



The minimally conscious state: much work still to be done

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The Aspen Work Group defined minimally conscious state (MCS) over twenty years ago (1). However, the need still exists for more research in the areas of improved diagnosis, prognosis, and treatment. In this issue of *Annals of Palliative Medicine*, Produturi *et al.* review the current state of MCS in their article: “The Minimally Conscious State: An Analysis of Current Clinical Trials Registered in ClinicalTrials.gov” (2). The authors do a commendable job of outlining the existing MCS clinical trials, which include interventional as well as observational studies. The most frequent type of interventional study utilizes brain stimulation of various modalities and locations, followed by behavioral therapy, and finally pharmacologic agents. Other topics include methodologies to better distinguish MCS from other disorders of consciousness. Observational studies focus on using standardized instruments and diagnostic studies to assess MCS patients. The authors make the important observation that, of the trials registered with ClinicalTrials.gov, several do not distinguish between the manner of injury: traumatic versus non-traumatic, nor the state of consciousness: chronic vegetative state (CVS) versus MCS. The authors emphasize that determining the correct state of consciousness is vital since treatments, outcomes, and prognoses are very different for the two states. This distinction is critical, because patients in the MCS can and do experience suffering, whereas suffering is likely impossible in the CVS (3). Thus, misdiagnosis can result in unrecognized and undertreated symptoms in MCS patients (4,5).

It is important to note that of the 41 clinical trials included in the review, none address the palliative needs of MCS patients. It is possible that these studies do exist and are not yet registered. However, a PubMed search for the terms MCS and palliative care reveals only a handful of articles, none of which contain either quantitative or qualitative research. Both Palliative Care and the Minimally Conscious State are emerging concepts in medicine, so this is not surprising. As Neuropalliative care gains more traction, hopefully research ensuring the comfort and relief of suffering in these medically and neurologically complex patients will follow (6).

MCS is ten times more common than persistent vegetative state (PVS) (7). However, there are significantly fewer studies focusing on MCS than on CVS and Coma. What are the challenges for further MCS research? An important factor is that MCS patients are unable to advocate for themselves. They are often hidden from sight in long term care facilities, or cared for in the home by loved ones, and therefore do not gain the attention of the public, except in rare instances involving legal battles or miraculous recoveries. Logistics can be challenging. Because of severe disability, transportation to research centers can be prohibitive. Furthermore, MCS clinical trials require large investments of time and resources. Changes in condition, or the lack thereof, are often slow, even with the best rehabilitative care and interventions. Finally, Palliative care demand still far exceeds the existing workforce. Those doing research are often doing so with a full clinical

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The authors do point out signs of progress. The majority of clinical trials were initiated in the last seven years, indicating an increasing interest as well as funding for this type of research. Despite the Covid 19 Public Health Emergency, many studies were completed, and at least one went on to peer reviewed publication. One way the palliative community can advance research of MCS patients is through strategic partnerships with our specialty colleagues. In our institution, we have embedded palliative care in specialty clinics, such as neurology. We have seen increases in access and patient satisfaction, as well as increased opportunities for educating our specialty colleagues. The same can be said of research partnerships. By expanding an existing study slightly to include qualitative and quantitative data relating to symptom control, a study can address palliative issues of MCS, and work towards not only improving outcomes, but quality of life for these patients.

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