

## Bringing Palliative Care and Neurology Together: Stroke by Stroke

Brain strokes are a major part of neurology practice. A surveillance study<sup>[1]</sup> in Bengaluru showed that strokes accounted for 7% of medical and 45% of neurological admissions. This is a serious diagnosis. In the same study, one-fifth of these patients were dead and one-third were dependent at 28-day follow-up. Stroke is also a major public health problem. In Gadchiroli (Maharashtra), it was the most frequent cause of mortality<sup>[2]</sup> and accounted for one in seven deaths in this rural community. The authors explain that this is because of an epidemiologic transition from deaths due to infection to hypertension-related mortality, which has been called “the age of receding pandemics.”<sup>[3]</sup> There has been substantial progress in acute stroke management, but much of this is inaccessible to the majority of our population. The burden of Indian stroke survivors requiring rehabilitation, palliative care (PC), and end-of-life care is likely to be massive and has, to my knowledge, never been estimated.

The caring neurologist has enough to be concerned about, and this is highlighted in the study by Lloyd *et al.*<sup>[4]</sup> in this issue. These authors interviewed 17 physicians involved in stroke care. Thematic analysis highlighted eight major issues. These included functional disability, physical burden including pain, psychological needs especially depression, socioeconomic decline which can be precipitous for the patient and the family, the caregiver burden and the unmet needs of counseling, spiritual distress, and end-of-life management. A major issue is the communication between patients, families, and doctors about PC and end-of-life care after stroke. Doubal *et al.*,<sup>[5]</sup> in a mixed-methods study, surveyed 599 health-care professionals. Their focus was the unmet learning needs of their study population, and they were able to accomplish this through an electronic survey with both open and closed questions. The educational topics identified as most important (>80%) included ensuring consistent messages to patients and family and handling unrealistic expectations while simultaneously discussing prognostic uncertainty. Another challenge was how to involve family in shared decision-making without making them feel responsible for the outcome. Family conflict management was another desired skill. Almost 80% wanted to be able to discuss the mode of death in these patients, and a similar number wanted to be able to facilitate oral “comfort” feeding in patients vulnerable to aspiration.

In 2014, the American Stroke Association issued a “scientific statement” on Palliative and End-of-Life Care in Stroke for health-care professionals.<sup>[6]</sup> This is an elaborate review of all the relevant literatures and although written for the neurologist, it is a valuable resource for both neurology and

PC professionals. The authors begin by emphasizing the need for primary PC, integrated and coordinated into the stroke service. The next major discussion is about handling prognostic uncertainty while setting the goals of care. The physician’s cognitive biases can often be crucial. Not many of us are aware of the substantial literature on self-fulfilling prophecies and the resultant therapeutic nihilism in acute intracerebral hemorrhage. Surrogate decision-making for a permanently uncommunicative patient has a lasting negative emotional impact on the family, and the medical team needs to be aware of cultural contexts as well as alternative sources of information that may be accessed. Diagnosing patient preferences is important, and this may conflict with the goals of the family surrogate. This is of critical importance in an illness where preference-sensitive decisions have to be made through both the acute and chronic stages. There are often two or more valid alternatives and choices made which can affect the quality and/or length of life. Caregiver burnout and requests for hastened death are downstream issues that may not be obvious during the acute phase. The same document goes on to discuss PC for chronic stroke patients including the management of pain, incontinence, nonpain physical symptoms, and psychological needs. As pointed out elsewhere,<sup>[7]</sup> it is obvious that there are few significant differences between the symptom burdens in oncology and nononcology PC.

PC has been oncology focused since its inception, especially so in this country. At one level, this is understandable. Cancer patients have voice and often a defined and predictable terminal trajectory. Neurology care is the exact opposite: a silent patient and a never ending, uncertain terminal decline. When PC is provided as a charity by a nongovernmental organization, choices have to be made. However, if we look at the broader societal needs, neurology is probably the largest field with PC needs, and the two specialties need to begin working together for our common “dharma.”

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