Caregivers for patients with chronic illnesses play a pivotal role in the provision and maintenance of care, but this often occurs at the expense of their quality of life and well-being. Fostering patient safety and a higher quality of care requires advocacy and mobilization of resources to cope with the growing demands of caregiving, in addition to involving family caregivers as collaborative partners in the plan of a dignified, caring process.

In particular, Huntington’s disease (HD) is a rare hereditary and neurodegenerative disease characterized by psychiatric symptoms along with the motor and cognitive decline. Although progression and symptom severity varies, HD has a disease duration of approximately 15 to 20 years. In later stages of the disease, most individuals are in need of institutional care, instead of family or community-based assistance seen in earlier stages. Research shows that caregivers of individuals diagnosed with HD “are burdened in their role as a caregiver”, and describe the experience as “lonely” as well as emotionally and
practically “stressful” (1). Given that HD is a rare disease, health care professionals may lack experience working with families affected by it, which can further complicate the process of understanding caregiver needs and challenges.

One significant stressor for caregivers, given the hereditary nature of HD and concerns for family members at risk, is information regulation. Regulating this information involves a balance of protection and disclosure, to avoid stress and negative reactions towards future challenges. Caregivers have expressed carrying a sense of guilt, pity, and responsibility for the future of some of their family members (1). Collaboration with healthcare professionals regarding having the conversation and informing their children in the early stages of HD has been found to yield positive caregiver experiences and use of better coping strategies (1).

As the functional decline of HD becomes more apparent, caregivers revealed that they shared the diagnosis with others to avoid social consequences and stigmatization (1). As the disease progresses and new care challenges are presented, caregiving overshadowed their own needs, preventing them from participating in everyday life, and limited their ability to live their lives (2). This increased sense of isolation and limitation experienced by caregivers has been described as “living in the shadow of HD” (1). Despite healthcare professionals advising caregivers to take care of themselves and their own emotional and physical health, caregivers voiced frustration at not having the knowledge or the resources to actually do so (1). Particular attention must be given to individual caregiver support needs for different stages in the caregiving process. This way, continuous contact and support from healthcare professionals may help combat feelings of isolation, fulfill needs that have been compromised, and stabilize family relationships.

Communication challenges can occur when caregiver knowledge on HD is limited and expectations of caregivers are unrealistic. Preventing this form of burden requires better communication and more effective coordination through
the sharing of knowledge, goals, and respect between caregivers and healthcare professionals. Family caregivers must be able to understand the illness course and their expected role in the care process, and share their concerns and observations with professionals that are trustworthy, competent, and familiar with the impact on specific family circumstances (2). Early consultations with health professionals can prepare caregivers for the illness impact and help understand their responsibilities as both a family member and a caregiver (2). Being involved in this dialogue enables caregivers to become more informed and contribute their understanding during consultations with all relevant professionals involved in the care of their family member.

Caregivers in families with HD are in complicated and multifaceted situations, as the disease can significantly impact many family members over time. The rarity, symptoms, onset and heredity of HD emphasize the need for knowledge sharing in early stages to facilitate future collaboration, care management, and individualized support. Health professionals have the ability to guide and empower caregivers to optimize the quality of life for themselves and their loved ones.

References
