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Parent-Reported Outcomes of Comprehensive Care for Children With Medical Complexity

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Abstract

The Medical Home Clinic for Special Needs Children (MHCL) at Arkansas Children's Hospital provides comprehensive care oversight for children with medical complexity (CMC). The objective of this study is to evaluate parent perceptions of health care delivery outcomes after 12 months of enrollment in the MHCL. This is a prospective cohort study of parents of MHCL patients, who completed surveys at initial and 12 months visits. Surveys assessed parent health, child health and function, family stress, and overall satisfaction, using previously validated measures and scales. Paired analyses examined differences in measures between baseline and 12 months. 120 of 174 eligible parents completed the follow-up survey at 12 months. Respondents were 63% white/Caucasian, 90% biological parent, and 48% with family income <\$20K. From baseline to 12 months, a greater number of respondents reported having a care plan (53% vs 85%, $p<.001$); fewer respondents needed help with care coordination (78% vs 31%, $p<.001$). No changes were seen in reports of having emotional needs met. Parents reported a decline in the physical subscale of the SF-12 Health-Related Quality of Life measure (49.1 vs 46.4, $p<.01$), with those parents with 1 additional child with special needs reporting a marked decline (49.2 vs 42.5, $p<.001$). No other changes in family impact were found. We conclude that comprehensive care oversight may improve care coordination for parents of CMC, but no association with improved parent health was found. Future studies should identify the factors that influence parental burden and tailor clinical interventions to address such factors.

Keywords

Children with Special Health Care Needs; Children with Medical Complexity; Medically Complex Children; Chronic Disease Management; Family Impact

Introduction

Children with medical complexity (CMC) are an important subset of children with special health care needs (CSHCN), increasingly recognized for their substantial impact on the

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health care system (Cohen, Kuo, et al., 2011). As the highest resource utilizers of all children (Neff, Sharp, Muldoon, Graham, & Myers, 2004), CMC are clinically recognized by at least one chronic condition that results in high family-identified service need, medical equipment to address functional difficulties, multiple subspecialist involvement, and elevated health service use (Berry, Agrawal, et al., 2011; Cohen et al., 2010; J. B. Gordon et al., 2007; Kelly, Golnik, & Cady, 2008; Tanios, Lyle, & Casey, 2009). Many CMC have neurodevelopmental delays, growth and nutritional/feeding problems, and technology dependence (Berry, Agrawal, et al., 2011). CMC account for increasing proportions of hospitalized children (Burns et al.; Simon et al.) and consume a disproportionate amount of health care resources compared to all children (Berry, Hall, et al., 2011; Neff et al., 2004).

The emotional, social, physical, and economic impact on families of CMC is substantial, due to the need for multiple subspecialty visits, medical equipment needs, and therapies to address neurodevelopmental concerns (Berry, Hall, et al., 2011; Srivastava, Stone, & Murphy, 2005). Families of CMC report high rates of employment loss, financial strain, and hours devoted to caregiving and care coordination (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). Families report the medical care system is fragmented and difficult to navigate (Ghose, 2003; Ray, 2002). Primary care providers report difficulties in being able to provide needed services (Kuo, Robbins, Burns, & Casey, 2011). Comprehensive care models for CMC, frequently based in tertiary care centers, can provide multidisciplinary services, care coordination, and specific medical expertise for CMC (Berman et al., 2005; Berry, Agrawal, et al., 2011; J. B. Gordon et al., 2007; Kelly et al., 2008; Klitzner, Rabbitt, & Chang, 2010). Although research is scant (Cohen, Jovcevska, Kuo, & Mahant, 2011), emerging evidence suggests substantial reductions in inpatient hospitalization rates, with concomitant reductions in overall health care costs (Casey et al., 2011; J. B. Gordon et al., 2007). However, little research has directly examined the effect of comprehensive care models on families. A full understanding of how tertiary care center-based comprehensive care addresses CMC family needs allows such programs to gauge the full impact of this innovative model of service delivery.

In 2006, Arkansas Children's Hospital (ACH) created the Medical Home Clinic for Special Needs Children (MHCL), offering multidisciplinary care oversight and tertiary care center-based care coordination for CMC (Tanios et al., 2009). By complementing existing care that is provided by primary and tertiary care services, the MHCL aims to help CMC and families experience comprehensive care consistent with the medical home concept as defined by the American Academy of Pediatrics (Casey et al., 2011; Pediatrics, 2002). Many MHCL patients have technology dependence, functional limitations, and severe neurodevelopmental disabilities that are static in nature. Prior analyses demonstrated a reduction in hospitalizations and overall health care costs after 12 months of enrollment in the MHCL (Casey et al., 2011). Despite the financial impact of the MHCL, the potential changes in parental perspectives on health care delivery and outcomes have not previously been described. The objective of this study was to evaluate parent-reported outcomes after 12 months of the child's enrollment in the MHCL, which would allow multiple points of contact to enable sufficient experience with the MHCL. This study examined parent health, child health and functioning, family stress, and overall satisfaction with clinical services. We hypothesized that parents would report decreased stress, improved health, and improved family functioning after 12 months of enrollment.

Methods

This is a pre-post cohort study of parent/family (henceforth referred to as parent) caregivers of children enrolled at a tertiary care center-based, comprehensive care, outpatient service for CMC.

Medical Home Clinic for Special Needs Children (MHCL)

The MHCL was started in August 2006 at ACH to address the needs of infants and children with multiple specialty care needs and frequent hospitalizations. This outpatient service provides team-based care and care coordination to ensure necessary medical, nutritional, and developmental care. Providers include pediatricians, nurses, nutritionist, speech therapist, social workers, and child psychologist. The team composition was influenced by the high prevalence of nutritional and feeding disorders. Eligibility criteria include a referral from primary care provider or specialist, 2 serious chronic conditions, and ongoing management by 2 pediatric subspecialists. Each patient is assigned a nurse coordinator who is available for telephone consultation during daytime hours, coordinates appointment, discusses acute care issues, and maintains an updated care plan. As children from throughout the state of Arkansas receive care at the MHCL, all children continue seeing their community-based primary care provider (PCP) for preventive care and immunizations, with varying levels of co-management with the MHCL. A previously published report (Berry, Agrawal, et al., 2011) and additional chart review found overall patient characteristics of 59% male, 73% preterm infants, a mean of 3.4 (sd 2.0) specialists seen, 64% with technology assistance such as gastrostomy tube or tracheostomy, and 2.6 (sd 2.4) hospitalizations in the past year. MHCL service eligibility criteria and patient characteristics are generally similar to comprehensive care services for CMC at other children's hospitals, specifically by number of chronic conditions, involvement with multiple specialists, the presence of complex chronic conditions, and technology assistance; MHCL children tend to be younger due to many direct referrals from the neonatal intensive care units (Berry, Agrawal, et al., 2011).

Study subjects and enrollment

Parents of MHCL patients were prospectively approached for potential study enrollment at the initial MHCL visit. Eligibility criteria included (1) the child being home from the neonatal intensive care unit (NICU) 6 months, to avoid potential NICU-related readmissions and to allow sufficient post-NICU experience with the MHCL; (2) not seen previously by a MHCL attending in other ACH clinics. Clinic staff identified eligible study participants through initial patient appointments. Upon family arrival in the clinic, a research associate explained the study and enabled parents to provide informed consent. The research associate then conducted an in-person interview in the clinic while the family was not seeing a provider. Parents were given the option of being sent home with the survey and a self-addressed stamped envelope. The 12-month follow-up survey contained scales and questions used in the initial survey, with additional questions examining MHCL care experience. Families with a twelve-month follow-up appointment were approached for the follow-up survey upon clinic arrival. If there was no timely scheduled appointment, the family received a letter in the mail reminding them of the study, accompanied by a written copy of the survey that parents were asked to complete and mail back in a self-addressed stamped envelope. Up to six follow-up phone calls were made by study staff if the survey was not returned within three weeks. Compensation at the time of both surveys included a stuffed animal for the child and a tote bag to the parent.

Because multiple outcome measures were assessed, a single generic sample size calculation was conducted. A sample size of at least 100 study subjects with completed pre and post data was calculated to be sensitive to a 0.40 standard deviation unit change (improvement or worsening) in outcomes at $\alpha=.05$, $\text{power}=.80$. Thus, study subjects were enrolled prospectively at initial visit until at least 100 study subjects completed the 12-month follow-up. At that time enrollment was closed, with 12-month follow-up surveys continuing. This study protocol was reviewed and approved by the Institutional Review Board at the University of Arkansas for Medical Sciences.

Study Variables

A framework for health care delivery in the MHCL [Figure 1] was developed from existing health care frameworks for chronic care and CSHCN (Antonelli, Stille, & Freeman, 2005; Bodenheimer, Wagner, & Grumbach, 2002; Perrin et al., 2007). Our framework specifies essential components of comprehensive and enhanced medical care, particularly care coordination, provision of information, and emotional support. The components were felt to lead to significant improvements in parent perceptions of child and family health and functioning. Successful family outcomes then result in higher family satisfaction with health care. Study outcome variables and the analytic framework were organized accordingly.

Health Care Delivery variables were defined by questions on experiences with care coordination, a written care plan, receipt of specific information related to the child's condition, and experiences with support on emotional needs. Study questions were adapted from prior surveys developed by New England SERVE that were specifically designed to measure health care experiences of families of CSHCN.

Parent Outcomes were measured by previously validated scales, each scored according to previously cited literature, including:

- Functional Status RII Measure (child functioning) (Kromer, Prihoda, Hidalgo, & Wood, 2000; Stein & Jessop, 1990): The 14-item short-version scale measures a child's capacity to perform age-appropriate roles and tasks in a variety of domains such as communication, mobility, mood, energy, sleeping, and eating.
- Family Support Scale (FSS) (Black et al., 2011; Burke & Alverson, 2010; Nolan, Orlando, & Liptak, 2007; Pediatrics, 2011): The six-item version examines parental satisfaction with support received from people, such as spouse, friends, and child care workers.
- Impact on Family Scale (J. Gordon, 2009; Huang, Kogan, Yu, & Strickland, 2005; Witt, Gottlieb, Hampton, & Litzelman, 2009): The 15-item scale used for ease of administration within the broader survey measures the effect of the child's chronic illness on the family. The parent rates each item on a 4-point Likert scale that ranges from (1) 'strongly agree' to (4) 'strongly disagree'. The Social subscale examines items related to travel and mobility; the Personal subscale examines items related to personal time and stress level.
- SF-12 (Health-Related Quality of Life) (Malouin & Merten, 2010; Peikes, Dale, Lundquist, Genevro, & Meyers, 2011): A 12-item scale that measures parents' health status. The physical subscale examines physical abilities and regular daily activities; the mental health subscale examines emotional feelings and sense of energy level. Higher scores represent better health status.

Satisfaction was measured by questions regarding the parent's satisfaction with doctors/nurses and primary care received. The 12-month follow-up survey also examined experiences and overall satisfaction with the MHCL.

Descriptive variables include parent gender, race/ethnicity, marital status, education, employment status, family income, and having another child with special needs.

Analytic plan

Descriptive data were provided for respondents at 12 months unless otherwise noted. Study outcomes were tested with a pre-post research design, examining changes in study scale ratings from enrollment to 12 months. In paired tests, each caregiver acts as his or her own control, thus no additional adjustment is needed for any confounding variables. Paired

analyses included t-tests for continuous variables and McNemar test for categorical data. Additional descriptive analyses were performed for variables that were obtained solely at the 12 month visit. Family outcomes analyses were stratified to examine specific subgroups of interest: hospitalized in the prior six months; number of specialists seen in the prior six months (dichotomized at the median); presence of another child with special health care needs in the household; and medical equipment need.

Results

Of 654 patients who came for an initial visit to the MHCL between October 2007 and April 2011, the parents of 276 were potentially eligible for study enrollment. There were three refusals, 21 who did not complete the baseline interview, and 46 parents who were missed due to research staff unavailability, leaving 206 (75%) completing baseline interviews. Study subject follow-up can be found in Figure 2. Six patients died before the 12-month follow-up and 26 were not yet 12 months at the time of this analysis, leaving 174 parents of children eligible for follow-up. Of that group, 38 children did not attend a 12 month follow-up visit and could not be reached at home after repeated attempts, 13 were discharged from the clinic due to being judged not to require ongoing services, 2 children were removed from parental custody, and 1 parent refused further study involvement, leaving 120 parents completing 12 month interviews (69.0% of parents eligible for follow-up).

Demographics of parent respondents at the 12-month visit can be found in Table 1. Almost all respondents (90%) were the biological parent. Most parents (84%) were female; 63% were white/Caucasian. About half of parents were married (53%) and high school graduates (51%). At 12 months, 36% were employed; this was higher than at baseline (31%), but the increase followed a non-significant trend by paired analysis ($p=.22$). Half of respondents reported income $<\$20,000/\text{year}$ and one-fourth reported having another child with special health care needs, with the range between 1 and 5 additional children. Parents reported that their children saw a median of 5 other specialists (interquartile range 3, 7) in the past six months. At follow-up, 41% of parents reported their child had been hospitalized at least once in the prior 6 months, a decrease from 60% at baseline ($p<.001$). Over two-thirds of parents (71%) reported their child depended on medical equipment for activities of daily living.

Health Care Delivery outcomes are found in Table 2. The proportion of parents who reported needing help with care coordination declined from 78% at baseline to 31% at 12 months ($p<.001$). The proportion of parents needing help specifically with school care coordination declined from 81% to 42% ($p<.001$). The proportion of parents who reported their child had a written care plan rose from 53% to 85% ($p<.001$). No changes were seen in parents reporting having received information regarding family support or information on current research. No changes were seen in families reporting that the medical team helped understand the child's emotional needs or show concern about the impact of the health condition on the family.

Parent Outcomes are found in Table 3. Non-significant trends were found between baseline and 12 month ratings of the Child Functioning (76.2 versus 76.6, $p=.76$), including all stratified analyses. Parents reported a marginally significant trend in the Impact on Family Social subscale (23.2 versus 26.0, $p=.06$). No difference was seen on the Personal subscale. In stratified analyses, the rise in the Social subscale was notable for marginally significant trends for children with medical equipment use (22.9 versus 26.3, $p=.09$), parents without any other children with special needs (23.6 versus 27.2, $p<.06$), and children who saw at least 4 specialists in the past year (22.8 versus 26.7, $p=.07$).

Scores on Parent Support Scale increased, but not significantly (3.6 versus 4.4, $p=.13$). Among subgroups with non-significant trends were children who were not hospitalized (3.5 versus 4.8, $p=.13$), no other children with special needs in household (3.7 versus 4.7, $p=.13$), and no equipment needs (3.6 versus 6.0, $p=.16$). Parents reported a significant decrease in the SF-12 physical subscale (49.1 versus 46.4, $p<.01$) but no changes in the mental subscale (45.4 versus 45.5, $p=.92$). The decrease on the physical subscale was particularly strong for parents with children who had medical equipment need (49.2 versus 46.1, $p<.01$) and even more so for parents who had another child with special needs (49.2 versus 42.5, $p<.001$).

Satisfaction measures can be found in Table 4. Parents reported overall high levels of satisfaction with choices of doctors and nurses, with an increase between baseline and 12 months that was marginally significant (90.0% versus 96.7%, $p=.06$). The increase in satisfaction with primary care was not significant (70.8% versus 76.7%, $p=.26$).

At the 12-month follow-up, 97% of parents rated the MHCL staff as usually/always available when they had concerns about the child's medical condition and 87% responded that MHCL staff usually/always showed concern about the impact of the child's health condition on the family. Most parents (87%) reported usually/always receiving specific information needed from MHCL staff, and 94% responded feeling like a partner in the care of the child. Relatively fewer parents (68%) responded that MHCL staff helped the family member understand the child's emotional needs.

Discussion

The presence of a complex and chronic health condition can have profound negative impact on the economic and social health of families (Kuo, Cohen, et al., 2011). We have previously reported significant reductions in overall health care costs for Medicaid-enrolled children in the MHCL, specifically by reducing inpatient utilization even with modest increases in outpatient utilization (Casey et al., 2011). Our current study found that after twelve months of enrollment in the MHCL, families reported high satisfaction with MHCL services and significant improvements in receipt of care coordination. We found less improvement in the domain of information receipt, although the proportions of families at 12 months reporting a written care plan (85%) and receiving specific information needed from MHCL staff (87%) were high. Given prior findings of reduced inpatient admissions and overall costs for enrolled children (Casey et al., 2011), we suggest that care coordination and information receipt are the likely pathways for potential cost savings for this group of vulnerable children. System of care navigation, which care coordination and information receipt directly address, has been described as the biggest concern for parents of children with special health care needs (Ray, 2002).

Despite enhanced care coordination, health care accessibility, and improved information receipt, only half of parents reported help with understanding the child's emotional needs, and no changes were found on meeting family emotional needs over 12 months. Our service has a social worker routinely address family needs at each visit; in more recent years, a pediatric psychologist has also been available for consultation during visits. However, we also found limited impact on parent-reported child and family functioning. Improvement on the Impact on Family Social subscale was seen only in the subgroups of parents who have children seeing multiple specialists, having equipment needs, and having no other child with special needs. The findings suggest modest respite is difficult to come by if there are other CSHCN in the household that may present competing demands.

Our findings may be in part due to immutable health factors of this extremely vulnerable population and the natural progression of disease in a population that has experienced

increasing rates of survival (Tennant, Pearce, Bythell, & Rankin, 2010). The decline in the caregiver physical scale of the SF-12 is striking, particularly within the subgroup of parents who have additional CSHCN. The decline in physical abilities may reflect ongoing, previously unreported physical stressors that result over time, a lack of respite (Macdonald & Callery, 2008), or the cumulative care burden, including persistent caregiving demands (Raina et al., 2005). “Chronic sorrow” that results from persistent care needs and ongoing reminders of the loss of the “perfect” child can result in a pathologic grief-like state if not properly recognized and addressed (J. Gordon, 2009).

We suggest that care coordination and enhanced information in the medical setting may be insufficient to address the pervasive emotional and physical needs of families of CMC. Medical care is only a portion of the system of care that families depend on in order to maximize the functioning of the child and family (Pediatrics, 2011; Perrin et al., 2007; Ray, 2002; Taylor, Lake, Nysenbaum, Petersen, & Meyers, June 2011), and fundamental misunderstandings exist among some providers on how to address family needs (Leiter, 2004; Liptak & Revell, 1989; MacKean, Thurston, & Scott, 2005). Principles of family-centered care, such as shared decision making, screening tools, and use of community resources (Kuo, Houtrow, et al., 2011) can lead to improved health and functioning of the child with special health care needs (Antonelli et al., 2005; Dunst, Trivette, & Hamby, 2007; Kuhlthau et al., 2010). A short psychosocial family member screening has been shown to increase referrals to community supports in the primary care setting (Garg et al., 2007). Further research should identify mutable factors outside of the clinical setting that can lessen the physical burden on families, meet family emotional needs, and further impact health care costs and utilization. The high satisfaction reported by parents in the MHCL suggests that even as families are pleased with their care experiences, they may also not be cognizant of what additional services may ameliorate their burden further. Such expectations should be explored in future studies.

There are a number of strengths of our study. We have previously demonstrated reduction in inpatient utilization and overall health care costs, and tertiary care center-based comprehensive services have attracted increasing attention for their potential for improving outcomes and achieving cost savings (Agrawal & Antonelli, 2011). We used previously validated scales to assess a range of family outcomes. The use of paired analyses through a pre-post analytic design enables examination of changes in outcomes on the family level, although paired analyses limits findings to the specific group of study subjects. The major limitation of our findings is that it is a study of one service model at a specific children’s hospital, without a control group or random assignment, and subject to study maturation, thus at best should be considered a preliminary study. Our findings could vary by patient population, clinical service, or hospital location. Our findings are parent reported without any external validation of results. The pre-post design of our study could be subject to a regression to the mean artifact, although we have not detected large improvements in health and functioning to suggest such a bias. Our study measures have not been subjected to validity testing when used within a long survey, nor has test-retest reliability been examined in the manner we utilized the study. We have no data on families that dropped out of our study prematurely. Due to exclusion criteria, our study results may not be representative of all patients in our clinic or children with medical complexity who would benefit from a comprehensive care service; specifically, we enrolled older children who remained enrolled in our service after 12 months. However, the study criteria likely identified children with the highest needs and costs whose families are most in need of intervention.

It is important to reiterate that the MHCL by itself does not provide a medical home; rather, our services complement existing services so that the child and family experiences comprehensive care that is consistent with a medical home. We emphasize that the key for

families of CMC is to receive overall care that is consistent with the medical home concept, and that the actual locus of care is not the determining factor of whether a child receives a medical home. In the case of the MHCL, children have to be referred to our service by a PCP or a specialist, and almost all PCPs provide consent for MHCL co-authority to provide referral, equipment and ancillary service authorizations, confirming a desire for co-management.

Conclusions

A comprehensive care model for CMC can improve care coordination and information receipt by families. However, we did not find improved parent outcomes, and our findings suggest that parent physical health may continue to worsen over time. Future studies should closely identify family stressors and the mutable factors that can improve parental outcomes.

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Abbreviations

CMC	Children with Medical Complexity
CSHCN	Children with Special Health Care Needs

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Figure 1.
Framework for health care delivery in the medical home clinic.

Figure 2.
Study enrollment.

Table 1

Demographics of Parent Respondents at 12 Month Visit (n=120).

	%
Female gender	84%
White/Caucasian	63%
Married	53%
Biological parent	90%
High school graduate	51%
Currently employed	36%
Income <\$20,000/year	48%
Has another child with special needs	25%

Table 2

Health Care Delivery Outcomes (n=120).

	Baseline (se), %	12 month (se), %	P value
Need help with care coordination	78.3% (4.6)	31.3% (5.2)	<.001
Child has a written care plan	52.9% (4.6)	84.9% (3.3)	<.001
Receive info about family support	45.7% (5.2)	55.3% (5.2)	.14
Receive info about current research	37.5% (4.8)	33.7% (4.7)	.52
Care team helps with understanding child's emotional needs	54.8% (5.2)	49.4% (5.2)	.46
Care team shows concern about impact of health on family	62.7% (4.5)	62.7% (4.5)	1

Table 3

Parent Outcomes (n=120).

	Baseline (se)	12 month (se)	P value
Functional Status RII (Child Functioning) Scale	76.2 (1.6)	76.6 (1.3)	.76
Impact on Family: Social	23.2 (.48)	26.0 (1.5)	.06
Impact on Family: Personal	14.6 (.34)	14.7 (.39)	.84
Parent Support Scale	3.6 (.09)	4.4 (.50)	.13
SF-12 Health-Related Quality of Life, physical subscale	49.1 (.93)	46.4 (1.1)	<.01
SF-12 Health-Related Quality of Life, mental subscale	45.4 (.97)	45.5 (.93)	.92

Table 4

Parent Reported Satisfaction (n=120).

	Baseline	12 month	P value
Satisfied with overall choice of doctors/nurses	90.0% (3.0)	96.7% (1.6)	.06
Satisfied with primary care received	70.8% (4.2)	76.7 (3.9)	.26