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Addressing Gaps in Social Work Services With Patients Diagnosed With Neurodegenerative Disorders: The Development of Therapeutic Patient Navigation; Notes From the Field

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Nearly two years ago, Catholic Charities Archdiocese of Washington, Anchor Mental Health, launched St. Jude's Project, a program funded by the Griffin Foundation. The program's objective was to provide comprehensive social work to patients diagnosed with neurodegenerative disorders, with a primary focus on Huntington's disease. Huntington's is a complex fatal hereditary disease that has often been called the "quintessential family disease" (Huntington's Disease Society of America, 2017). Other illnesses served through the program—Parkinson's, multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS)—are also progressive life-limiting illnesses. As a result of patient needs, St. Jude's Project adopted an approach to treatment centered on several combined, evidenced-based models, now called Therapeutic Patient Navigation.

While researching existing care models for neurodegenerative disorders, in preparation for developing of the program's design, we found that no easily identifiable evidenced-based model of social work existed to address the specific needs of this population. Subsequently, as the program launched, several gaps in care became evident. The needs of patients with neurodegenerative disorders are inherently different than those of the chronically and acutely terminally ill. Neurodegenerative disorders have a range of functional challenges related to illness symptoms—such as mobility, cognitive, behavioral, and psychiatric complications—and they are often combined. In addition, quality of life is often definitively impaired, and it deteriorates for many years before complications from the illness result in end of life. The prolonged and complex nature of neurological illnesses required that St. Jude's Project conceptualize a rigorous and dynamic approach to providing meaningful support to this population.

One of the several traditional models of care serving medically challenged patients, Patient Navigation, was evaluated for the targeted approach

to patient care it implements. This groundbreaking care model seeks to help patients improve medical adherence and lessens barriers to health care (The Harold P. Freeman Patient Navigation Institute, 2017). Patient Navigation has proven that better access to preventative and sustained health care would ultimately improve health outcomes to previously underserved populations (The Harold P. Freeman Patient Navigation Institute, 2017). Neurodegenerative disorders are progressive and would not necessarily improve substantively through improved preventative care, medical adherence, or better access to general health care, as there is no known cure for these illnesses. However, the model of providing a partner to assist the patient and family with utilizing the specialized health care system is of value to patients with neurodegenerative disorders.

In addition, medical social work, as defined by the National Association of Social Workers, outlines the comprehensive role of social workers with patients in hospitals and medical settings (NASW, 2011). This definition does not include how to address many of the common service challenges that arise from serving patients with

prolonged complex illnesses outside of medical institutions. Even so, the medical social work model provides a foundation for work with a variety of patients, including those with neurodegenerative disorders. Furthermore, the model highlights the comprehensive range of scope of practice that is required to provide services to patients and can be applied to the program population.

The wraparound service model was also researched for its useful application to the St. Jude's Project. The model is a natural fit for the program, as the philosophy of the concept rests on intensive community treatment planning (National Wraparound Initiative, Regional Research Institute, School of Social Work, Portland State University, 2017). Catholic Charities Archdiocese of Washington, Anchor Mental Health, has a long history of providing wraparound services to populations that need intensive community treatment. The wide range of service supports provided throughout the agency creates an easily accessible referral base for the patient needs. Although wraparound services alone cannot resolve navigation issues related to obtaining and adhering to specialized health care and care planning, it is a salient model for providing service referrals.

It became clear after some evaluation that the program would have to rely on several proven models of care to meet the needs of patients with neurodegenerative disorders. The implementation of evidenced-based models, Patient Navigation, medical social work, and the wraparound service models were combined to create Therapeutic Patient Navigation, which is now utilized to address the complex long-term needs of the program population.

The service goals of Therapeutic Patient Navigation would include counseling individuals and families, linking patients to specialty care, assisting with medical adherence, participating in the health planning process, educating patients and family about the illness, and providing extensive support with daily functioning via wraparound service referrals. The outcomes seek to improve symptom management, improve patient emotional support, and increase the patient quality of life by decreasing the confusion that results from navigating the medical system. Ultimately, tackling the potential needs of these patients shaped the program design, objective, and outcomes.

Once the program began, the team immediately observed that patients needed to have the workers come to them in the community on a regular basis. Nationwide, many outstanding social workers have competently supported patients with Huntington's disease through the HD Centers of Excellence; however, these programs are usually based in a hospital or a medical center. The mobility challenges of patients with advanced symptoms often limited their ability to travel to the Washington, DC, office. The program is now exclusively a community-based one, and it responds to the need for regular outreach to many rural parts of the DC metropolitan area. Additionally, the program team assesses the acute needs of the patient and his or her family by observing them in their environment. The patient and family are often more at ease in their own homes and community, and they can build a solid rapport with team members. Such in-person contact can also further facilitate quality care. "Eyes on the patient in the home" has become an essential aspect of getting a holistic view of the patient and his or her level of functioning.

Attending medical appointments with patients and their caregivers is a vital aspect of patient care in the St. Jude's Project. We observed that patients with neurodegenerative disorders may not always have a total awareness of the degree of the degeneration of their functioning. As trained professionals who assess the patients over time, along with caregivers in the home, we often provide the medical team with the much-needed information about the patient illness progression and functioning. Some patients and their caregivers have also expressed that they find medical team meetings intimidating. Assisting the patient and his or her family in the medical setting, as well as following up with the medical team, gives the entire care team the opportunity for collaboration, more patient/family input, and treatment cohesion.

Providing wraparound services to the patient and caregivers includes assisting with many of the daily challenges that result from the prolonged strain of attending to medical illness. Wraparound service for our patients may include assisting with referrals to a wide range of community partners who provide access to housing, financial resources, legal assistance, transportation, medial and/or disability insurance, and food resources. Understandably, it is particularly difficult to focus on health goals at the most optimal level if there are other outstanding needs in terms of the patient and his or her home environment. Therefore, being a referral-based program requires extensive community building and strong organizational partnerships, which are especially vital to linking patients to wraparound services.

Another unique goal of the program is to provide specific support to caregivers. Often the burden of the caregiver during a prolonged life-limiting illness is grossly undervalued. This burden often leaves the caregiver overwhelmed, as he or she must take on the responsibilities of caring for patient as well as managing his or her own life (Penning, 2016). The program addresses caregivers as an integral part of the patient team, but it also treats them as another program patient who requires education, emotional support, and wraparound services. Invested caregivers are likely to be the fiercest advocates for their loved ones, and the more informed and supported they are, the more empowered the family unit is in the face of a prolonged complex illness.

Through St. Jude's Project, providing care in a holistic manner to patients who have been diagnosed with neurodegenerative disorders and their families has required an intensive evaluation of the specific population that we serve. Working within an evidenced-based context as we crafted the program design meant building on a few existing models of care. It also called on us to expand what already existed in order to provide social work that fit the identified needs of this patients group. The

model of care called Therapeutic Patient Navigation was created to work with a population that has traditionally been underserved. Through this work, our team hopes to fill the gaps in care and give our patients and their families comprehensive support—support that is often needed over the prolonged and often complicated trajectory of a neurodegenerative illness.

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