

Connecting Families. Supporting Health.



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Defragmenting Patient Service of Healthcare for Complex Kids

Multiple streams of change are impacting the provision of health care services in the United States and beyond. First is a renewed focus on the importance of addressing the social determinants of health on par with clinical care. Second is an increasing recognition of the negative consequences of failing to properly coordinate care, particularly for those with low health literacy. Third is a belated effort to harness technology in service to maintaining health. Fourth is the recognition that mental and physical health are intimately connected and that the siloing of mental and dental health services from primary care leaves many patients with undiagnosed and/or untreated disorders. Fifth is the spiraling cost of health care, particularly as it relates to primary care sensitive emergency room visits and/or hospitalisations. This narrative explores these issues in the context of explicating an innovative model of care known as the CHECK program.

Coordination of Healthcare for Complex Kids: CHECK

The CHECK program currently being implemented in Chicago, Illinois (USA) focuses on children and young adults up to the age of 25 at time of enrollment who have one or more chronic illnesses and are enrolled in a state-run public health insurance program for low income individuals and children. The goal of CHECK is to increase the quality of primary care services and to expand the scope of those services to support patients and/or their families in successfully managing the chronic illness. CHECK has been funded by the United States Federal government as an innovative program designed to improve the quality of care while reducing the cost of care for children and

young adults who have chronic diseases such as asthma, sickle cell, or diabetes, or illnesses related to prematurity.

Social determinants of health

CHECK places particular emphasis on addressing the social determinants of health – the “conditions in which people are born, grow, live, work, and age that can contribute to or detract from the health of individuals and communities,” as defined by the World Health Organization.¹

Traditionally, primary care providers have not been trained to ask about issues such as unemployment, homelessness, lack of food, substandard housing, poverty, violence, and a host of other problems that can have an out-size effect on patients’ health.² In fact, the social service system is typically separated from the health care system and operates under a very different set of rules in terms of access and cost of services. While some social service organisations are government operated, most are non-profit organisations operating with government and/or grant funding and charitable donations. Community members need to figure out how to access these services, navigating the variety of rules and regulations that govern each.

CHECK uses Community Health Workers (CHWs), community members who have a common background and experience with the patients they serve, to provide the connections and resources that families need in order to access social services. CHWs are non-clinicians who receive specialised training in the diseases their clients face, and in the social service resources available to meet other needs. CHWs look like their patients, come

s: Coordination (CHECK)



Benjamin Van Voorhees

from the same communities, and speak the same language as their patients, creating an important connection that makes families feel comfortable sharing their concerns and challenges.

The more than 6000 participants currently enrolled in the CHECK program were prescreened for eligibility and their billing history, if available, was reviewed to establish a baseline cost of care profile. Once CHECK staff make contact with the patient or caregiver, they complete an assessment which includes questions on mental and dental health needs, as well as queries on the family's access to food and adequate shelter, employment status, language barriers, transportation challenges that cause difficulty in keeping medical appointments, and a variety of other social

concerns. CHWs follow-up with referrals for needed social services and dental care, and make referrals to CHECK's mental health team for follow-up on any identified concerns.

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The work of the CHW is to help patients and families engage in the process of maintaining health and managing chronic illness. As CHWs assist with non-medical needs and provide needed referrals, they address issues that distract from a family's ability to focus on health. The personal touch of the CHW helps establish a foundation of trust that can be built upon to engender acceptance of health education and other services to improve health status.

Coordination of care

A key element of quality primary care is the appropriate coordination of care. On the patient side, that means making sure that patients follow through with keeping scheduled appointments, that they get their medications and understand how and when to use them, that they make and keep appointments for lab work or specialty care when recommended, and that they know who to ask when they have a question or concern. On the provider side, coordination of care means that primary care providers are informed of what specialty providers are seeing their patients and what they have recommended for their patients' care, that they know when their patients have



visited the emergency room, been prescribed different medications, or been hospitalised.

Coordination of care for patients is a challenge for health care practices from the United States to England and other European countries.³ As chronic diseases have become an increasingly significant component of health care, as opposed to the historical focus on acute care and trauma, the challenge is to coordinate all the parts of a patient's care such that they form a seamless whole. By definition, chronic illness requires ongoing care and puts the onus of that care on the patient and family. The time spent in a doctor's office is minimal compared to the daily efforts needed to manage a chronic illness. The challenge is even more difficult when patients are dealing with more than one chronic illness that involves multiple specialists,

and/or conditions that are expected to last a lifetime, creating the need for age adjusted care.

In the United States, the separation of specialty and hospital care from primary care further complicates care coordination. There are a litany of reasons, including medical record systems that can't talk to each other, changes in health insurance that lead to changes in the physicians who provide care to the patient, and patients' lack of understanding of their illness and how to follow the care plan they have been given.

CHECK CHWs play an important role in care coordination for patients. They provide home visits to support patients who have recently been hospitalised, and timely follow-up contacts after emergency room visits to identify the cause of

any acute episode and preventive measures for future episodes. They also provide their contact information to patients and families so if questions arise or if they need help with transportation to keep a primary care appointment, they can call. If patients need help understanding medication instructions or education on how to minimize asthma attacks or manage diabetes, CHWs can provide that. CHWs also follow-up to be sure that patients make any specialty care appointments that may be needed, or complete recommended lab work.

“Mental health disorders are highly correlated with poverty⁴ and in the United States more than 1 in 5 children under 18 years of age lives in poverty.⁵ For minority children who comprise the bulk of CHECK participants, 39% of Black children and 32% of Hispanic children live in poverty.”

In short, CHECK is designed as a patient-centered holistic care model to address real-time practical concerns that have the potential to negatively impact health and wellness. CHECK incorporates CHWs into the health care team as a culturally sensitive and cost effective means of expanding the scope of services provided to support health. For families with high levels of need and ongoing medical crises, CHWs provide the link for families to meet their challenges and thereby improve the health of their child or young adult.

Use of technology

Beyond the human touch that CHWs provide, CHECK takes advantage of technology and social media strategies to maintain an ongoing communication with complex patients, as necessary. Diabetics receive email and/or text reminders to check blood sugar and follow their recommended care plan. Asthmatic children and their families receive periodic updates on

environmental factors that can trigger an acute episode. These contacts can include everything from alerts on elevated pollen levels and impending harsh weather to reminders to dust a bedroom or adhere to a medication schedule. A web portal for both CHECK participants and their families provides disease specific and age appropriate health education modules to improve disease management skills.

Technology is also brought to bear in the development of a specialised electronic database known as Consensus which is designed to share information on patient status across a variety of domains with their health care team. Upcoming appointments, missed appointments, information on social needs, hospitalisations, emergency room visits, lab work, and patient contacts are maintained in the database as a means of enhancing communication and strengthening care coordination activities. The system can generate appointment reminders for patients, as well as prompts for needed follow-up contacts for CHWs.

Mental and oral health

The separation of behavioral and oral health services from primary care leads to a particularly challenging constellation of problems. Physical, mental, and oral health are intimately connected for the patient. An infected tooth or depressive episode has profound effects on a patient's sense of well-being and ability to deal with other health problems.

Primary care providers are typically those who have the most regular contact with patients and they serve as the first line of defense in identifying health problems. However, if they are not prepared to identify behavioral or oral health issues, then there is a missed opportunity to provide care that the whole patient needs rather than just addressing the reason for presentation. CHECK uses CHWs to follow-up on screening results that indicate a

need for mental health or dental services, providing referrals or making appointments as needed.

Mental health disorders are highly correlated with poverty⁴ and in the United States more than 1 in 5 children under 18 years of age lives in poverty.⁵ For minority children who comprise the bulk of CHECK participants, 39% of Black children and 32% of Hispanic children live in poverty. It is no surprise that the category of service for publicly-insured youth with the highest level of expenditure was for the care and treatment of mental disorders. And even at that level, estimates are that only one-third of adolescents with mental disorders receive services for their illness and that half of adolescents with severely impairing mental disorders never receive service. This is particularly true for minority youth.⁶

Because mental health disorders that first manifest in youth can cause lifetime health problems^{7,8} mental health services are a high priority for CHECK. Its mental health team provides both preventive services, as well as supportive approaches based on Cognitive Behavioral Therapy.

Preventive services are particularly focused on helping families with infants learn how to soothe them and deal with crying behaviors. Educational videos are provided to parents of infants to help prevent stress in the family, as well as reduce the likelihood of child abuse in the home. CHECK also incorporates an online teen resilience program that helps youth develop coping behaviors and learn how to deal with their feelings. Given that mental health disorders typically first manifest in the teen years, it is particularly important to provide young people from disadvantaged backgrounds with the tools to deal with the anger and disaffection they often feel. As necessary, CHECK mental health counselors provide individual and group therapy sessions, as well as telehealth sessions over the internet. Serious mental illness is handled by referral to specialty care.

Many dental providers in Chicago do not accept the public insurance program because the reimbursement rate is so low. Finding oral health care is therefore very difficult for low-income families. CHECK addressed this need by establishing a partnership with the local dental school to provide services to its patients. CHWs make the referrals and follow-up to be sure that patients keep their appointments. CHECK is also implementing a dental health mobile program which will provide oral health screenings and education in neighborhood locations.

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Cost of care

As part of the development of the CHECK model, Dr. Van Voorhees undertook an analysis of cost data for high cost users of care. High cost care typically involves multiple emergency room visits and/or hospitalisations. CHECK staff calculated the anticipated cost savings that could be realised by increasing primary care visits and medication adherence such that high cost crisis episodes could be reduced or eliminated. The anticipated mechanisms of impact for this cost reduction are: 1) prevention of primary care sensitive emergency room visits and hospitalisations, 2) appropriate chronic disease management through patient education and support, 3) attention to the social determinants of health that are critical to maintaining health, 4) technology touches, and 5) care coordination that includes referrals for mental and oral health concerns. It is not insignificant that CHWs are lower cost personnel who provide the patient support and assistance that, in turn,

yields a positive return on the investment in their services. One estimate suggests that CHWs provide a more than 2 to 1 return in health care cost savings as compared to their cost.⁹ CHECK staff are confident their innovations and attention to critical components of health will reduce health care costs across the lifespan for CHECK participants.

Lessons

As England struggles with integrating its mental health and social services as part of “whole person care”, the model of care established by CHECK may provide some useful lessons. Although CHECK has yet to conduct a financial analysis of cost savings, the qualitative difference it is making in the lives of patients and families is indisputable. The long term cost savings and health benefits generated by patients understanding how to manage their chronic illnesses and adhere to a care plan, thus reducing expensive crisis episodes; having their social, mental and oral health needs met; and building a relationship with their health care team through the work of the CHWs is incalculable.

1 World Health Organization. http://www.who.int/social_determinants/en/. Accessed March 3, 2016.

2 O'Brien MJ, Garland JM, Murphy KM, Shuman SJ, Whitaker RC, Larson SC. Training medical students in the social determinants of health: the Health Scholars Program at Puentes de Salud. *Advances in medical education and practice*. 2014;5:307-314.

3 Osborn R, Moulds D, Schneider EC, Doty MM, Squires D, Sarnak DO. Primary Care Physicians In Ten Countries Report Challenges Caring For Patients With Complex Health Needs. *Health Aff (Millwood)*. Dec 1 2015;34(12):2104-2112.

4 Pratt LA, Brody DJ. Depression in the U.S. household population, 2009-2012. *NCHS data brief*. Dec 2014(172):1-8.

5 Kids Count Data Center. Children in Poverty by Race and Ethnicity. [http://datacenter.kidscount.org/data/Line/43-children-in-poverty-100-percent-](http://datacenter.kidscount.org/data/Line/43-children-in-poverty-100-percent-poverty?loc=1&loct=2#1/any/false/869,36,868,867,133/asc/any/322)

[poverty?loc=1&loct=2#1/any/false/869,36,868,867,133/asc/any/322](http://datacenter.kidscount.org/data/Line/43-children-in-poverty-100-percent-poverty?loc=1&loct=2#1/any/false/869,36,868,867,133/asc/any/322). Accessed March 3, 2016.

6 Merikangas KR, He JP, Burstein M, et al. Service utilisation for lifetime mental disorders in U.S. adolescents: results of the National Comorbidity Survey-Adolescent Supplement (NCS-A). *J Am Acad Child Adolesc Psychiatry*. Jan 2011;50(1):32-45.

7 Weissman MM, Wolk S, Goldstein RB, et al. Depressed adolescents grown up. *JAMA*. May 12 1999;281(18):1707-1713.

8 Chen H, Cohen P, Kasen S, Johnson JG, Berenson K, Gordon K. Impact of adolescent mental disorders and physical illnesses on quality of life 17 years later. *Archives of pediatrics & adolescent medicine*. Jan 2006;160(1):93-99.

9 Whitley EM, Everhart RM, Wright RA. Measuring return on investment of outreach by community health workers. *Journal of health care for the poor and underserved*. Feb 2006;17(1 Suppl):6-15.

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