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Family Caregivers of Children With Medical Complexity: Health-Related Quality of Life and Experiences of Care Coordination

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Abstract

Objective: To examine the association between care coordination experiences of family caregivers of children with medical complexity (CMC) and caregivers' health-related quality of life (HR-QOL).

Methods: From July 2018 to July 2019, family caregivers of CMC completed an electronic survey (n = 136) at the time of initial contact with a regional complex care medical home. Information on caregiver HR-QOL and receipt of care coordination services were assessed using the Center for Disease Control's HR-QOL-14 measure and Family Experiences of Care Coordination questionnaire, respectively. Negative binomial regression, adjusted for caregiver and child characteristics, examined associations between caregiver HR-QOL and caregiver experiences of care coordination.

Results: In the 30 days prior to initial contact, CMC caregivers reported a median of 3.5 mentally unhealthy days, 2 days felt depressed, 7 days felt anxious, and 16 days with insufficient sleep. Caregivers who had a knowledgeable, supportive care coordinator who advocates for their child reported significantly fewer days mentally unhealthy (incidence rate ratio [IRR], 0.46; 95% confidence interval [CI], 0.22–0.95), depressed (IRR, 0.44; 95% CI, 0.21–0.91), or anxious (IRR, 0.5; 95% CI, 0.29–0.85). Having a shared care plan was associated with significantly fewer days mentally unhealthy (IRR, 0.46; 95% CI, 0.23–0.93) or anxious (IRR, 0.53; 95% CI, 0.31–0.92). Having a written visit summary with appropriate content was associated with fewer days of insufficient sleep (IRR, 0.63; 95% CI, 0.43–0.93).

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Supplementary Data

Supplementary data related to this article can be found online at <https://doi.org/10.1016/j.acap.2020.06.014>.

Conclusions: CMC family caregivers report experiencing mentally unhealthy days and negative mental symptom days. The experience of specific care coordination activities was associated with higher caregiver mental HR-QOL.

Keywords

care coordination; caregiver emotional well-being; caregiver health-related quality of life; children with medical complexity

CHILDREN WITH MEDICAL complexity (CMC) are characterized by chronic and severe health conditions, significant health service needs, major functional limitations, and high health care utilization.¹ They have the highest risk of all children for poor health outcomes with the highest rates of morbidity and mortality.^{2,3} In response, the patient-centered medical home and its focus on care coordination specifically has emerged as a central strategy for improving CMC outcomes, such as enhanced health care effectiveness and reduced health care utilization.^{4,5}

The majority of CMC live at home with their families.⁶ Their family caregivers are responsible for providing direct medical care and arranging their child's complex care plans, often with little home- or community-based supports.⁷⁻⁹ In combination with the uncertainty of their child's future and socioeconomic hardships, these stressors can negatively impact CMC caregivers' health and quality of life – undermining their ability to continue caring and advocating for their child.^{10,11} While care coordination focuses on improving child-level outcomes, care coordination may also improve CMC family caregiver well-being, either directly by relieving caregivers of specific tasks, or indirectly by improving their child's health.

Our understanding of CMC family caregivers' health and quality of life is limited and largely consists of qualitative reports.¹²⁻¹⁴ The benefit of receiving care coordination support on CMC caregivers' quality of life is unknown. Improved understanding is needed to properly guide CMC health care providers in attending to family caregivers' needs.¹⁵ To address these knowledge gaps, we examined the association between CMC family caregivers' self-reported health-related quality of life (HR-QOL) with their experiences with care coordination. We hypothesized higher-quality experiences of care coordination would be significantly associated with higher caregiver HR-QOL, with greater positive association with caregiver mental health relative to physical health.

Methods

Study Design and Setting

This is a cross-sectional analysis of survey data collected from family caregivers about their HR-QOL and experiences of care coordination prior to an initial visit at our pediatric institution's "complex care clinic" (C3). Data were collected at the time of initial caregiver contact with C3 as baseline data for a longitudinal study of family caregivers between July 2018 and July 2019. Patients eligible to establish care at C3 have a high level of medical complexity: experiencing 3 or more chronic health conditions (requiring medical subspecialty care) and/or medical technology dependence (eg, gastrostomy tube or

mechanical ventilation). Patients are ineligible to establish care at C3 if they are older than 26 years old or live in a long-term residential facility. While there are numerous pediatric practices recognized as patient-centered medical homes in western Pennsylvania, C3 (established in 2017) was the first in our region focused on serving CMC.¹⁶ The primary modes of referral to C3 are subspecialist, hospitalist inpatient, and parent self-referrals.

Participants and Recruitment

All family caregivers of CMC scheduled for their initial appointment at C3 were screened for eligibility to participate in this study if they were 18 years of age. Because we were interested in experiences of care coordination in outpatient settings, we excluded caregivers of patients <1 year of age.¹⁷ We excluded caregivers who lacked medical decision-making authority (eg, temporary foster parents) and those who were unable to participate in English.

Eligible CMC family caregivers were identified by the C3 medical director. Eligible caregivers were then contacted via telephone 1 to 2 weeks prior to their child's first scheduled C3 visit or while attending their child's first appointment at C3, if not already contacted. After obtaining informed consent via telephone or in-person, participating caregivers completed the survey electronically (survey link emailed prior to appointment or via electronic tablet at the initial appointment) using Research Electronic Data Capture.¹⁸ Participants were also offered the option of having the survey read to them in-person by a research assistant who then entered their responses into the electronic tablet for them. Only one family caregiver per patient was enrolled. Participants were compensated with a \$10 gift card for their time and efforts. This study was approved by the University of Pittsburgh Institutional Review Board.

Outcomes and Measures

To assess CMC family caregiver HR-QOL, we used the Center for Disease Control's HR-QOL-14.¹⁹ The "healthy days" module consists of items measuring overall, physical, and mental health. For example, the physical health item asks, "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" The "symptom days" module assesses number of days experiencing pain, depression, anxiety, sleeplessness, and fatigue. For example, the anxiety days item asks, "During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?" Descriptions for each item are described in Table 2.

To evaluate family caregivers' experiences of care coordination during the prior year, we used the *Family Experiences of Care Coordination* (FECC) survey developed by the Center of Excellence on Quality of Care Measures for Children with Complex Needs.

The FECC was developed with funding from the Agency for Healthcare Research and Quality and Centers for Medicare and Medicaid Services for CMC specifically and consists of 20 caregiver-reported quality measures assessing multiple aspects of care coordination.²⁰ Several of these measures have been endorsed by the National Quality Forum to evaluate core care coordination services. These measures have been validated and are significantly associated with provider ratings, access to care, and care coordination outcomes.²¹ Measures

are intended to be considered individually and were not designed to be combined to generate overarching composite scores. Item response options are either binary (yes/no) or ordinal (never/sometimes/usually/always) and inquire about experiences in the preceding 3 to 12 months. We used 12 of the 20 FECC measures, selected due to their focus specifically on outpatient care coordination experiences.

For unadjusted and adjusted analyses, we examined caregiver and child characteristics previously demonstrated to be associated with self-reported HR-QOL and care coordination experiences. Child characteristics included age, sex, medical technology assistance, and organ systems impacted by chronic conditions.³ Caregiver/family characteristics included caregiver age, sex, race, marital status, and educational attainment.²² As a proxy for socioeconomic status, we used caregivers' ZIP code median income instead of child's insurance status as over 95% of C3 patients are enrolled into Medicaid due to their medical complexity.

Data Analysis

We summarized baseline patient and caregiver characteristics, caregiver HR-QOL, and FECC quality measure scores using descriptive statistics. We assessed associations between patient and caregiver characteristics and caregiver general health status using chi-square tests. To examine associations between healthy days and symptom days with caregiver and patient characteristics and experiences of care coordination, we used Kruskal-Wallis and Wilcoxon Rank Sum tests. To identify specific FECC quality measures independently associated with caregiver HR-QOL, we conducted multivariable negative binomial regression with HR-QOL as the dependent variable and FECC quality measures as the independent variables adjusted for sociodemographic variables selected due to association with HR-QOL in unadjusted analyses at an alpha level of 0.1.²³ To investigate potential interactions between different care coordination activities, we used separate, multivariable negative binomial regressions for healthy days and symptom days with independent variables of 1) perception of care coordinator supportiveness, 2) receipt of written documentation (ie, shared care plan or written visit summary), 3) an interaction term for combinations of these care coordination quality measures, and 4) previously specified sociodemographic variables. We determined the significance of interactions between care coordination quality measures using adjusted Wald's and likelihood ratio tests. We estimated associated number of healthy days and symptom days using predictive margins. In sensitivity analyses, we included additional independent variables in negative binomial regression models, including caregiver sex, family household income, and medical technology dependence. We also conducted sensitivity analyses in which patients 18 years were excluded from multivariable regression models. Statistical analyses were performed using Stata 15.1 (StataCorp, College Station, Tex). Statistical significance was determined using alpha level of <0.05. We did not adjust for multiple comparisons as we did not formally test singular, preplanned hypotheses and aimed to identify hypothesis-generating, rather than hypothesis-confirming, associations.^{24,25}

Results

Of the 205 caregivers presenting with their child as a new C3 patient between July 2018 and July 2019, 185 were eligible for enrollment. Of those eligible, 136 enrolled and completed baseline survey instruments (73.5%). Of those completing the survey, 51 (37.4%) completed prior to the initial appointment via an emailed survey link and 82 (60.3%) completed the instrument in-person on an electronic tablet while awaiting their initial C3 appointment. Three participants requested survey items be read aloud in-person and recorded by the research assistant into the electronic tablet.

The majority of respondents identified as white (85.3%) were parents (91.2%), female (93.4%), and lived in households with another adult (70.6%; Table 1). Over three quarters reported that their child utilized medical technology assistance, and their children's medical conditions most commonly involved the neurologic/neuromuscular (91.9%), gastrointestinal (87.5%), and respiratory (66.2%) organ systems.

Overall, almost a quarter of caregivers in our sample rated their general health status as fair or poor (Table 2). The median number of physically and mentally unhealthy days in the preceding 30 days was 2 and 4, respectively. In the prior 30 days, caregivers reported a median of 2 days feeling depressed, 7 days feeling anxious, 16 days of not getting enough sleep, and 25 days of not feeling full of energy. Unadjusted relationships between patient and caregiver characteristics with HR-QOL are presented in Supplemental Tables 1 and 2.

The majority of caregivers (85 of 136 [62.5%]) indicated that someone “*helped manage their child's care or treatment from different doctors/providers*” in the prior 12 months, and thus *had a care coordinator* (Table 3).²⁰ Of these caregivers, most reported their care coordinator was a physician or nurse, with a minority of caregivers identifying a dedicated care coordinator (8 of 85 [9.4%]) or social worker/case manager (13 of 85 [15.3%]).

Among caregivers who reported having a care coordinator, less than half perceived this person to be “*knowledgeable, supportive, and an advocate for their child's needs*” (38 of 85, 44.7%). Similarly, a minority of care coordinators helped with arranging specialist referrals, helped with obtaining community services, or initiated unprompted contact with the family in the previous 3 months.

Most caregivers (110 of 136 [80.9%]) reported receiving a written visit summary from their child's main provider in the preceding 12 months, but only 42.7% reported summaries contained appropriate content. Few caregivers reported creating and receiving a shared care plan from their child's main provider (40 of 136 [29.4%]).

Relationship Between Caregiver HR-QOL and Families Experiences of Care Coordination

In unadjusted analysis, having a care coordinator who was “*knowledgeable, supportive, and advocated for child's needs*” was associated with fewer days spent feeling mentally unhealthy, depressed, anxious, or with insufficient sleep ($P < .01$). Receiving a shared care plan created by the child's main provider was associated with the same findings ($P < .01$).

Fewer associations were found between FECC and physical health or physical symptoms (Supplemental Table 3).

In multivariable negative binomial regression adjusted for caregiver age, race, marital status, educational attainment, and child age, the relationship between individual care coordination activities and caregiver mental HR-QOL persisted (Table 4). Specifically, caregivers who felt their “*care coordinator was knowledgeable, supportive, and advocated for their child’s needs*” experienced significantly fewer mentally unhealthy days (incidence rate ratio [IRR], 0.46; 95% confidence interval [CI], 0.22–0.95), depressed days (IRR, 0.44; 95% CI, 0.21–0.91), and anxious days (IRR, 0.5; 95% CI, 0.29–0.85). “*Receiving a shared care plan from their child’s main provider*” was associated with significantly fewer mentally unhealthy days (IRR, 0.46; 95% CI, 0.23–0.93) and anxious days (IRR, 0.53; 95% CI, 0.31–0.92). “*Receiving a written visit summary with adequate content*” was associated with significantly fewer days of insufficient sleep (IRR, 0.63; 95% CI, 0.43–0.93). In this adjusted analysis, there were no significant associations between specific care coordination activities and general health status, physical health, or physical symptom days. Sensitivity analyses in which we 1) adjusted for caregiver sex, family household income, and child medical technology assistance, and 2) excluded caregivers of patients 18 years of age did not significantly alter estimates for the association between care coordination activities and healthy days and symptom days.

Finally, we estimated the adjusted number of healthy days and symptom days associated with cumulative receipt of multiple specific care coordination activities, focusing on caregivers’ mentally unhealthy days, depressed days, anxious days, and insufficient sleep days. Having a knowledgeable and supportive care coordinator was associated with significantly fewer days feeling mentally unhealthy (−4.8; 95% CI, −8.9, −0.7), depressed (−3.8; 95% CI, −6.9, −0.7), and anxious (−6.4; 95% CI, −10.8, −1.9). Receiving a shared care plan from their child’s main provider was associated with significantly fewer days feeling mentally unhealthy (−4.9; 95% CI, −9.0, −0.8), depressed (−3.5; 95% CI, −6.9, −0.1), and anxious (−5.9; 95% CI, −10.7, −1.1). Receiving a written visit summary with adequate content was associated with significantly fewer days of insufficient sleep (−6.6; 95% CI, −12.0, −1.3). Receipt of multiple care coordination activities was associated with further reduction in mentally unhealthy and symptom days, larger than any care coordination activity alone (Figure). However, this cumulative impact appeared to be additive rather than multiplicative, as evidenced by the lack of a significant interaction between having a supportive care coordinator and receiving a shared care plan or having a supportive care coordinator and receiving a written visit summary with appropriate content (all $P > .40$).

Discussion

In this cross-sectional analysis of CMC family caregivers reporting on their experiences receiving medical care prior to establishing care at our institution’s complex care center, we found that caregivers’ mental HR-QOL was significantly associated with specific aspects of care coordination. We observed that caregivers who reported having a knowledgeable and supportive care coordinator who advocated for their child’s needs and caregivers who received thorough and up-to-date written care plans reported significantly fewer mentally

unhealthy, depressed, and anxious days than caregivers who had not experienced these care coordination activities.

CMC family members and clinician experts have identified characterizing caregiver health, well-being, and quality of life as a research priority, as studies on this topic are largely limited to qualitative reports.^{14,15,26,27} Our study addresses this knowledge gap by characterizing both physical and mental HR-QOL among family caregivers of CMC presenting for an initial visit to our institution's C3. Our sample's reported days of negative mental health symptoms was higher than population averages of similarly aged persons and comparable to the mental HR-QOL reported among persons living with chronic diseases.²⁸ Whereas US adults ages 25 to 54 report a mean of 2 to 3 days feeling mentally unhealthy, 4 to 5 days feeling anxious, 5 to 8 days with insufficient sleep, and 19 to 20 days full of energy; our sample reported a median of 4 days mentally unhealthy, 7 days anxious, 16 days without sufficient sleep, and 5 days full of energy. The number of days our sample reported feeling mentally unhealthy and anxious was more consistent with the ranges reported by adults with chronic medical conditions (eg, cancer, chronic breathing problems, prior stroke, and heart problems).²²

These findings should not be surprising as CMC family caregivers must manage a uniquely stressful set of responsibilities.¹⁰ CMC family caregivers are responsible for providing difficult, strenuous, and unpaid skilled and unskilled care with inadequate home- and community-based supports.²⁹ Concurrently, they must arrange the complex care plans of their children and keep numerous clinicians up-to-date within fragmented health care systems.¹⁰ Additionally, caregivers also report experiencing financial hardships due to direct financial costs and reduced work hours secondary to caregiving responsibilities.⁹

Family caregivers' anxiety, fatigue, and insufficient sleep warrant specific consideration given the potential impact on child health.^{12,31} Constant vigilance is necessary to not only monitor a child's day-to-day health, but also to double-check clinicians' medical decisions and ensure these decisions are made using accurate information.⁸ The uncertainty and unpredictability of their child's medical conditions often leave families with little control over day-to-day events and make it difficult to adequately prepare for the future.^{32,33} Furthermore, caregivers often report experiencing difficulty finding competent home nursing and respite care providers, even when payment is approved by insurers.³⁴ Consequently, CMC family caregivers report little time and energy for their other children, their spouses/partners, and themselves – often assigning their own health needs the lowest priority.¹⁰ Our results quantify the degree to which this 24/7 caregiving role can culminate in negative mental health consequences for caregivers.

Our findings regarding the positive association between care coordination support and CMC caregiver HR-QOL underscore the potential value certain care coordination activities have for CMC caregivers. We found that caregivers who felt their care coordinator was knowledgeable, supportive, and advocated for their child's needs described a higher mental HR-QOL, reporting significantly fewer mentally unhealthy, depressed, and anxious days. Prior work has found that this care coordinator quality measure is associated with families' satisfaction with their child's provider and overall care coordination.^{21,35} We note, however,

that less than one third of our sampled caregivers reported having a knowledgeable and supportive care coordinator. This should prompt providers to continue striving to work collaboratively with parents and to have personal knowledge of their children.^{30,36}

Mental HR-QOL was also higher among CMC caregivers who had received helpful documentation from their child's main provider, including shared care plans and written visit summaries (containing appropriate content) of outpatient appointments. These services have also been associated with positive provider ratings among CMC families.²¹ Both forms of documentation have the potential to alleviate a caregiver's worries about forgetting and/or not communicating important information to clinicians by providing a consolidated summary about their child's past health history, current conditions and needs, members of the child's medical team, and goals of active medications/therapies.⁸ Documentation that can be easily updated, shared, and viewed by clinicians through the electronic health record is likely to be even more helpful.¹⁰ The process of creating the documentation may also enhance relationships between families and providers, as it promotes jointly developing the treatment plan and goals of care in a structured and organized manner.³⁷ We note that most caregivers reported not receiving such a written visit summary or a shared care plan.

While further work is needed to confirm and better understand the directionality of the associations we observed, we believe our findings support increased attention on the quality of care coordination provided to CMC and their families. Specifically, focusing on strategies to improve caregivers' experiences of care coordinators' supportiveness and increasing provision of helpful documentation are particularly promising. However, our results demonstrate that many CMC caregivers experience significant gaps in receipt of care coordination activities. Although creation of "complex care" clinics at academic centers is one strategy, our findings highlight the need to address barriers hindering community practices in translating the medical home model into practice. Provider- and system-level factors like time-constraints, lack of ancillary support, infrequent exposure to high clinical complexity, and poor compensation for non-face-to-face services all make it challenging to implement care coordination activities.^{6,36} Better dissemination of clinician resources summarizing best-practices and providing real-world templates for how to integrate these services into routine CMC care may be ways to overcome some of these barriers.^{38,39}

Limitations

This study has several limitations. First, our survey was cross-sectional and involved a small number of participants. We note that this analysis is not able to determine directionality of association, and it is possible that caregivers with higher HR-QOL are better able to find adequate care coordination support and/or build relationships with their child's health provider. Second, we focused on caregiver HR-QOL because evidence suggests that attention to caregiver HR-QOL can have meaningful impact on child health outcomes in other pediatric populations.¹² However, further investigation of this relationship within the CMC population is needed.⁴⁰ Additionally, our HR-QOL measure reports on a person's past 30 days, whereas FECC measures typically ask about experiences over the preceding 12 months. Third, our findings may not be representative of all CMC receiving care in community settings as we recruited CMC caregivers transitioning their child's care to a

single complex care medical home. By focusing on caregivers transitioning care, this may have biased the sample to those with less positive experiences of care coordination and/or poorer HR-QOL. While this may underestimate care coordination activities received in community practices, the observed relationship between care coordination experiences and HR-QOL would remain valid. Fourth, sampling at the time of intake into a new clinical setting may impact self-reflection and self-report. Additionally, our participants all spoke English and largely identified as white females. While this is similar to C3's overall patient population (80% white; <5% speak a language other than English), studies in more diverse settings are warranted. Lastly, we have limited information on survey nonresponders. However, our survey response rate of 73.5% was higher than response rates observed in other pediatric surveys.^{41,42}

Conclusions

Among family caregivers of CMC, specific aspects of care coordination were associated with self-reported mental HR-QOL. Having a supportive care coordinator and receiving adequate documentation from their child's main provider was associated with fewer days feeling mentally unhealthy, anxious, depressed, and with insufficient sleep. Further examination of these associations through longitudinal studies and experimental designs are needed.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What's New

Family caregivers of children with medical complexity report experiencing days feeling mentally unhealthy, anxious, depressed, and lacking sufficient sleep. Having a supportive care coordinator and receiving adequate written documentation from their child's main provider was associated with higher caregiver mental health-related quality of life.

Number of days associated with specific care coordination activities estimated through negative binomial regression adjusted for caregiver age, race, marital status, educational attainment, and child age. As interaction terms for each set of care coordination activities were not significant, these models did not include an interaction term, but did estimate cumulative effect. In each of the four analyses, caregivers reporting both of the indicated care coordination activities were estimated to experience significantly fewer mentally unhealthy and symptom days than caregivers having neither ($p < 0.05$). Error bars indicate 95% confidence intervals.

Abbreviations: #, number; KSA-CC, care coordinator was knowledgeable, supportive, and advocates for child's needs; SCP, shared care plan; WVS, written visit summary with adequate content

Figure.

Estimated number of mentally unhealthy and symptom days in past 30 days.

Table 1.**Family Caregiver and Child Characteristics**

Caregiver Characteristics	N = 136 (%)
Female	127 (93.4)
Relationship to child	
Parent	124 (91.2)
Foster parent	2 (1.5)
Grandparent/relative	10 (7.3)
Age	
18–34	44 (32.4)
35–54	80 (58.8)
55	12 (8.8)
Race/ethnicity	
White, non-Hispanic	116 (85.3)
Black, non-Hispanic	11 (8.1)
Hispanic/Latino	1 (0.7)
Other	8 (5.5)
Marital status	
Married	80 (58.8)
Nonmarried, living with partner	15 (11.0)
Single	41 (30.1)
Education level	
Less than high school	10 (7.4)
High school or equivalent	26 (19.2)
Some college	48 (35.3)
College or more	52 (38.2)
Home ZIP code median income	
<100%FPL	3 (2.2)
100%–199%FPL	55 (40.4)
200%–399% FPL	70 (51.5)
400% FPL	8 (5.9)
Child Characteristics	N = 136 (%)
Age	
1–5	63 (46.3)
6–11	32 (23.5)
12–17	33 (24.3)
18	8 (5.9)
Male	78 (57.4)
Medical technology	106 (77.9)
Chronic conditions	
Neurologic/neuromuscular	125 (91.9)
Cardiovascular	42 (30.9)

Caregiver Characteristics	N = 136 (%)
Respiratory	90 (66.2)
Renal/genitourinary	53 (39.0)
Gastrointestinal	119 (87.5)
Malignancy	3 (2.2)
Neonatal/prematurity	22 (16.2)
Transplant	4 (2.9)
Hematologic/immunologic	33 (24.3)
Metabolic	55 (40.4)
Congenital/genetic	97 (71.3)

FPL indicates 2017 Federal Poverty Level (for 4-member household).

Table 2.

Family Caregiver Health-Related Quality of Life

Caregiver HR-QOL	
General health status	N = 136(%)
Excellent, very good, or good	106 (77.9)
Fair or poor	30 (22.1)
Healthy Days	Median (IQR)
Days physical health not good in past 30 days	2 (0–7)
Days mental health not good in past 30 days	3.5 (0–15)
Days poor physical or mental health prevented performing usual activities in past 30 days (unhealthy days)	0 (0–6)
Symptom Days	Median (IQR)
Days pain interfered with usual activities in past 30 days	0 (0–6.5)
Days felt sad, blue, or depressed in past 30 days	2 (0–7)
Days felt worried, tense, or anxious in past 30 days	7 (1–22.5)
Days not enough sleep in past 30 days	16 (4.5–30)
Days felt full of energy in past 30 days	5 (0–20)

HR-QOL indicates health-related quality of life; IQR, interquartile range.

Table 3.

Family Caregiver Experiences of Care Coordination

FECC Quality Measures	No. Eligible	Yes
Has a care coordinator	136	85 (63%)
Care coordinator within main provider's office	85	56 (66%)
Care coordinator outside of main provider's office	85	29 (34%)
Unprompted contact from care coordinator in last 3 months	85	42 (49%)
Care coordinator asked about caregiver concerns and child's health changes	42	33 (79%)
Care coordinator was knowledgeable, supportive, and advocated for child's needs	85	38 (45%)
Care coordinator assisted with specialist referrals	85	34 (40%)
Care coordinator helped to obtain community services	85	35 (41%)
Written visit summary provided in last 12 months	136	110 (81%)
Written visit summary had appropriate content	110	47 (43%)
Shared care plan created by main provider	136	40 (29%)

FECC indicates Family Experience of Care Coordination; No., number.

Table 4.

Associations Between Healthy Days and Symptom Days With Care Coordination Services

Care Coordination Quality Measure	(Incidence Rate Ratio [95% CI] ^a)							
	Mentally Unhealthy Days	Depressed Days	Anxiety Days	Insufficient Sleep Days	Physically Unhealthy Days	Unhealthy Days	Pain Days	Fatigued Days
Has a CC	1.00 (0.53–1.92)	1.04 (0.54–2.00)	0.89 (0.56–1.43)	0.91 (0.63–1.33)	1.43 (0.74–2.76)	1.03 (0.43–2.51)	1.28 (0.54–3.05)	1.25 (0.73–2.14)
Unprompted contact from a CC in last 3 months	1.01 (0.49–2.06)	1.32 (0.62–2.81)	0.95 (0.56–1.62)	0.86 (0.57–1.31)	0.66 (0.33–1.32)	0.80 (0.34–1.9)	1.01 (0.39–2.57)	0.98 (0.54–1.77)
CC was knowledgeable, supportive, and advocated for child's needs	0.46 (0.22–0.95)	0.44 (0.21–0.91)	0.50 (0.29–0.85)	0.68 (0.45–1.03)	0.68 (0.33–1.37)	0.55 (0.23–1.31)	0.95 (0.35–2.55)	0.97 (0.55–1.73)
CC assisted with obtaining specialist referrals and/or community services	1.01 (0.48–2.13)	1.14 (0.52–2.50)	1.03 (0.60–1.78)	0.88 (0.58–1.33)	1.17 (0.56–2.44)	1.06 (0.41–2.73)	1.18 (0.43–3.22)	0.76 (0.42–1.37)
Has a shared care plan	0.46 (0.23–0.93)	0.49 (0.23–1.05)	0.53 (0.31–0.92)	0.74 (0.48–1.14)	0.83 (0.36–1.88)	0.6 (0.25–1.44)	0.99 (0.32–3.06)	1.28 (0.68–2.39)
WVS provided in last 12 months	1.15 (0.53–2.48)	1.00 (0.46–2.18)	1.09 (0.63–1.92)	0.8 (0.51–1.26)	0.81 (0.37–1.76)	0.96 (0.37–2.48)	0.87 (0.31–2.42)	1.14 (0.56–2.32)
WVS has appropriate content	0.59 (0.31–1.14)	0.65 (0.33–1.27)	0.64 (0.39–1.04)	0.63 (0.43–0.93)	0.59 (0.29–1.18)	0.84 (0.38–1.89)	0.5 (0.21–1.2)	1.34 (0.77–2.34)

CI indicates confidence interval; CC, care coordinator; and WVS, written visit summary.

Bold values are those that are statistically significant.

* Negative binomial regression models adjusted for caregiver age, caregiver race, caregiver marital status, caregiver educational attainment, and child age.