52.4% vs. 48.3%, $p < 0.035$). The proportion of unfavorable ratings was also different (5.4% vs. 12.3%, $p = < 0.001$). SCP families felt care was directed at the whole child and consistent. Non-SCP families reported more unmet needs and less recognition of their role.

Conclusions—Parents of children with CCMI perceive inpatient care as more family-centered when provided in conjunction with a SCP. Children receiving non-SCP care may benefit from inclusion in SCPs dedicated to their needs. Further studies to determine the best way to provide this care are needed.

Keywords

Family-centered care; children with complex chronic medical illness; parents perceptions of care; MPOC

1. Introduction

The impact of chronic disease in childhood is enormous. Children with special health care needs accounted for 42% of total medical care costs for US children in 2000 [12]. In addition to the economic burden, chronic illnesses and disabilities in children have been shown to negatively impact the mental and physical health of their parents, who find themselves in unexpected caregiving roles [11]. Poor caregiver health and family-related issues have been associated with 30% of recurrent hospitalizations in children with chronic illnesses [5]. Family-centered and coordinated healthcare for children with disabilities reduces parental stress and can decrease inpatient expenditures [2,8]. Strong healthcare partnerships between the families

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of children with disabilities and their healthcare providers are associated with fewer unmet child and family needs, improved access to specialty care, and increased satisfaction with care [3]. However, the provision of family-centered and coordinated care requires medical expertise, familiarity with available resources, awareness of the needs and preferences of individual families, and collaborative relationships with numerous providers [15]. Care coordination is often complicated by the lack of a single point of entry into multiple systems of care, the availability of funding and services among public and private payers, and by economic, psychosocial and cultural barriers [1]. Providing coordinated and family-centered care for children with complex, chronic conditions during hospitalizations for acute illnesses is a major challenge that healthcare providers and systems currently face [10].

Family-centered care involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively, and providing parents with needed information. A well-described tool in the literature that measures family-centered care is a survey-based instrument known as the Measure of Processes of Care (MPOC) [7]. In this study, we use the MPOC to measure the perceptions of parents of the extent to which care provided for their children with chronic complex medical illnesses (CCMI) during hospitalizations is family-centered. In addition, we compare the experiences of families of children with CCMI cared for in structured clinical programs (SCP) with those who are not cared for in SCP (non-SCP). We hypothesize that families of children with CCMI that were in SCP would perceive care to be more family-centered than those in non-SCP. Understanding the perceptions of care processes from the perspective of care recipients is an important first step to developing targeted interventions to optimize family-centered care and improve outcomes for children with disabilities and chronic condition and their families.

2. Methods

2.1. Setting

This study was conducted at Primary Children's Medical Center (PCMC) which is owned and operated by Intermountain Healthcare, a large vertically-integrated, not-for-profit health care system in the Intermountain West. PCMC is a 232-bed children's hospital in Salt Lake City, UT, that serves children, particularly those with complex conditions, in the Intermountain West (UT, ID, MT, NV, WY) [13]. PCMC has SCPs for children with specific diagnoses such as spina bifida, diabetes, blood disorders, and cancers.

A Chronic Care Task Force was convened at PCMC in 2003 to coordinate and improve the care rendered to children with CCMI and their families. This interdisciplinary team included: a nurse practitioner for children with spina bifida; two pediatric hospitalists; a pediatric physical medicine and rehabilitation specialist; administrators from nursing, family support services, and quality improvement; a care coordinator, and two data analysts/project managers.

2.2. Participants

To identify met and unmet needs among children with CCMI and their families receiving care at PCMC, we planned a survey of this population according to specific criteria. Criteria were based on the intensity or complexity of inpatient care, chronic experience with the study hospital, and current use of the hospital. We used information available in an administrative database (the Enterprise Data Warehouse [EDW], Intermountain Healthcare). The EDW includes clinical, financial, and administrative data in an easily searchable format [14]. Findings from a thorough review of the literature for definitions of CCMI, a structured modified Delphi technique to refine criteria for children with CCMI, and queries of the EDW coupled with clinical review of patients identified culminated in the defined criteria for the population to be surveyed.

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Children with CCMI and their families were included in the survey sample if they were admitted to PCMC between 1/1/2002 and 6/1/2006 *and* met the following: 1) ≥ 3 hospitalizations during one calendar year of the study period (intensity/complexitycriteria); 2) ≥ 1 hospitalization since 1/1/2005 (current/chronic criteria). Children were assigned to a SCP or non-SCP group based on their participation in a SCP clinic program. Children in a SCP clinic were hypothesized to benefit from an enhanced degree of continuity and comprehensive care during hospital admissions, including ongoing care provision from familiar medical and ancillary services, even though the admitting attending for both groups might be an unfamiliar specialty attending, or a pediatric hospitalist; and they were frequently cared for on pediatric house staff teams. Exclusion criteria were children with CCMI who had died, and those for whom data needed to assign them to a SCP or non-SCP program was lacking. CCMI cared for in a SCP were identified by the diagnoses of *spina bifida*, *blood disorders and malignancies*, and *diabetes*. Those children assigned to the non-SCP group had non-categorical conditions including but not limited to: cerebral palsy, unclassified neurologic impairments, and genetic disorders. The final list of study participants was reviewed in its entirety by the data analyst who extracted the information and a physician investigator to confirm the extraction of an appropriate cohort of children with CCMI for this survey.

2.3. Study design

We conducted a cross-sectional mail survey using the MPOC instrument to measure the perceptions of parents of children with CCMI regarding the degree of family-centered, professionally provided care rendered during hospitalizations at PCMC. The MPOC is a 56-item, validated instrument to measure perceptions of family-centered care [7]. Although the MPOC is designed primarily for use in rehabilitation centers, it was the most applicable, standardized measure available for purposes of this study and has been used in other settings [9,16]. The five scales of the MPOC address: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care, and respectful and supportive care. The MPOC allows analysis of responses with descriptive approaches, such as percent responding favorably or unfavorably, and on a question by question level of detail depending on needs [6].

The MPOC was mailed in three separate mailings in order to optimize response rates. A cover letter instructing participants to respond in reference only to their inpatient experiences at PCMC was included. Participation was voluntary, as emphasized in the cover letter which represented a consent document. Survey return was taken as consent to participate. The Institutional Review Boards of the University of Utah and Intermountain Healthcare approved this study. The survey was conducted through Intermountain Healthcare Department of Strategic Planning and Research.

Comparisons between the SCP and non-SCP groups, including scaled score comparisons, were made using Student’s t-test for continuous variables and Pearson chi-square or 2-sided Fisher’s exact test (if conditions for chi-square were not met) for categorical data. We report descriptive statistics of scaled scores for the two groups (mean, SD) as outlined in the MPOC Manual in the ‘administration and scoring’ section [6], and t-test comparison between the groups (all statistics adjusted for response rate per question and meeting validity criteria for MPOC subscale scoring). We determined the percentage of strongly positive responses (scores of 6 or 7 on the 1–7 scale) and strongly negative responses (scores of 1 or 2), as well as scores of “sometimes or less” (1 through 4) and “more than sometimes” (5 through 7); and compared these between children cared for in SCPs to non-SCPs using the student’s t-test (two group comparison of means assuming equal variance). We considered responses representing “sometimes or less” perceptions to be indicators of areas amenable to improvement. Questions with more than 33% of respondents ranking 4 or less were individually evaluated to identify

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specific areas of potential improvement, and questions with highly positive responses were likewise evaluated to identify strengths (see MPOC manual [6]). Perceptions of family-centered care among the two groups were compared. Qualitative statements provided by respondents were summarized.

3. Results

The EDW query returned a total of 621 children who met inclusion criteria. The 621 children were then reviewed to verify intensity/complexity of care, chronicity, and that diagnoses observed reflected the anticipated mix based on expert opinion and current literature. Thirty-three (5.3%) were deceased, and therefore excluded from the study. Of the remaining 588, 245 (41.7%) were classified as receiving care through SCPs and 343 (58.3%) through non-SCPs. Children cared for in SCPs were in the following groups: spina bifida (n = 25, 10.2%), blood disorders and malignancies (n = 199, 81.2%), and diabetes (n = 21, 8.6%). Non-SCP diagnoses varied widely and included neurologic impairments, seizures, hydrocephalus, and congenital heart diseases.

The MPOC and cover letter were mailed to 588 families on 09/08/2006, with two follow up mailings to initial non-responders. Responses were received from 222 of the 588 families; 214 (36.4%) usable surveys were returned, 7 were incomplete, 1 was miscoded. Response rates within the SCP and non-SCP groups were 98/245 (40.0%) and 116/343 (33.8%). Table 1 compares demographic variables between the two groups. Children in SCP categories were slightly older than non-SCP children.

Parents of children cared for in SCPs reported a higher scale for the provision of general information and providing respectful and supportive care compared to parents of children in non-SCPs (mean score 4.82 vs. 4.30, $p = 0.021$; 5.66 vs. 5.31, $p = 0.040$). There were no differences in the other scaled scores between the two study groups (see Table 2). Table 3 compares overall responses to the 56 questions on the MPOC by percent responses in high (satisfied) and low (less satisfied) ranges. Mean responses were consistently more favorable from parents of children involved in SCP care.

Table 4 illustrates areas where efforts might be concentrated to improve family-centered care, represented by percent response of 1 to 4 (“sometimes or less”) on each of the 56 questions. Questions are grouped by scaled scoring category, and the percentage of families responding “sometimes or less” is listed. This table confirms the data presented in Table 3, and graphically supports the category comparisons in Table 2. It also illustrates that the provision of general knowledge is lacking in both groups.

The qualitative comments provided by respondents suggest that the parents of children with complex, chronic illnesses cared for in SCPs were more likely to perceive care as directed at the whole child and consistent among providers, whereas non-SCP parents reported more unmet information needs and less recognition of their caregiving roles.

4. Discussion

Parents of children with CCMI perceive their child’s inpatient care as more family-centered when rendered as part of a SCP. Like others, we found that parents of children with chronic conditions and frequent hospitalizations generally report significant unmet information needs [16]. Although it seems possible to develop general educational and informational materials describing specific diagnoses, meeting the needs of families for information regarding their individual children is challenging, particularly for children with non-categorical conditions and without SCPs. Even though the scaled score difference did not all reach statistical significance, it is evident that the non-SCP group feels a deficit in the areas of “coordinated

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and comprehensive care” and “respectful and supportive care” as suggested by their responses tabulated in Table 4. Free text comments suggest that parents of children with complex, chronic conditions cared for in SCPs are generally more satisfied with hospitalizations than were the non-SCP.

This study has limitations related to the survey design, including recall bias and parent self-report. The observed response rate was acceptable for the entire group, but slightly lower for the non-SCP group. The generally lower response rate may relate to the study population, as parents of children with CCMIs have increased caregiving responsibilities that may limit time available for survey completion. The large percentage of patients in the SCP group with blood disorders and malignancies may have introduced bias, as this service line offers outstanding family support at PCMC. Although the structure of SCPs might influence parental perceptions of family-centered care, our study is underpowered to detect such differences. In addition, our definition of children with CCMI focused on chronicity and intensity of care in an acute, inpatient setting, and our results may not generalize outside of these parameters. However, we believe that PCMC is similar to other medium and large sized children’s hospitals across the US.

The parental perceptions of in-hospital care for their children with CCMIs in this study are similar to the scores for family-centered care reported in the validating studies, and in subsequent studies utilizing the MPOC [7]. The areas of deficit, particularly the general information scale, are likewise similar to other institutions and seem to reflect a general area of weakness in the delivery of family-centered care to children with CCMI [4,16]. Our study reports novel information on the differences that emerge when children with complex, chronic conditions receive care through structured clinical programs (such as the multidisciplinary approach to spina bifida), or without structured programs or systems of care coordination. Using children with spina bifida as an example of a diagnostic cohort that typically receives SCP care, we found no published studies that objectively demonstrate that SCPs provide more family-centered care than do other models of care. Programs structured around children with CCMI need to objectively evaluate outcomes, including the impact of family-centered services. Moreover, structured clinical programs for all children with complex, chronic conditions (non-categorical approach), rather than targeted diagnostic groups, are needed.

In this study, the diagnoses of the children with CCMI in the non-SCP group may have influenced parental perceptions of the family-centeredness of in-patient care. Children with neurodevelopmental disabilities and genetic disorders don’t typically fall into clear diagnostic groupings, leaving providers and parents with uncertainty and unmet information needs. Their numerous appointments with a variety of specialists may lead to less coordinated and comprehensive care. In addition, it is difficult for the families of such children to remain engaged with healthcare providers who may offer conflicting recommendations regarding a single condition. The findings of this study suggest that SCPs do deliver more family-centered care. A more complete understanding of what the components of the SCP are, and how these may be best replicated for those children with CCMI who are not currently in a SCP, need further study. Advocacy efforts to ensure that all children with CCMI, regardless of specific diagnoses, receive care in the model of a specialized program for chronic, complex conditions are needed.

5. Conclusions

Parents of children with CCMI perceive inpatient care as more family-centered when rendered as part of a SCP. Specific differences were noted in the “providing general information” and “respectful and supportive care” scales favoring children with CCMI in SCPs. Although many children with neurodevelopmental disabilities, genetic disorders and other complex chronic

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conditions do not fit neatly into diagnosis-based clinical programs, they and their families may benefit from inclusion in targeted clinical care programs that are dedicated to meeting their individualized needs. Future studies to determine the best way to provide care for children with non-categorical complex chronic conditions are needed.

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Table 1

Demographics

Variable	**SCP (*n* = 245)**	**Non-SCP (*n* = 343)**	**p-value**
Age at survey – mean(SD), years	8.65 (5.64)	6.35 (5.72)	< 0.001 *
Sex male	54.69%	53.94%	0.86**
Number of admissions during study period – mean (SD)	7.06 (5.61)	7.51 (5.36)	0.34 *
Utah, metro Salt Lake area	71.84%	74.64%	0.57**
Utah, rural	13.88%	13.99%	0.57**
Residence outside Utah	14.29%	11.37%	0.57**
Survey completed	98/245 (40.0%)	116/343 (33.8%)	0.17 *

[*] Two-sided t-test, equal variances assumed.

[**] Pearson Chi-square or 2-sided Fisher’s exact test as appropriate.

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Table 2

Scale scoring comparison of means*

	Scale name	SCP mean (SD)	Non-SCP mean (SD)	p-value
1	Enabling & Partnership	5.48 (1.06)	5.24 (1.33)	0.158
2	Providing General Information	4.82 (1.45)	4.30 (1.72)	0.021
3	Providing Specific Information about the Child	5.14 (1.24)	4.89 (1.58)	0.265
4	Coordinated & Comprehensive Care	5.36 (1.13)	5.03 (1.41)	0.061
5	Respectful & Supportive Care	5.66 (1.08)	5.31 (1.37)	0.0395

*Two-sided T-test equal variance assumed.

For calculations, sample n for SCP/sample n for non-SCP: 1- $n = 97/n = 116$, 2- $n = 93/n = 109$, 3- $n = 93/n = 109$, 4- $n = 95/n = 116$, 5- $n = 97/n = 115$.

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Table 3
Comparison of mean response by percent response to high and low categories

Percent category	SCP mean (SD)	Non-SCP mean (SD)	p-value[*]
% answering 1 or 2	5.37% (5.05%)	12.31% (7.63%)	< 0.001
% answering 6 or 7	52.38% (9.96%)	48.31% (10.21%)	0.035
% answering “Sometimes or less” (1 through 4)	26.79% (9.26%)	34.75% (10.41%)	< 0.001
% answering “More than sometimes” (5 through 7)	73.21% (9.26%)	65.25% (10.41%)	< 0.001

[*] Two-sided t-test, equal variances assumed.

Summed responses to the 56 question MPOC questionnaire by SCP category (*n* = 56 questions in all categories.)

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Table 4

“Sometimes or less”; percent responses ≥ 33%[*]

Question #	Questions ordered by scale	% SCP responding “sometimes or less” N = 98	% non-SCP responding “sometimes or less” N = 116
	Scale 1: Enabling and Partnership		
2	fully explain treatment choices to you	24.00%	18.10%
3	offer you positive feedback or encouragement (e.g., in carrying out a home program)	21.30%	27.80%
8	tell you about options for treatment or services for your child	32.60%	**37.50%**
12	trust you as the “expert” on your child	22.40%	30.20%
15	anticipate your concerns by offering information even before you ask	**36.10%**	**45.20%**
16	make sure you have a chance during visits to the hospital to say what is important to you	23.50%	31.00%
17	let you choose when to receive information and the type of information you want	29.00%	**33.30%**
19	tell you about the reasons for treatment or equipment	20.00%	25.00%
22	provide opportunities for you to make decisions about treatment	19.10%	25.00%
23	answer your questions completely	11.20%	22.40%
25	recognize that your family has the final say when making decisions about your child’s treatment	17.70%	22.80%
28	consult with you when discussing equipment or services	18.90%	21.90%
30	tell you details about your child’s services, such as the reasons for them, the type of therapies and the length of time	22.10%	26.70%
35	make sure you have opportunities to explain what you think are important treatment goals	24.20%	**34.50%**
36	make you feel like a partner in your child’s care	22.70%	30.10%
43	listen to what you have to say about your child’s needs for equipment, services, etc.	18.90%	26.40%
	Scale 2: Providing General Information		
46	The hospital has information available to you in various forms, such as a booklet, kit, video, etc.	27.10%	**34.80%**
48	The hospital gives you information about the types of services it offers	**33.30%**	**38.40%**
49	The hospital promotes family-to-family gatherings for social, informational or shared experiences	**42.60%**	**49.00%**
50[**]	The hospital provides opportunities for special guests to speak to parents on topics of interest	**47.70%**	**58.50%**
51	The hospital provides support to help cope with the impact of childhood disability	**41.10%**	**54.90%**
53	The hospital has information available about your child’s disability	**33.30%**	**42.50%**
54	The hospital provides advice on how t o get information or to contact other parents (e.g. parents resource library)	**38.50%**	**61.30%**
55	The hospital provides opportunities for the entire family to obtain information	**45.60%**	**53.10%**
56	The hospital has general information available about different concerns (e.g., financial costs or assistance, genetic counseling, dating and sexuality)	**41.90%**	**56.60%**
	Scale 3: Providing Specific Information About the Child		
24[**]	explain what they are doing when you are watching your child in therapy	16.00%	20.80%

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Question #	Questions ordered by scale	% SCP responding "sometimes or less" N = 98	% non-SCP responding "sometimes or less" N = 116
26	tell you about the results from assessments	16.50%	28.70%
27**	provide you with written information about what your child is doing in therapy.	27.80%	**47.10%**
39	provide you with written information about your child's progress	**40.90%**	**49.10%**
52**	The hospital notifies you about the reasons for upcoming case conferences, meetings, etc.	**47.60%**	**47.80%**
	Scale 4: Coordinated and Comprehensive Care		
1**	suggest therapy plans that fit with your family's needs and lifestyle	31.30%	29.70%
4**	explain things to your child in a way that your child understands	18.50%	24.30%
5	take the time to establish rapport with you or your child when changes occur in your services	28.00%	32.10%
6	discuss with you everyone's expectations for your child, so that all agree on what is best	29.00%	**33.00%**
7	make sure that your child's skills are known to all persons working with your child, so the skills are carried across services and service providers	31.90%	**37.00%**
10	provide ideas to help you work with the healthcare system	32.60%	**43.40%**
11	recognize the demands of caring for a child with special needs	25.00%	**33.30%**
13	look at the needs of your "whole" child instead of just a physical needs	24.70%	**36.20%**
14	show sensitivity to your family's feelings about having a child with special needs	19.60%	**36.00%**
20	follow u p at the next appointment on any concerns you discussed at the previous one	25.00%	**34.80%**
21	make sure that at least one team member is someone who works with you and your family over a long period of time	25.50%	29.20%
32	develop both short-term and long-term goals for your child	29.20%	**33.60%**
34	plan together so they are all working in the same direction	27.70%	**34.50%**
37	make sure you are informed ahead of time about any changes in your child's care	**33.70%**	**33.30%**
40	seem aware of your child's changing needs as he/she grows	26.10%	30.90%
44	make themselves available to you as a resource	22.70%	**38.90%**
45	give you information about your child that is consistent from person to person	29.50%	**40.70%**
	Scale 5: Respectful and Supportive Care		
9	accept you and your family in a non-judgmental way	9.40%	19.30%
18	remember personal details about your child or family when speaking with you	20.40%	**33.60%**
29	provide a caring atmosphere rather than just give you information	19.40%	**33.00%**
31	treat you as an individual rather than as a "typical" parent of a child with a disability	22.90%	28.80%
33	treat you as an equal rather than just as the parent of a patient	**39.20%**	**44.70%**
38	help you feel competent as a parent	18.80%	30.70%
41	provide enough time to talk so you don't feel rushed	18.60%	**34.20%**
42	treat you and your family as people rather than as a "case"	18.80%	20.20%
47	The hospital has support staff that are polite and courteous to you and your family	9.30%	20.20%

Question #	Questions ordered by scale	% SCP responding “sometimes or less” N = 98	% non-SCP responding “sometimes or less” N = 116

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[*] The bold-type percentages indicate that the question received a rating of "sometimes or less” (numerical ratings from 1 through 4) 33% or more of the time [6].

[**] Non-response rates per question were generally low (< 5%); > 15% non-response for SCP group was noted in questions 1, 4, 24, 27, 52; for non-SCP questions 4, 24, 27, 50, 52. MPOC questions reproduced with permission.

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