Ryan White: An Unintentional Home Builder

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As Indiana native John Mellencamp might say, "Ryan White was born in a small town." Kokomo, Ind, in 1971 indeed was a thriving, relatively small community in America's Heartland. A town founded on family values, hard work, and a full belief in the American Dream, where everyone could have a home of their own. However, in 1984, an unexpected encounter with a 120-nanometer virus turned 12-year-old Ryan White's American Dream into a nightmare. Soon after Ryan became infected with HIV, he suffered unimaginable discrimination, fueled by ignorance, fear, and prejudice culminating in a bullet passing through his living room window in mid-1987. The incident forced his family to leave their home in Kokomo and relocate in Cicero, Ind, a much more tolerant and accepting community, where Ryan and his family established residence until he died in April 1990. No one could have predicted then that Ryan White would later, through his remarkable legacy, become a home builder of incredible stature.

Throughout Ryan White's ordeal in Kokomo, he garnered the support of national celebrities who, with steadfast advocacy from his mother Jeanne, convinced Congress to pass the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act within 4 months of his death. The Ryan White CARE Act was composed of 4 Titles and 3 targeted components. (For a full description, see the 2005 report from the Institute of Medicine,[1] specifically pages 29-30.) Titles I and III, now known as Parts A and C, provide support for adult care through funding of local planning councils that distribute funds to clinics on a competitive basis (Part A) or via direct funding from the Health Resources and Services Administration to clinics that provide comprehensive HIV primary care (Part C). Individual states can supplement funding to clinics via Part B (formerly Title II), but the bulk of Part B money is earmarked for the AIDS Drug Assistance Program, which provides payment for HIV-related medications. The Ryan White CARE Act has been remarkably successful in its mission of reducing the burden of care delivery in high-impact areas and in other regions of the country.

A principal outcome of the Ryan White CARE Act has been the establishment of HIV specialty clinics throughout the country. Owing to the complexity of HIV care, the psychosocial burden of stigma and discrimination, the frequent presence of concomitant substance use and comorbid conditions, and the high frequency of poverty, Ryan White–funded clinics readily developed the capacity to deliver a wide range of comprehensive services. Such services include primary medical care, case management, psychological counseling, social services, pharmacy consultation, substance use treatment, palliative care, subspecialty medical services, spiritual counseling, adherence counseling, and capacity to see "drop in" patients. To accommodate the large patient burdens, most clinics established "teams" of health care providers assigned to each patient, typically consisting of a primary physician, nurse practitioner or physician's assistant, clinic nurse, social worker, and pharmacist.

Coincident with the establishment of Ryan White–supported clinics, a movement emerged to create so-called medical homes for patients. Medical homes were initially introduced in 1967 by the American Academy of Pediatrics but did not fully take root until 2001 with the publication by the Institute of Medicine entitled *Crossing the Quality Chasm: A New Health System for the 21st Century.*[2] In this report, the Institute of Medicine rails at the increasing fragmentation of health care wherein the patient and his or her family are required to take increasing responsibility for coordination of their care.[2] A central principle of the medical home is patient-centered health care founded on a transformation in the physician-patient relationship. This results in a higher degree of personalized care coordination, managed by a team of health care personnel, each with specific roles and duties. Tying the team together is a highly sophisticated adoption of information technology used for care management and quality improvement. The essential services of a highly functional medical home are outlined in Table 1.

Since the publication of the Institute of Medicine's report, several prestigious groups, including the American College of Physicians, the American Academy of Family Physicians, and the American Academy of Pediatrics, have endorsed the establishment of medical homes as the gold standard of primary care delivery. These endorsements are based, in part, on concerns related to the increasing complexity and fragmentation of care for those with chronic conditions and to the growing shortage

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of primary care providers. The medical home offers a solution to the coordination of management for complex chronic conditions and, if paid for properly, should increase provider satisfaction and remuneration for services. Key questions that have emerged, however, are who will pay for these services and what will they cost?

Remarkably, the answer to these questions can be found in Ryan White–funded clinics. An unintended, but extremely positive, consequence of the Ryan White CARE Act has been the establishment of the comprehensive delivery of multiple services for patients with a complex disease. Ironically, the same stigma, prejudice, and complexity of care that created barriers to the access of high-quality care led to the establishment of medical homes for HIV-infected persons at many Ryan White–funded clinics in the United States. Comprehensive, highly coordinated primary care and psychosocial services are routinely provided at most Ryan White–funded clinics. Moreover, in order to create efficiency of care delivery, most of the clinics evolved naturally to establish teams of providers who are assigned to each patient to deliver specific services under the direction of a primary care physician.

Extensive use of nurse practitioners and physician assistants, registered nurses, social workers/case managers, pharmacists, and other non-physician professionals creates efficiencies of service delivery. In several of these clinics, such as the University of Alabama at Birmingham (UAB) 1917 Clinic, a fully functional EMR is used to provide easy access to health information, produce quality and safety metrics, and direct the provision of communication capabilities. By most definitions, these Ryan White–funded clinics represent the best aspects of a medical home. To elucidate what is required to fund a medical home, it is necessary to first assess how much Ryan White clinics are reimbursed for care versus how much the home actually costs.

In 2006, a study done at the UAB 1917 Clinic evaluated the reimbursement for care at its Ryan White–funded clinic.[3] In that study, the overall cost of care for an HIV-infected patient was $18,640 per year (Table 2). As expected, expenditures were dramatically higher for those with more advanced disease ($36,532/patient/y) than for those with early infection ($13,885/patient/y). Regardless of stage of disease, over 75% of the reimbursed cost of care is for medication expenditures (antiretroviral and non-antiretroviral medication costs), 13% for hospitalizations, and 6% for laboratory and ancillary tests. Less than 2% of all expenditures ($359/patient/y) are allocated to cover the costs of clinics through third-party payers. The way the 1917 Clinic and most other HIV clinics survive, therefore, is through support from the Ryan White funds.

To address the question of "How much does it cost to run a medical home?" a full accounting of the actual expenditures required to provide all of the clinic-related services is needed. A "back of the envelope" assessment at the 1917 Clinic shows the cost of care overall is roughly $2768/patient/y (or $4.43 million per year for 1600 patients). These data underscore the critical role the Ryan White program plays in providing access to care.

Detailed cost data from Ryan White–funded programs can help inform the debate on how to fund medical homes and at the same time help policy makers predict future costs of HIV care created by the anticipated influx of new patients identified by the implementation of "opt-out' universal testing. This policy of testing everyone for HIV carries with it an assumption that all persons with newly diagnosed infection will have access to care. But will they? Funding for Part C clinics has remained flat for the past decade despite 50% increases in patient load.[4] For clinics to develop increased capacity, funding for Part C needs to be increased substantially.

In the current economic climate, however, there is lit-

Table 1. Characteristics of a "Medical Home"

- Personal relationship: Patients have an ongoing, meaningful, long-term relationship with the physician and the entire primary care team.
- Team approach: The primary care provider leads a team of health care professionals who collectively provide ongoing patient care in a clearly defined way.
- Comprehensiveness: The primary care provider is responsible for providing or ensuring provision of all the patient's health care at all stages of life.
- Coordination: Care is coordinated and integrated through the use of information technology, especially electronic medical records (EMRs) and advanced communications that facilitate health information communication and exchange.
- Quality and safety: Ongoing, real-time assessment of quality and assurance of safety to allow patient-based decisions. This effort is enhanced through the use of registries and EMR technology.
- Access to care: Access to care is enhanced through use of open scheduling, expanded hours, and advanced communications among patients, their families, and the primary care team.
- Reimbursement: Providers who establish a medical home should receive compensation commensurate with the effort and level of service provided. This is in recognition of the cost savings to the overall health care system through substantially improved efficiency of health care delivery and improved outcomes.

Table 2. Cost of HIV Care at the UAB 1917 Clinic (N = 635)

CD4+ cell count category (number of patients)	Cost per CD4 category	ART medication costs	Non-ART medication costs	Hospital costs	Other outpatient costs[a]	Physician/clinic costs
< 50/µL (n = 62)	$36,532	$10,855 (30%)	$14,882 (41%)	$8353 (23%)	$1909 (5%)	$533 (1%)
50/µL - 199/µL (n = 99)	$23,864	$11,862 (50%)	$6685 (28%)	$3369 (14%)	$1416 (6%)	$532 (2%)
200/µL - 349/µL (n = 143)	$18,274	$11,935 (65%)	$3452 (19%)	$1186 (7%)	$1365 (7%)	$336 (2%)
≥ 350/µL (n = 331)	$13,885	$9407 (68%)	$1855 (13%)	$1408 (10%)	$930 (7%)	$285 (2%)
Overall expenditures	$18,640	$10,500 (56%)	$4240 (23%)	$2342 (13%)	$1199 (6%)	$359 (2%)

UAB, University of Alabama at Birmingham; ART, antiretroviral therapy.

Note: Percentages shown are row percentages (ie, percentage of total cost for each CD4 category).

[a] Other outpatient costs include radiology, laboratory tests, procedures, and home health care.

Adapted with permission from Chen RY et al. *Clin Infect Dis*. 2006.[3]

tle tolerance in Congress for providing increased funding to existing programs. Within the Ryan White CARE program, the majority of funds are directed toward provision of medication costs and to large urban areas that were disproportionately affected by HIV infection in the early 1990s, when the Ryan White CARE Act was first authorized. The AIDS epidemic today, however, is vastly different than it was in 1990. Then, patients were dying; today persons with HIV/AIDS are living. Most HIV-positive persons today are predicted to live a close-to-normal life span under conditions of optimal virological suppression.[5] Therefore, the focus of the Ryan White program needs to be realigned to reflect these changes in the epidemic. A careful analysis of the Ryan White program in its entirety is needed in order to redistribute funds in accordance with the new, positive reality of HIV today.

Although only an adolescent at the time of his death, Ryan was an inspirational leader who held a mirror to Middle America and showed us what we looked like during the beginning of the AIDS epidemic. His illness brought out the worst in some of us: discrimination and hatred bred from fear and ignorance. But Ryan's illness also brought out the best in far more—especially our ability to use compassion, awakened by the suffering of one, to create a program that has relieved the suffering of many. What no one could have anticipated at the time of inception of the Ryan White CARE Act was that Ryan White was a home builder. The act created in his memory, unintentionally, created medical homes that are the best examples of how all of us should receive primary care.

With the emerging movement for meaningful health care reform proposed by President Obama, we should learn some lessons once again from Ryan White—namely, how to create a fully functional medical home and determine how much it will cost. Once we gain insight into the costs, we can begin to create medical homes for everyone in need: a subdivision of modern primary care delivery that will help all of us live in a better, more friendly, and more effective health care neighborhood. Ironically, if we do this well for everyone, we will no longer need the Ryan White CARE Act and all HIV-infected persons will be treated in the same kinds of "homes" as the rest of the population. As Ryan and his family moved from their home in Kokomo to escape discrimination and build a new home in Cicero, who would have imagined that this was just the beginning of Ryan's journey as a home builder? What a lasting legacy. Indeed! □

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