

Trends in Internal Medicine

Social Determinants of Health and Barriers to Healthcare for an Adult with Spina Bifida

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ABSTRACT

Inequalities in healthcare access remain to be one of the largest predictors when it comes to a patient's overall outcome. Patients with seemingly simple pathology can quickly spiral into a more complicated case when the barriers to healthcare prohibit them from receiving the care they desperately need in a preventive and comprehensive manner. Many of these barriers are out of the control of the patient and are further fueled by various social determinants. This case report explores some of the systemic shortcomings of modern medicine through the lens of a patient with spina bifida, a neural tube defect that often results in numerous comorbid pathologies. Further discussion of potential solutions to these barriers are presented by clinical pearls in the use of holistic approaches to healthcare when treating patients with complex medical history.

Keywords

Primary care, Spina bifida, Social determinants of health, Barriers to healthcare.

Introduction

Spina bifida is a neural tube defect (NTD) involving embryological development pathology of the spine leading to the neural tube failing to close. This results in a corresponding neural tube and subsequent skin defect where the spinal cord and meninges are exposed. It is the most common permanently disabling birth defect in the United States, still occurring in 1 in 1000 live births [1,2]. Morbidities and the wide range of associated symptoms burdened upon those with NTDs adversely impact quality of life [3,4]. Some studies suggest reducing the number of secondary medical conditions with proactive and preventative approaches to health care could reduce the morbidity, mortality, and the financial burden of health care cost for those within this group [4-6]. Urinary tract infections (UTIs), device complications or malfunctions, pressure ulcers, soft tissue infections, and pneumonia are most frequently the motive to seek emergency or acute medical care in all age groups with NTDs. Consequently, it is crucial these diagnoses are

targeted for preventive care interventions with the goal to limit emergency department visits, decrease need for hospitalizations, and maximize overall patient health [4,7-9]. Here, we describe a complex case of an adult male with spina bifida, his medical management, and the associated socioeconomic implications and barriers to health care he encountered.

Case Summary

A 52-year-old, wheelchair bound, paraplegic male with a history of congenital spina bifida presented via primary care clinic for hospital follow-up for left lower extremity cellulitis. The patient was previously treated in-hospital with intravenous antibiotics and discharged with oral linezolid (Zyvox). The erythema was much improved since hospital discharge, however swelling and mild erythema persisted; no associated fevers, chills, or night sweats were found. Additionally, he was hospitalized multiple times for sepsis, secondary to chronic stage IV sacral decubitus ulcer, and recurrent UTIs, respectively. His complex medical history includes a history of a solitary kidney, urostomy at age 9, Hartmann's Pouch colostomy at age 42, Fournier's gangrene S/P penectomy and orchiectomy at age 50, as well as chronic ischial

tuberosity osteomyelitis, anemia of chronic disease, acquired hypothyroidism, chronic kidney disease 3b, and well-controlled type 2 diabetes mellitus (Table 1). The patient does not drink alcohol or smoke cigarettes, he lives independently at home, drives, and has no issues with activities of daily living (ADL's). Along with his chief complaint, on physical exam, he presented with a chronic sacral decubitus ulcer and chronic ischial tuberosity ulcer.

Table 1: Pertinent lab results upon discharge.

Analyte	Value	Significance
HA1c	5.8%	Normal
WBC	6.5 cells/ μ L	Normal
TIBC	148 mcg/dL	Low
RBC	3.41 cells/ μ L	Low
Transferrin	111 mg/dL	Low
Hb	8.3 g/dL	Low
Hct	27.1%	Low
MCV	80 fl	Normal
Ferritin	973 ng/mL	High
Iron	22 mcg/dL	Low
GFR	41 mL/min	Low
TSH	5.32 μ U/dL	High
Testosterone (Free)	24.4 pg/mL	Low
Testosterone (Total)	98 ng/dL	Low

After initial assessment, the patient was hospitalized two additional times for recurrent fevers due to worsening lower extremity cellulitis and multidrug resistant (MDR) *E. coli* UTI. He would next be seen in the primary care clinic three months later for follow-up of *Clostridium difficile*-associated colitis with fatigue. The patient conveyed frustration with his current situation as over the years, as he has had extensive hospitalizations, presenting to multiple emergency departments, and subsequently hospitalized for infection related illnesses secondary to comorbid conditions. To this point, the patient had been hospitalized five times in the current year and it was decided the goal moving forward would be to keep him out of the hospital to the best of the primary care team's ability using intensive preventative care. Due to the overall complex health history, the patient agreed to weekly clinic follow-up visits and lab studies for two months, subsequently transitioning to monthly follow-up visits if successful. During the same visit, he also expressed socioeconomic concerns that would not be overlooked for medical decision making.

Treatment Plans and Interprofessional Care Steps

When managing medically complex patients, several treatment goals must be established. One of the primary goals for this patient was to "get ahead" of the various pathologies that were present by establishing routine care. This process was facilitated by the recurrent, weekly visits with primary care and the regular monitoring of lab values. By utilizing this, as well as a holistic and thoughtful interview at these visits, several contributing factors to the patient's current health status presented themselves.

The patient had inconsistent care by only presenting himself for

emergency room-level exacerbations of chronic illness. This was often the fault of inconsistent access to transportation for the patient to arrive at his scheduled appointments with the various specialists he was established with. Furthermore, due to the patient having pathology in numerous body systems, this required the patient to visit numerous sub-specialty providers which often proved to have longer wait times, delay of care, and higher expenses. Unfortunately, this burden of specialist-focused health care has led to similar consequences to other medically complex patients [10]. This shortcoming was addressed by the primary care team by offering free visits to the clinic, extra flexibility with scheduling, and extended visit times to ensure a thorough exam and history at every appointment.

Although the patient had numerous providers for his various complications, the patient did not have a reliable primary provider who helped coordinate and manage care prior to presenting to the care team. A medically complex patient requires an established provider who provides attention to their complex medical needs while also designing a patient-compliant program of care [11,12]. Factors that contributed to his comorbidities such as social determinants of health and significant barriers to consistent and frequent healthcare were chronically unaddressed. This compromise in his care ultimately led to a spiral of worsening health and frequent emergency room visits. By allowing the primary care team to act as his patient-centered medical home, this ensured the priority of continuity of care without delay, an emphasis on comprehensive and preventative care, and allowed greater communication with specialists while promoting patient advocacy [11-13]. Numerous other comorbid factors revealed themselves, including the patient's lack of access to proper nutrition. The patient struggled with having enough money to afford nutrient-dense food for everyday consumption, which further fueled his deterioration. Once these deficiencies in care were managed, his conditions improved and had successfully remained out of the hospital.

Discussion on Current Barriers and Examples of Current Solutions

For patients suffering from long term conditions, there remain several important barriers that often prevent the patients from being able to properly engage in their own care and continued wellness. In this patient's case, as listed above, there are several barriers which could have led to his overall well-being falling into disarray if not addressed. These included lack of access to preventative care, lack of consistent transportation, difficulty with payments for clinic visits, and proper nutrition.

Due to the increased consequences from lack of access to care for patients suffering from chronic disease states, those patients in the emergency department who suffer from exacerbations of their disease should be given referrals to local primary care clinics and encouraged to set up primary care appointments during their presentation. Associated primary care physicians or even a list of local doctor's offices increases the likelihood of the patient's ability to set up appointments. In one recent study, a program where a rapid (within a few days of initial ED Visit) primary care

follow up improved the likelihood of good outcomes in patients presenting to the ED [14]. Similar programs and encouraging scheduling upon discharge increases the likelihood of the patient receiving appropriate care.

Another common struggle for patients is lack of reliable and consistent transportation for clinic visits as well as difficulty in making payments. One current solution that exists for this situation is inclusion of social work and taking a social history of patients while at the clinic; through careful questioning and evaluation of what social supports and resources that the patient has access to, troubleshooting activities can be accomplished. In many states and local areas, there are resources for providing public and private transportation that work with patients and their families to ensure that their transportation needs can be met. One underutilized service is the 211-transportation resource in Arizona, which offers free transportation for specific needs, including health-related appointments [15].

Other specific programs that remain underutilized include State Medicaid programs, which provide for the financial needs of patients who are currently suffering from many chronic conditions. According to a report released for Congress in 2017, many of the individuals who should be receiving Medicaid and Medicare benefits simply are not [16], and through proper education of the programs that exist and increased knowledge, patients can access those programs and receive the benefits that are readily available. Further, discussions with outpatient billing specialists may reveal additional coverage of services with discovery of financial assistance programs that the patient may be unaware of. Lastly, a visit with a Registered Dietician can provide for the needs of the patient as many patients desire to improve their overall health as many already know that a good diet and exercise plan can provide those benefits. One of the biggest problems with this colloquial knowledge is that much is based on a lack of information and access to those that can provide this, therefore referrals to Registered Dieticians can improve the overall likelihood of success in these individuals and is imperative for their overall health status.

Future Directions

Based on the solutions to the chronic problems this patient has suffered, one future direction is inclusion of social work visitation during hospital stays to address concerns with education, transportation, and nutritional management outpatient. Moreover, providing patients with informational pamphlets about the disease state to ensure they are aware of resources available to them would be beneficial. One study found that the creation of video resource guides both improved the ability of the patient to make educated shared decisions and reduced anxiety [17]. Another thesis found that in an area with poor information about resources available to those suffering from end stage renal disease, patients had worse biomarkers for nutritional status than those in the surrounding area [18], showing that the availability of such information can make a marked difference as well as the lack thereof having a profound difference in outcomes. Therefore, while a small change, a set of pamphlets or videos on local resources can make a difference in

the lives of patients suffering from chronic disease states.

Conclusions

In this case of a 52-year-old man suffering from spina bifida in addition to complex medical issues, the care team was made aware of the numerous socioeconomic barriers preventing this patient from receiving access to required care. Upon interview and evaluation, it was made apparent to the care team that these common barriers highlight the many shortcomings in the way in which care facilities let these complex patients fall through the cracks. Addressing these barriers with a dedicated primary medical home has shown success, as with this patient, in better management of chronic health concerns and avoiding subsequent hospitalizations. By making minor, but highly impactful changes such as informational guides, videos, and/or thorough social history-taking, these care facilities have the potential to improve the lives and overall health of many patients that would normally be at a disadvantage to receiving proper medical treatment.

References

1. Wang HH, Wiener JS, Ross SS, et al. Emergent care patterns in patients with spina bifida: A case-control study. *J Urol.* 2015; 193: 268-273.
2. Salih MA, Murshid WR, Seidahmed M. Epidemiology, prenatal management, and prevention of neural tube defects. *Saudi Med J.* 2014; 35: 15-28.
3. Rofail D, Maguire L, Kissner M, et al. A review of the social, psychological, and economic burdens experienced by people with spina bifida and their caregivers. *Neurol Ther.* 2013; 22: 1-12.
4. Fremion E, Kanter D, Turk M. Health promotion and preventive health care service guidelines for the care of people with spina bifida. *J Pediatr Rehabil Med.* 2020; 13: 513-523.
5. Wilson R, Lewis SA, Dicianno BE. Targeted preventive care may be needed for adults with congenital spine anomalies. *PMR.* 2011; 3: 730-738.
6. Thibadeau J, Walker Jr WO, Castillo J, et al. Philosophy of care delivery for spina bifida. *Disabil Health J.* 2020; 13: 100883.
7. Burke R, Liptak GS, Council on Children with Disabilities. Providing a primary care medical home for children and youth with spina bifida. *Pediatrics.* 2011; 128: 1645-1657.
8. Piatt JH. Adults with myelomeningocele and other forms of spinal dysraphism: hospital care in the United States since the turn of the millennium. *J Neurosurg Spine.* 2016; 25: 69-77.
9. Dicianno BE, Wilson R. Hospitalizations of adults with spina bifida and congenital spinal cord anomalies. *Arch Phys Med Rehabil.* 2010; 91: 529-535.
10. Andersen GF, Ballreich J, Bleich S, et al. Attributes common to programs that successfully treat high-need, high-cost individuals. *Am J Manag Care.* 2015; 21: 597-600.
11. Maciejewski ML, Powers BJ, Sanders LL, et al. The intersection of patient complexity, prescriber continuity and acute care utilization. *J Gen Intern Med.* 2014; 29: 594-601.

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12. Walker J, Payne B, Clemans Taylor BL, et al. Continuity of care in resident outpatient clinics: A scoping review of the literature. *J Grad Med Educ.* 2018; 10: 16-25.
 13. Epstein JA, Wu AW. Delivering complex care: Designing for patients and physicians. *J Gen Intern Med.* 2021; 36: 772-774.
 14. Carmel AS, Steel P, Tanouye R, et al. Rapid primary care follow-up from the ED to reduce avoidable hospital admissions. *West J Emerg Med.* 2017; 18: 870-877.
 15. <https://211arizona.org/crisis/heat-relief/transportation/>
 16. <https://www.macpac.gov/wp-content/uploads/2017/08/Medicare-Savings-Programs-New-Estimates-Continue-to-Show-Many-Eligible-Individuals-Not-Enrolled.pdf>
 17. Koor JG, McIntyre D, Chik WW, et al. Clinician-created educational video resources for shared decision-making in the Outpatient management of chronic disease: Development and evaluation study. *J Med Internet Res.* 2021; 23: 26732.
 18. Leslie SL. Nutrition education resources used by renal dietitians for the education of the outpatient dialysis population in Michigan. Eastern Michigan University Master's Theses and Doctoral Dissertations.