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## Integrated multiple sclerosis care: New approaches and paradigm shifts

Chronic medical conditions affect 125 million individuals in the United States [1]. These conditions are a major cause of disability and functional limitations. The frequency of such conditions rises exponentially with age, with 43 percent of Medicare beneficiaries having three or more chronic conditions [2]. By 2030, over 70 million “baby boomers” will have reached the ranks of the elderly, producing a dramatic demand for chronic disease care. Despite these trends, the American healthcare system has not developed the capacity to effectively care for chronic conditions. The focus remains on acute care and medical procedures, with little coordination among providers, wasteful duplication of diagnostic tests, and conflicting care plans. Moreover, the price tag for our healthcare system, as measured by per capita expenditures, is double that of other Western nations [3]. An urgent need exists to improve chronic disease care within the United States that will optimize care coordination, maximize outcomes, and lower costs.

Multiple sclerosis (MS) is an example of a chronic disabling neurological disease requiring specialty care and coordination. In this discussion, MS is used as a model to examine both concerns and potential solutions for comprehensive chronic disease care.

MS is the most common progressive neurological disorder of young adults, affecting 350,000 to 400,000 people in the United States [4]. The median age of onset is 30 years, an age when many are starting careers and families. MS most commonly presents with intermittent relapses and evolves to a progressive form. Common symptoms include weakness, sensory loss, disturbances of vision, ataxia, bladder dysfunction, cognitive deficits, and fatigue. Several medications have been developed to reduce disease morbidity and provide symptom relief. By 15 years from first symptom onset, 21 percent require a cane to walk [5]. This percentage increases to 69 percent by 40 years from onset.

Because MS is a dynamic disease producing multifocal neurological deficits and disability, a wide range of healthcare specialists is required to assist in its management throughout the life of the patient. The neurologist is typically the principal caregiver, but referrals to rehabilitation specialists, psychologists, ophthalmologists, urologists, speech pathologists, wound specialists, and social workers are common. Multidisciplinary care is frequently promoted by MS advocacy groups within the United States. Yet, there have been few attempts to define MS multidisciplinary care models or test their effectiveness. Like other chronic conditions, coordination and continuity of care for patients with MS are often suboptimal.

Jansen et al. recently evaluated the literature on integrated MS care [6]. Integrated care is defined as comprehensive in nature and coordinated

between health and social care sectors to deliver seamless care to patients with multiple needs. The authors found several studies that documented significant unmet needs in patients with MS, the consequences, at least in part, of discontinuity and fragmentation of the healthcare system. Jansen et al. cited only two studies, both from Europe, that assessed integrative care initiatives across different healthcare settings for patients with MS [7–8]. Makepeace et al. used a multidisciplinary community team to deliver care to a group of MS patients [7]. A home-based care multidisciplinary team was the intervention deployed by Pozzilli et al. [8]. Both groups showed cost savings with their intervention. High patient satisfaction was noted by Makepeace et al., and quality of life measures improved significantly in the Pozzilli et al. study. Continuity of care and rigorous clinical outcomes were not assessed in these studies. Overall, there is potential for interdisciplinary care for MS care, but more research is needed to demonstrate overall utility.

## NEW MODELS FOR CHRONIC CARE

What lessons can be learned from models of comprehensive care for other chronic diseases? While there is no consensus on a specific model, an expert panel has recently advocated reforms that would strengthen the primary care system, encourage care coordination, and promote care management of patients with complex conditions who have high medical costs [9]. The Institute of Medicine commissioned a study to identify evidence-based successful models of comprehensive care for adults with chronic disease [10]. Fifteen care models were found to improve at least one outcome in chronically ill adults. These models fall within the following broad topical areas: interdisciplinary primary care, models that supplement primary care, transitional care, models of acute care in patients' homes, nurse-physician teams for residents of nursing homes, and models of comprehensive care in hospitals [10].

The use of technology in the form of home telemedicine has been effective in integrating several of these models outlined in the Institute of Medicine

study [10]. Finkelstein and Wood have developed a Home Automated Telemanagement (HAT) system for MS that supports patient self-management, comprehensive patient-provider communication, and multidisciplinary care coordination [11]. The HAT system has been successfully implemented in a variety of other chronic diseases, including asthma [12–13], hypertension [14], and inflammatory bowel disease [15]. Overall, these studies have shown increased patient adherence to care plans and improved clinical outcomes.

An organizational framework that has received renewed attention in the past few years to facilitate improvement in care coordination is the patient-centered “medical home” (PCMH) [16]. The PCMH is a model that was promulgated by the pediatric community in the 1970s to facilitate care coordination for children with complex needs that were not being adequately addressed [17]. In 2007, a number of medical societies developed a set of “joint principles” to describe key attributes of the PCMH [18]. These include a physician-directed medical team practice, a whole-person orientation, coordinated care across specialties, quality and safety principles that drive care, and enhanced access through scheduling modifications and electronic communication. These principles provide a context for care delivery for all patients throughout the stages of life.

Little is known about the extent to which specialty providers use PCMH principles. A recent national survey of internal medicine subspecialty practices by Casalino et al. attempted to address this issue [19]. One question in the survey asked, “In some cases, specialists also serve as primary care physicians for their patients. To the best of your knowledge, for approximately what percentage of patients, if any, do the physicians in your practice serve as primary care physicians as well as specialists?” A total of 81 percent of practices reported they served the primary care needs of 10 percent or fewer of their patients. Only 2.7 percent of the specialty practices surveyed served as the primary care providers for over 50 percent. These numbers provide evidence that few specialty practices within internal medicine are providing primary care for their patients.

Several private and public demonstration projects have been initiated to evaluate the PCMH model in recent years. The U.S. Congress recently passed the Patient Protection and Affordable Care Act (P.L. 111-148) and the Health Care and Education Reconciliation Act (P.L. 111-152) establishing a new Innovation Center to test novel PCMH models of care within Medicare, Medicaid, and the Children's Health Insurance Program [20–21]. Concerns have been raised about adequate payment to support the PCMH and the difficulties of small practices to adopt the model. Another issue is how specialty medicine interacts with or becomes a PCMH. Kirschner and Barr argue that specialty practices can serve as a PCMH for a subgroup of patients or function as a PCMH “neighbor” that interfaces with PCMH practices [22]. For example, an endocrinology practice may function as a PCMH for patients with complicated diabetes mellitus by managing diabetic-related problems and providing care consistent with the joint principles just noted, which include first-contact and comprehensive care. A PCMH “neighbor” is a middle-ground approach in which the specialty clinic works along with PCMH practice to enhance coordination of care, improve consultation access, and create a seamless transition for patients with complicated chronic conditions. An integrated MS clinic could serve as a PCMH “neighbor” by providing principal MS care or care that requires special expertise but also meets many of the patient's general healthcare needs. Specialty models of care within the PCMH require further development in communication flow, accountability for care, and outcomes.

As part of the Transformation-21 initiatives, the Veterans Health Administration (VHA) launched a program in 2010 to transform all VHA primary care practices into a PCMH [18]. This PCMH will incorporate the core principles just noted, emphasizing a patient-driven, team-based approach that delivers efficient, comprehensive care through active communication and coordination of healthcare services. A typical PCMH team will consist of a small group of medical, social service, and administrative staff that will have responsibility for caring for the primary care needs of about 1,000 patients. Communication between providers and patients will be facilitated by

the well-developed information technology pathways in the VHA. These include the Computerized Patient Record System (CPRS), electronic clinical reminders, an Internet-based patient Web portal (My Health-eVet), and a comprehensive telehealth program. Open access scheduling and remote visits will offer flexibility in the daily schedule of primary care clinics and will be a noted advantage for both patients and providers, with more real-time electronic encounters and fewer face-to-face visits.

## INTEGRATED MS CARE WITHIN VHA

Approximately 25,000 patients with MS use the Department of Veterans Affairs (VA) healthcare system, with treatment taking place largely in outpatient clinics. Patients with MS require more visits per person than all but a handful of other diagnostic groups. MS therapy includes complex and expensive pharmacological agents as well as multidisciplinary medical and rehabilitation services and assistive technology. In 2003, because of surveys showing wide unexplained variations in the care of patients with MS across the VHA, the VA established two MS Centers of Excellence (MSCoEs) to improve access to MS specialty care, to develop national standards of care, and to implement those standards through a network of regional MS programs. The VA Central Office, with input from the MSCoE and a network of over 70 VA MS programs, released a handbook for MS care in December 2009, “Multiple sclerosis system of care procedures,” VHA Handbook 1011.06 [23]. This is the first MS healthcare policy directive that has been created outlining a comprehensive plan of care for patients with MS.

### Standards of Care

The MS Handbook describes the diagnostic and therapeutic healthcare services that are required by patients with MS, including primary care, MS specialty care, rehabilitation, palliative care, respite care, home care, long-term care, mental healthcare, social work services, telehealth services, and access to disease-modifying and symptomatic pharmacological therapies. The nationally integrated CPRS is

an integral part of communication and coordination of care between MS caregivers and the patient.

The MS Handbook specifies that every patient with MS should undergo an annual evaluation in which the care plan is reviewed by a provider knowledgeable in MS and a simple electronic clinical data surveillance tool is completed. This standard annual visit and tool would help identify patients with MS and populate the VA MS Registry. Ideally, this evaluation would take place in a face-to-face office visit with an MS subspecialist. However, this requirement could be satisfied through a visit with another provider knowledgeable in MS or through a telehealth or telephone interview.

### **National System of Care**

The MS Handbook specifies that the location of care should be dictated by individual needs and should be as convenient as possible. To support this, the handbook outlines a regional hub and spoke network. Every Veterans Integrated Service Network (VISN) should support at least one MS Regional Program (hub site). The MS Regional Program team consists of a physician with MS specialty expertise, a nurse, a social worker, and an administrative assistant. These individuals will lead and coordinate the integrated MS care of the local medical center and assist in the care of patients with MS at outlying facilities within the VISN. VA facilities without an MS Regional Program are designated as spoke sites that will have an MS Care Coordinator designated to assist with the MS care at that facility. Spoke sites will work with the regional hub to deliver MS care to the local MS population through consultations, referrals using telehealth and informatics approaches.

### **CONCLUSIONS**

The current healthcare system in the United States has a suboptimal structure to provide comprehensive, cost-effective care for patients with MS and other complex chronic diseases. Many specialty practices function as “silos” with limited incentives for coordination between other providers caring for the patient. Evidence-based medicine and decision support tools

are underused. The result is a fractured healthcare experience with little care coordination on behalf of the patient. The patient-centered focus of the PCMH is a welcome paradigm shift in chronic care delivery that holds much promise for providers and patients alike.

In an ideal PCMH, a patient with MS would receive both primary care and specialty care at the appropriate time, moving seamlessly between providers who communicate with each other and the patient. A sophisticated electronic medical record would be the major communication vehicle used by healthcare providers and the patient. Decision support tools with clinical guidelines would be made available within the electronic medical record to help create an individualized care plan for the patient. A home Internet telemanagement system would engage the patient to be involved with care by providing targeted patient and caregiver education, telerehabilitation, webcam visits, and tools to improve compliance. Measurement of morbidity endpoints for desired outcomes would help improve care quality and allow for more informed therapy decisions. The incentives in the ideal PCMH would be to use models of care to improve outcomes and minimize costs. Identifying the most effective models for MS care will require more intensive research.

The VHA is an ideal laboratory to demonstrate a variety of care models of MS care. Its size, infrastructure, and capability to capture costs would make trials of different care models relatively easy to design and implement. Because it is a capitated system, it is not constrained by the fee-for-service model of health insurance or Medicare. Models of care that employ the HAT system open up educational, diagnostic, and therapeutic delivery for patients who are separated from clinics by distance or disability. In addition to being convenient, such programs may save substantial costs. The level to which a given MS Regional Center is involved in a patient's MS care will be influenced by the stage of their disease and physical location. Different MS care models that incorporate more consultative and telemanagement approaches may need to be developed for patients with MS residing in rural areas with limited access to specialists.

The development of the VHA Handbook is an important step toward improving MS care and making it more uniform within the VHA. It incorporates many of the key components of the PCMH and can serve as a model for specialty care delivery for other complex chronic diseases.

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