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Impact of Embedding a Care Manager from A Publicly Funded Health Care Organization into a Sickle Cell Team

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Abstract

Objectives: The quality improvement pilot project was designed to preliminarily investigate if a partnership between a publicly funded health care organization and the Sickle Cell Team (SCT) would benefit children with sickle cell disease. A care manager (CM) was embedded into the sickle cell team with the goal of improving outpatient clinic adherence and reducing urgent care visits as an attempt to improve care.

Methods: A one-year partnership between the SCT and a designated CM was created so that the CM could become a member of the SCT and assist caregivers of children with sickle cell disease with psychosocial and economic needs including behavioral health, housing, transportation, and food resources with the goal of increasing clinic adherence and reducing urgent care utilization.

Results: At a cost of approximately $1000 per caregiver, there was no improvement in outpatient clinic adherence or reduction in urgent care utilization. However, whereas no caregivers sought behavioral health preceding the CM integration into the SCT, 38% did so with CM support.

Conclusion: Embedding a CM into the SCT, by collaborating with a publicly funded health care organization, increased costs of care and facilitated access to behavioral health care which could, if sustained, potentially translate to improved outcomes and a reduction in cost of medical care. However, in the short term, adherence to clinic appointments and urgent care utilization was unaffected.

Introduction

Sickle Cell Disease (SCD) is a chronic illness that affects roughly 100,000 largely socio-economically challenged, predominantly African Americans, in the United States with an annual estimated cost of medical care that "exceeds 1.1 billion dollars." [1]. Roughly 83% of the costs are associated with urgent care; hospitalizations 80% and 3.2% for Emergency Department (ED) visits.

There is an interest in increasing outpatient clinic visit adherence as a potential means of reducing the need for urgent care and improving outcome. Care management has been reported to decrease illness complications by offering patients with complex chronic illnesses a set of activities intended to "improve patient care and reduce the need for medical services" thereby improving quality and reducing cost of care [2,3]. Care management is defined as, "a set of activities designed to assist patients with the aim of increasing their support systems in managing medical conditions and related psychosocial problems more effectively" [4]. Care managers function as trained liaisons between patients and the medical community by providing resources for both medical and non-medical, health-contributing services including access to health insurance, Primary Care Providers (PCP), specialists including those who provide behavioral support and assistance with food, finances, transportation, and housing, all perceived to aid the patients in improving their health.

There is scant literature addressing care management in marginalized communities affected by structural violence and health inequity such as those with SCD. However, it is established that both poverty and structural violence have a profound negative effect on the well-being of children with SCD [5]. Theoretically, with care management strategies, access to resources could be improved to overcome the limitations experienced by those affected by SCD.

We proposed that forming a SCD disease management partnership with a non-profit, publicly managed, health care organization to embed a Care Manager (CM) into the sickle cell health care team (SCT) may benefit the population affected by SCD. Utilizing a health equity framework to underscore "the relationship between equity and empowerment in generating positive health outcomes. ", we did so [6,7,8]. We were interested in whether clinic adherence could be improved and urgent care utilization reduced. Here we report the outcome of the pilot project embedding a CM into a SCT.

Methods

An author (RN) approached the Colorado-based non-profit managed care organization with the concept of partnering with the SCT. A designated CM was identified for a cohort of children with SCD and embedded into the SCT for one year as a pilot project the calendar year 2015. The health care organization designated a female Ethiopian immigrant as the CM in hopes that she would be well received.

The children received care at the only pediatric sickle cell center in the Rocky mountain region encompassing Colorado, Montana, Wyoming, and western Nebraska and Kansas. The center is located at the Children's Hospital Colorado (CHC) in Aurora, Colorado. Approximately two-hundred children with SCD are cared for by the SCT located at CHC. The SCT consists of a part time hematologist and nurse and a full time coordinator. Scheduled visits with the SCT vary from monthly to every 6 months depending upon the children's clinical needs. Care is delivered and referrals directed as per the national, evidence-based, management of sickle cell disease recommendations [9]. Children are seen in the clinic for both routine and urgent care during business hours. After hours' urgent care is rendered in the ED and all hospitalizations occur at CHC. Children with SCD generally receive all subspecialty care at CHC as well. Primary care is either at CHC or an outlying office with accessible electronic medical records.

A targeted sampling strategy was utilized to identify twenty children with coverage through the health organization who had attended at least one comprehensive sickle cell clinic in 2014. The intention was to compare health care utilization in 2014 to that in 2015 with the CM support. Twenty caregivers were approached, informed of the pilot project in detail, and all gave oral consent to participate. Approval for data collection for 2014 and 2015 was obtained from the Children's Hospital Colorado Operational Research Risk and Investigational Quality Review Panel.

Demographic data was captured from electronic medical chart review and information shared that established the caregiver's social determinants of health such as age, gender, education, income, housing and access to food and transportation. Medical chart data was analyzed for years 2014 and 2015 including: (1) appointment adherence (visits for sickle cell including comprehensive care, hydroxyurea follow up, hospital follow-up, labs, and transfusions), PCP, cardiology and pulmonary visits and (2) behavioral health visits (stress is commonly reported in families affected by SCD and affects coping with pain. Depression may be increased in the population as well). [10-14]. Visits for urgent care to the ED and the sickle cell clinic as well as hospitalizations were also reviewed. The data were reviewed for discrepancy through stages of data aggregation. Statistical analyses were undertaken in Microsoft access and excel (2016) software to analyze trends in demographics and utilization data.

Results

Demographics and Social Determinants

Twenty caregiver /child dyads (approximately 10% of the SCD population) agreed to participate in the pilot project. Subsequently, two were excluded as one had a child who had a bone marrow transplant and the other caregiver's child was diagnosed with an additional significant chronic disease. Thus, 18 caregivers of 18 children; 10 girls and 8 boys, aged 2-18 years old, comprised the cohort. Fourteen children had homozygous sickle cell, 10 were being treated with hydroxyurea and four were receiving chronic red cell transfusions, three children had hemoglobin SC and one sickle beta +thalassemia.

Fifteen children had at least one sibling who lived with them. Eighty percent of the children lived primarily with their mother, 15% alternated living with mother and father but spent more time with mother and one (5%) lived with a great grandmother. For 55% of the children, both parents had some involvement in their life. During the two years of the project, all children and primary caregivers lived within 20 miles of CHC.

Socio-demographic characteristics of the caregivers are shown in Table 1. All primary caregivers were female; 15 African American, two recent immigrants from Africa and one Haitian immigrant. All participants were English speaking. Over half of the caregivers experienced chronic unemployment. Whereas the children always had a place of residence, half of the caregivers experienced homelessness sometime during the two years studied. A little under half of the caregivers reported experiencing domestic violence. Although, 90% of the caregivers had a cell phone

and two-thirds reported internet access, the phones were prone to intermittent disconnection. Half of the caregivers reported smoking cigarettes and 25% marijuana (legal in Colorado).

Gender	Number (%)
Female	**18 (100)**
Age (years)	
20-29	6 (33)
30-39	2 (11)
40-49	8 (44)
50-59	1 (6)
>70	1 (6)
Child resides with:	
Single Mother	14 (80)
Intermittently with father	3 (15)
Great Grandmother	1 (6)
Nationality	
Immigrant	3 (17)
US	5 (83)
Chronic Unemployment	9 (55)
Chronic Homelessness	9 (55)
Domestic Violence	9 (55)
Education:	
Some high school	4 (22)
Completed high school	4 (22)
Post high school education	10 (55)
Financial Support	
Employed	6 (33)
Child's SSI	6 (33)
Both of above	6 (33)
Housing	
No government assistance	6 (33)
Section 8/low income	7 (39)
Transitional	1 (6)
Would not disclose	4 (22)
Food assistance	14 (78)
Own vehicle	12 (67)

Table 1: Socio-demographic characteristics of the caregivers.

CM Interactions

The CM spent an average of 12 hours a week working with the caregivers at an estimated cost of $18,000 for the year. The CM made a total of 567 attempts to reach caregivers; range 16-46/caregiver. Twelve of 18 caregivers (66%) were more receptive to the CM and had 53% more contacts than the less receptive. The CM attended 42 appointments for sickle, primary care, cardiology or behavioral health with the caregivers. She sent out 31 letters and 16 email appointment reminders. She made 477 phone calls, visited in person with 7 caregivers during a child's hospitalization and once in the ED. The CM provided resources for housing/shelters, food, diapers, clothing, payment for utilities, transportation, an automobile and plumbing repairs. The CM attended two social events (birthday and holiday party). She attended 13 interdisciplinary care planning conferences with the SCT. The SCT coordinator and CM discussed child care/caregiver needs about 3-5 times per week with an average two hours spent.

Clinic Appointment Adherence, Urgent Health Care, Primary Care and Behavioral Health Utilization

Data shown on Table 2 shows completed versus scheduled appointments. There was an average of 14 scheduled appointments/child with approximately 64% completed. In 2014 no behavioral health visits were reported whereas seven of 18 child/caregiver dyads (38%) accessed behavioral health services at least once in 2015.

	2014 Completed/Scheduled/%		2015 Completed/Scheduled/%		p-value
Sickle Clinic	102/154	66	105/169	62	0.67
Transcranial Doppler	9/11	82	8/14	57	0.72
Cardiology	8/10	80	11/16	68	0.27
Pulmonary	7/21	33	13/29	45	0.25
Primary Care Provider	31/43	72	26/49	53	0.51
Total	157/239	66	163/263	62	0.56

Table 2: Completed Versus Scheduled Appointments.

There were 38 urgent visits to the sickle cell clinic or ED in 2014 and 33 in 2015. All of the clinic visits were sickle-cell related whereas 70% and 81% of ED visits were sickle cell-related in 2014 and 2015, respectively.

There were 22 hospitalizations in 2014; 70% were unscheduled and sickle cell related. In 2015 there were 18 hospitalizations; 95% were unscheduled and sickle cell related. There was no statistically significant difference in the number of urgent visits or hospitalizations between 2014 and 2015. There were no statistical differences in urgent visits or hospitalizations relative to receptivity to the CM or not.

Discussion

Care coordination has been cited as a barrier to accessing outpatient care by the population affected by SCD. Rattler, et al. found informal care coordination done by the hematology team for 101 children with SCD, had no impact on reducing acute care utilization [15]. We are the first to describe the outcome of CM for the population affected by SCD. We postulated disease management partnership with CM support could translate to improved outpatient care utilization and a reduction in need for urgent care.

However, we found, despite the CM facilitating care by making appointments, calling with reminders, assisting with transportation, offering community resources and providing social support, outpatient care utilization and adherence was unchanged. Cronin, et al. recently reported the results of a survey of 331 SCD caregivers who stated the primary barrier to clinic adherence as forgetting the appointment; we found having a CM call, text, etc. to remind the caregivers of appointments did not improve appointment adherence [16].

We also found urgent care utilization and hospitalizations were unchanged with the availability of the CM. Simon, et. al. recently reported that access to a hospital-based comprehensive case management service for 331 children with medical complexity (disease not stated) also did not reduce hospital utilization but did increase overall health care costs [17]. Our findings are like those of Simon, et. al. We added an additional cost of care at approximately $1000/child and did not alter need for urgent care but that may be because outpatient clinic adherence was not improved.

A surprising finding of our partnership with the health care organization, is that with CM support, whereas no caregivers had previously accessed behavioral health services, 38% were willing to do so. This is of significance given stress and depressive symptoms are common in those affected by SCD and increase the risk for poor outcome [10]. Support has been shown to increase caregiver's ability to access care for their child and their ability to support their children which reduces depressive symptoms [11-13]. Catastrophizing by parents and affected children leads to disability and cognitive behavioral therapy may be helpful [12].

Limitations to our findings include the limited size of the participatory population due to the exploratory nature of the collaboration (although about 10% of our population did participate). Also, only caregivers of children who were known to the SCT due to at least one contact for comprehensive sickle cell care participated. We do not know if behavioral health service utilization was sustained.

In conclusion, the pilot project suggests that caregivers of children with SCD, generally single women with greater than one child, who have financial, housing and food insecurity, were more likely to access behavioral health services with the assistance of a CM. However, in the short term, embedding a CM into the SCT increased cost of care and did not augment outpatient clinic adherence or reduce urgent care utilization. Theoretically, sustained receipt of behavioral health services could benefit those affected by SCD and perhaps reduce urgent care utilization in the long run. Alternatively, it has been suggested that community health workers, who are not employees of a health care insurer, may be more immediately effective in improving care for those affected by SCD.

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References

1. Kauf TL, Coates TD, Huazhi L, Mody-Patel N, Hartzema AG (2009) The cost of health care for children and adults with sickle cell disease. Am J Hematol 84: 323-327.
2. Berry-Millett R, Bodenheimer TS (2009) Care management of patients with complex health care needs. Synth Proj Res Synth Rep.
3. Bodenheimer T, Wagner EH, Grumbach K (2002) Improving primary care for patients with chronic illness: The chronic care model, part 2. JAMA 288: 1909-1914.
4. Care Management of Patients with Complex Health Care Needs. RWJF.
5. Farmer, Nizeye B, Stulac S, Keshavjee S (2006) Structural violence and clinical medicine. PLoS Med 3: 1686-1691.
6. WHO | Measurement and evidence. WHO.
7. What is Health Equity?
8. Rifkin SB (2003) A Framework Linking Community Empowerment and Health Equity: It Is a Matter of CHOICE. J Health Popul Nutr 21: 168-180.
9. Yawn BP, Buchanan GR, Afenyi-Annan AN, Ballas SK, Hassell KL, et al. (2014) Management of sickle cell disease summary of the 2014 evidence-based report by expert panel members. JAMA 312: 1033-1048.
10. Jonassaint CR, Jones VL, Leong S, et al. (2016) A systematic review of the association between depression and health care utilization in children and adults with sickle cell disease. Br J Haematol; 174:136-47
11. Raphael JL, Butler AM, Rattler TL, Kowalkowski MA, Mueller BU, et al. (2013) Parental Information, Motivation, and Adherence Behaviors Among Children with Sickle Cell Disease. Pediatr Blood Cancer 60: 1204-1210.
12. Sehlo MG and Kamfar HZ (2015) Depression and quality of life in children with sickle cell disease: the effect of social support. BMC Psychiatry15:78
13. Sil S, Dampier C, Cohen LL (2016) Pediatric sickle cell disease and parent and child catastrophizing. J of Pain 17: 963-971.
14. Adam SS, Flahiff CM, Kamble S, Telen MJ, Reed SD, et al. (2017) Depression, quality of life, and medical resource utilization in sickle cell disease. Blood advances 1: 1983-1992.
15. Rattler TL, Walder AM, Feng H, et al. (2016) Care coordination for children with sickle cell disease. A longitudinal study of parent perspectives and acute care utilization. AmJ Prev Med 51: S55-61.
16. Cronin RM, Hankins JS, Byrd J, Pernell BM, Kassim A, et al. (2018) Modifying factors of the health belief model associated with missed clinic appointments among individuals with sickle cell disease. Hematology.
17. Simon TD, Whitlock KB, Haaland W, Wright DR, Zhou C, et al. (2018) Effectiveness of a comprehensive case management service for children with medical complexity. Pediatrics 141: S212-223.