


VIEWPOINT



Caring for Coma after Severe Brain Injury: Clinical Practices and Challenges to Improve Outcomes: An Initiative by the Curing Coma Campaign

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Abstract

Severe brain injury can result in disorders of consciousness (DoC), including coma, vegetative state/unresponsive wakefulness syndrome, and minimally conscious state. Improved emergency and trauma medicine response, in addition to expanding efforts to prevent premature withdrawal of life-sustaining treatment, has led to an increased number of patients with prolonged DoC. High-quality bedside care of patients with DoC is key to improving long-term functional outcomes. However, there is a paucity of DoC-specific evidence guiding clinicians on efficacious bedside care that can promote medical stability and recovery of consciousness. This Viewpoint describes the state of current DoC bedside care and identifies knowledge and practice gaps related to patient care with DoC collated by the Care of the Patient in Coma scientific workgroup as part of the Neurocritical Care Society's Curing Coma Campaign. The gap analysis identified and organized domains of bedside care that could affect patient outcomes: clinical expertise, assessment and monitoring, timing of intervention, technology, family engagement, cultural considerations, systems of care, and transition to the post-acute continuum. Finally, this Viewpoint recommends future research and education initiatives to address and improve the care of patients with DoC.

Keywords: Coma, Consciousness disorders, Point-of-care, Brain injury

Introduction

Severe brain injury can result in absent or decreased states of arousal and awareness, termed “disorders of consciousness” (DoC). The spectrum of DoC includes the behavioral phenotypes of coma, vegetative state/unresponsive wakefulness syndrome (VS/UWS), and minimally conscious state (MCS) [1]. The most common severe brain injury etiologies that can result in DoC

include traumatic brain injury (TBI), hypoxic-ischemic brain injury, and stroke. Kondziella et al. [2] reported the annual incidence and prevalence of coma to be 135 and 258 per 100,000 in the UK and USA. Prevalence of DoC has increased because of multiple factors, including advancement of medical and surgical interventions for acute brain injury, prevention of secondary injury, evolution in neurocritical care, efforts to reduce prognostic nihilism, and premature withdrawal of life-sustaining treatments (WOLST) [2–4].

Energies to reduce prognostic nihilism have been amplified because of the continued evidence demonstrating that a large majority of individuals with

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prolonged DoC recover consciousness and achieve return of function and a level of independence [5–7]. Consequently, clinicians are treating patients with DoC at a higher frequency. This emphasizes the need to ensure evidence-based care to promote recovery of consciousness and improve outcomes.

The Curing Coma Campaign (CCC) is a Neurocritical Care Society interdisciplinary initiative examining DoC [8]. The goals, structure, and organization of the CCC are detailed in previous publications [8, 9] (Fig. 1). Care of the Patient in Coma (COPIC) is a scientific workgroup within the CCC. COPIC’s focus is the contemporary science of caring for patients with DoC throughout the continuum of recovery and seeks to investigate care that can influence recovery. The workgroup conceptualizes “coma care” as interdisciplinary interventions to achieve medical stability, prevent complications, and promote overall health and recovery of function. COPIC differentiates coma care from “curing” or removing the illness or injury.

In 2020, COPIC performed a gap analysis of DoC care. This involved review of the literature, including guidelines and clinical practices addressing care of DoC along the acute and post-acute continuum. The gap analysis led to the identification of discrepancies in providing bedside care, paucity of research and guidelines to direct clinical practice. Through this process, workgroup members achieved consensus on scientific initiatives organized into eight domains of DoC care and conceptualized domains as interdependent across the continuum of acute and post-acute inpatient care: clinical expertise, assessment and monitoring, timing of interventions, technology, family communication and engagement,

religion and culture, systems of care, and transitions to post-acute care. This Viewpoint reports findings of COPIC’s evidence review and gap analysis in identified DoC care domains. The authors describe the need for future research, infrastructure development, and implementation to promote quality care and outcomes for DoC (Table 1).

Clinical Expertise

Clinical care of DoC involves treatment and management of clinical phenotypes, complications, and comorbidities related to severe brain injury. Evolving expertise of neurological intensive care has spawned specialists in the management of neurocritical care (NCC) patients. Evidence suggests specialized NCC intervention is associated with improved patient outcomes [10, 11]. However, a survey of clinicians providing DoC care revealed wide variability of practice. Results support the need for standardized approaches to education and training of professionals who serve the DoC population within acute and post-acute settings [12]. However, there is a paucity of available DoC standardized education and training to harmonize approach to care. The absence of systematic and accessible DoC professional education has also been identified as a gap by additional work groups within the CCC [13].

COPIC posits the CCC and additional stakeholders are required to support the development, accessibility, and dissemination of DoC curriculum for interdisciplinary clinicians. Ensuring sufficient training in the management of DoC, along with neurological and medical comorbidities that frequently complicate DoC presentation, is

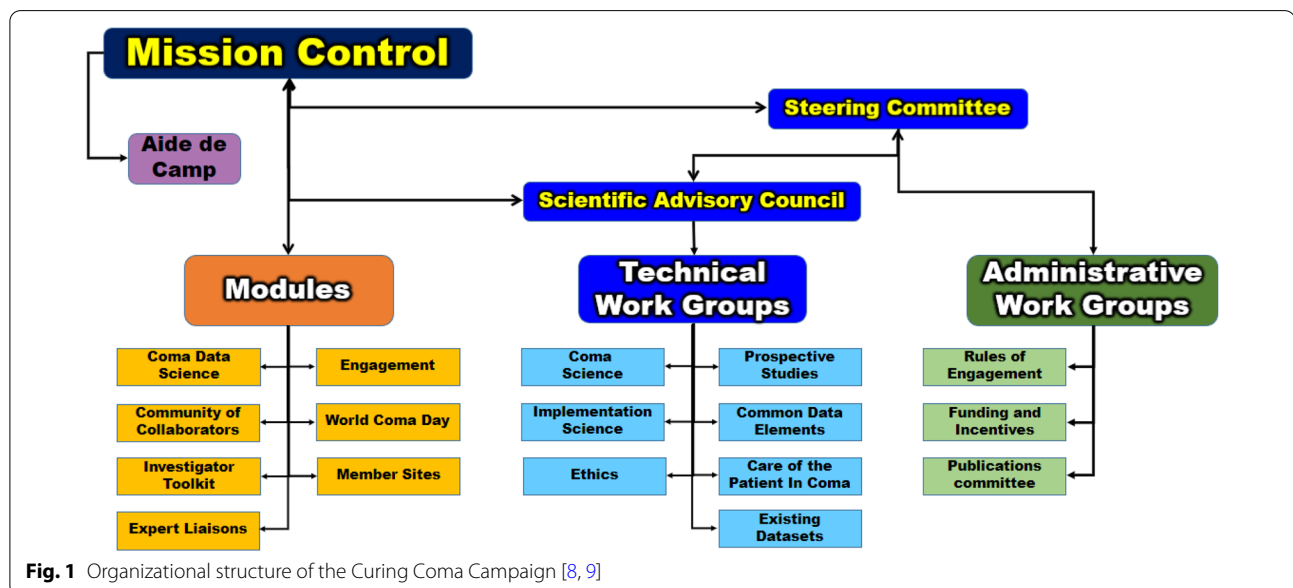


Fig. 1 Organizational structure of the Curing Coma Campaign [8, 9]

Table 1 Domain synthesis of current practice, gap analysis, future research, and implementation in the clinical setting for DoC care through COPIC consensus

Care domain	Current state of practice	Gaps in knowledge and evidence	Future research needs	Practical implementation in clinical setting
Clinical expertise	Use of NCC specialists Heterogeneous practice approach	Absence of standardized DoC training and education	Investigate DoC training experience Develop curriculum for interdisciplinary professionals	Develop systematic DoC professional education across the continuum of care
Assessment and monitoring	Heterogeneity of assessment Wide use of GCS Inaccuracies in assessment Real-time multimodal monitoring	Standardized assessment Consensus on interruption of sedation Recognition of CMD Use of monitoring data	Assessment results relation to acute outcomes Assessment results relation to longitudinal outcomes Bedside assessment of CMD	Collection of monitoring data to measure efficacy of interventions Assessment to guide treatment interventions Assessment data integrated in health learning systems
Timing of interventions	Neurochecks ICP placement Tracheostomy	Understanding of timing and frequency on recovery and outcome	Frequency and timing of bedside neuro-checks Timing of sedation cessation Initiation of rehabilitation	Evidence-based practice guiding timing of interventions Development of clinical processes to promote appropriate timing of treatment
Use of technology	Use of CT, MRI, and EEG Increased use of advanced neuroimaging	Use of data for health learning systems Global accessibility to technology Standardized protocols for technology use	Longitudinal neuroimaging and recovery of consciousness Data harmonization and large data sets Utility of data harmonization	Standardize use of accessible technology at bedside Development of protocols for implementation of technologies
Family communication and engagement	Heterogeneous family counseling and support Families confronted with decisions with poor understanding	Understanding families lived experience Informational needs along continuum Training of communication for professionals	Investigating the needs of families and caregivers Develop DoC-focused communication paradigms	Development of processes to consistently communicate with families or family meeting Systematic dissemination of DoC family education
Religion and culture	Culture and religion influence family decisions	Understanding of how culture and religions affects family decisions Professional training addressing culture and religion	Investigate ethnic and religious experience and impact on care decisions Impact of religious/cultural advisor in care decisions	Consistent integration of clergy and cultural mediators within care team Providing educational material in preferred language
Systems and transitions of care	Fractured pathway of care Influence of third party payers on access Prognostic nihilism AAN guideline of specialized multidisciplinary rehabilitation referral	Gap in standardized pathway for patients after ICU Absent third party payer recognition of specialized post-acute resources Gaps in health care policy to support DoC recovery Lack of specialized post-acute access Paucity of post-acute expertise	Investigate efficacy of post-acute rehabilitation Funding support to fill care system gaps Development of DoC education for post-acute settings	Develop relationships with acute and post-acute rehabilitation partners Consistent referral to specialized post-acute rehabilitation

Abbreviations: NCC neurocritical care, DoC disorders of consciousness, GCS Glasgow Coma Scale, CMD cognitive motor dissociation, ICP intracranial pressure, CT computed tomography, MRI magnetic resonance imaging, EEG electroencephalogram, AAN American Academy of Neurology, ICU intensive care unit

crucial. DoC-specialized training is a fundamental step toward improving bedside care for patients with DoC and supporting long-term recovery needs after discharge.

Assessment and Monitoring

Comprehensive clinical assessment and monitoring is the first step in caring for the patient with DoC and is imperative to guide subsequent plans for interventions [1]. Currently, there is wide heterogeneity in the assessment of DoC, with the Glasgow Coma Scale and National Institutes of Health Stroke Scale most commonly used [12]. Use of real-time monitoring of neurophysiologic signs and symptoms, referred to as multimodal monitoring, is also part of quality care. This approach incorporates the evaluation of several different variables, including intracranial pressure, brain tissue oxygenation, depth electroencephalography, and microdialysis. Neuromonitoring can provide crucial information in managing patients with DoC and help clinicians make informed treatment decisions to improve outcomes. However, this is also an area in which a wide heterogeneity in implementation of neuromonitoring exists [12].

Unfortunately, routine clinical examination and neuromonitoring fail to differentiate VS/UWS from MCS, which will reduce prognostic accuracy [14, 15]. Assessment is further confounded by lack of intensive care unit (ICU) protocols for interrupting sedation before behavioral assessment [12]. The Coma Recovery Scale-Revised (CRS-R) has demonstrated efficacy in identifying behaviors consistent with coma, VS/UWS, and MCS and is recommended for use in clinical practice [16]. Use of the CRS-R in the ICU is limited for various reasons, including time constraints for implementation. Administration (between 15 and 30 min) is particularly challenging given recent recommendations for frequent repeated measures for reliable DoC diagnosis [17]. Additionally, the level of experience seems to affect the reliability of CRS-R scores [18]. Consequently, there is a significant gap in use of standardized serial bedside assessment of consciousness. Abbreviated assessments, such as the Simplified Evaluation of Consciousness Disorders and CRS-R for Accelerated Standardized Assessment, may provide time-efficient alternatives for assessment in the ICU and improve accuracy of identifying level of consciousness [19–21].

Bedside assessment may fail to identify 15–20% of behaviorally unresponsive patients who demonstrate covert awareness, also known as cognitive motor dissociation (CMD) [22], by following commands through neuromodulation identified by active and passive imaging paradigms [23, 24]. Patients demonstrating CMD by functional magnetic resonance imaging (MRI)

while in the ICU have greater long-term recovery compared with patients in whom CMD is not identified [23, 25]. Current gaps in knowledge related to CMD, use of consistent nomenclature of the clinical phenomenon, and limited access to advanced imaging for assessment can limit the detection of CMD [22, 26]. Research and advocacy are needed to enable the development of easily adoptable methods for CMD detection and incorporate advanced neuroimaging in the routine assessment for CMD globally [22, 26].

Consistent bedside neurobehavioral assessment, monitoring, data collection, and analysis would promote precision medicine in DoC care. Currently, the Neurocritical Care Society endorses 21 performance measures supporting data collection to track efficacy of clinical care and patient outcomes. Examples of these measures include acute interventions for ischemic stroke and avoidance of steroids for TBI and intracerebral hemorrhage. Unfortunately, coma did not meet the evidentiary threshold to support development of a coma performance measure. Research efforts are required to evaluate the efficacy of assessment and monitoring modalities in DoC bedside interventions and identify DoC care quality indicators to measure and track clinical outcomes [12].

Timing of Interventions

When caring for patients with DoC, the timing for both major and minor interventions may significantly impact recovery [27]. For example, in patients with large hemispheric ischemic stroke, morbidity and mortality are affected by the timing of hemi-decompressive craniectomy, whereas studies on hypoxic-ischemic brain injury focus on rapid initiation of targeted temperature management [28, 29]. Early initiation of rehabilitation with DoC and management of complications, such as infections or pressure injuries, can optimize functional outcomes and improve quality of life [30–32].

Studies focusing on the timing of various medical and procedural interventions for DoC have not been undertaken. Consequently, there is an absence of evidence guiding the timing of interventions for DoC and a lack of data on the impact of the timing of interventions on the recovery of consciousness. The timing of bedside interventions for DoC, (e.g., endotracheal suctioning, sedation cessation, mobilization) are routine and embedded into daily practice. However it is unclear, due to the lack of evidence, if these interventions have a cumulative or independent impact on recovery. Focused research is required to appreciate the effect of timing of interventions on DoC care and recovery.

Use of Technology

Current technology in DoC care intends to classify pathophysiology, monitor clinical evolution, and predict outcomes. Advances in MRI and electroencephalography (EEG) allow clinicians to better understand DoC and help promote a holistic approach to treatment. MRI and EEG are rapidly evolving as higher-powered magnetic fields provide brain images of higher resolution for the identification of previously undetectable lesions that could serve as new targets for DoC treatments [33, 34]. Advances in EEG technology and signal processing, combined with machine learning and evolving analytical strategies, provide new electrophysiological insights into diagnosis, prognosis, and recovery assessment impacting DoC care [35]. Current and future trends in use of imaging and electrophysiological technology emphasize the implementation of active, passive, and resting-state paradigms to improve quality of care for the patient with DoC [36]. Similarly, use of advancing technology to promote improved consciousness, such as deep brain stimulation and transcranial direct current stimulation, is under active investigation through clinical trials and various control trials [37].

Despite the role of technology in the care of patients with DoC, several gaps remain. First, the maximum value of the technological tools outlined in this article and several others currently under development will only be realized when overall accessibility and full integration of these technologies at the bedside can be achieved globally, regardless of geographic location and socioeconomic position. Second, the absence of uniform protocols for deploying technologies along the care continuum impacts DoC outcomes [38]. Third, the value, utility, and data gained from advanced technologies require further investigation to ensure benefits for patients with DoC. The value of technology will be enhanced when captured within large data sets produced during hospitalization and after the widespread adoption of electronic medical records as health learning systems. Finally, a standardized approach to harmonize data collected from these technologies during bedside care is essential to establish a large cohort analysis and precision medicine for DoC.

Family Communication and Engagement

Families play a significant role in the care of their loved ones in DoC. Severe brain injury occurs unexpectedly, and patients typically do not have written advance directives or have not discussed their medical care preferences with their families in the event of incapacitation. Family understanding of DoC and the needs of their loved one can have a direct impact on the care decisions and bedside interventions. Most patients

with DoC require early life-or-death treatment decisions. Families are confronted with these decisions when they are overwhelmed with emotions, including grief. A recent qualitative study reported caregivers perceive communication with the physician to be an emotional experience that is uncomfortable and stressful. They report emotional distress ahead of conversations due to fear of receiving negative information. Furthermore, caregivers feel overwhelmed by the demand and the complexity of the content and the language of the information they were provided [39]. After medical stabilization, when the hospital is ready for discharge, families are frequently unprepared for the next steps both emotionally and mentally and have a poor understanding of postdischarge destinations and next steps [40].

Families require a holistic palliative care approach that includes psychosocial, emotional, spiritual, and informational support. Communication skills include asking families what type of information they require and what role they want to play in the decision-making process. Listening to families and exploring their individual needs are as important as explaining the brain injury, complications, management, and prognosis. Prognostic uncertainty is the rule in DoC and requires skilled communication. Explaining evidence-informed prognostic information can help engage families in decision-making related to goals of care [41]. Palliative care communication paradigms were developed for nonneurologic trajectories and fail to meet the unique informational and communication needs of families [40]. There is a need for research, specifically addressing and understanding the needs of families of patients with DoC across the continuum of care, to develop accessible resources for families and assist professionals in effective communication with families to support engagement in the care of and decisions for their loved ones.

Religion and Culture in DoC Care

Individual religious and cultural beliefs can impact decisions about goals of care and interventions provided in DoC [42]. For example, although patients with DoC may develop anemia, Jehovah's Witnesses do not accept blood transfusions [43]. Orthodox Jews often do not accept WOLST, whereas Reform Jews usually make decisions based on perceptions about therapeutic effectiveness [44].

A patient's or family's religion and culture can substantially affect care decisions, especially around continuation of life-sustaining treatments or WOLST and brain death determination. The determination of brain death is a complex issue influenced by various cultural and religious perspectives. In Western medicine, brain death is often equated with the cessation of all brain

activity, which legally and ethically permits WOLST and organ donation. However, this concept is not universally accepted. For instance, in Japan, cultural beliefs place significant emphasis on the holistic view of life and death, resulting in greater skepticism toward brain death criteria and a lower rate of organ donation [45, 46].

Religious and cultural impact on care decisions can continue to increase in complexity within the chronic phases of DoC as patients become medically stable and may not require life-sustaining interventions, such as a ventilator. Catholicism is an example that views artificial hydration and nutrition as basic care and WOLST as unethical and impermissible, even in cases of a persistent vegetative state [47].

As clinicians engage in goals-of-care discussions for patients, cultural humility is a fundamental skill, as it presents the genuine attempt to understand how a person's identity (regarding religion, race, gender, ethnicity, etc.) may influence decisions. Approach in care perspectives vary within a given religion or culture, and there is a gap in understanding of how various cultures and religions impact the approach to care decisions and understanding of DoC by families and caregivers. Families must be supported by the health care team and have access to religious advisors to express their concerns, help contextualize the information clinicians provide, and create a compassionate space. Research is needed to explore the knowledge and perceptions of cultural and religious leaders and followers of different faiths about DoC to implement patient- and family-centered care.

Systems of Care for DoC

Patients with DoC are not widely viewed as requiring tertiary or quaternary care referral. Consequentially, a systematic referral system for DoC care does not exist. The current US health care system is highly influenced by third-party reimbursement, which can limit access to specialized DoC post-acute care. This contradicts the 2018 American Academy of Neurology (AAN) DoC Practice Guidelines, which recommend "referral to specialized, interdisciplinary rehabilitation once medical stability is achieved..." [48]. Health care policy supporting DoC care has lagged because of continued debates regarding the prognostic uncertainty of clinical trajectory related to recovery outcomes [49].

The National Academies of Science, Engineering, and Medicine published the first-ever report on the challenges of current health care service provision, gaps that limit access to appropriate services to survivors of TBI (including DoC), and recommendations to address identified gaps. Some of these recommendations include integrating acute and long-term person- and

family-centered management of TBI, integrating TBI care and research into learning health systems, and reducing unwarranted variability in clinical care [50]. Unfortunately, a paucity of effective care pathways for DoC is not isolated to the United States and is a global challenge. International studies have concluded similar fractures in systems of care and access to care in multiple countries [51, 52].

Financial and infrastructure resources are needed to address gaps in health care systems and policies to support access to specialized services in both acute and chronic DoC to ensure access to quality care across the continuum. Concepts addressing the benefits of care systems have been put forth to promote health policy approaches to employ comprehensive therapeutic tools in an evolving scientific environment for patients with DoC [53]. Research is needed to provide robust evidence for efficacy of improving outcomes for prolonged rehabilitation and care services for patients with DoC.

Transitions from Acute to Post-Acute Care

As discussed, there is an absence of care pathways to ensure patients with DoC have access to specialized post-acute services to promote recovery [50, 53]. Medically stable patients are often discharged from ICU to long-term care settings, where they receive little specialized care [54, 55]. Post-acute settings typically do not contain the resources or clinical expertise to manage the complex medical and rehabilitation needs of patients with chronic DoC. This perpetuates lower recovery rates, higher complication rates, and poorer long-term outcomes, including increased mortality [56].

The AAN DoC Practice Guidelines express the recovery potential and need for expert multidisciplinary care to maximize functional outcomes. DoC-focused minimal competency recommendations outline the staff, goals, and management strategies that should be in place in a DoC rehabilitation program [48, 57]. Evidence demonstrates that among patients with traumatic DoC selected to receive inpatient rehabilitation, up to 80% achieve consciousness and a positive trajectory toward long-term function, including independence in mobility, self-care, and, in many cases, eventually a return to school or work [6, 7, 58].

Regardless of outcome, DoC remain grossly marginalized and underserved. There is a pressing need to restructure post-acute care accessibility and management. Access to specialized care and rehabilitation after severe brain injury is a civil rights issue, given the striking discrepancy in access to rehabilitation for this subgroup compared to other populations [59]. Targeted research and policy advocacy efforts are required to promote access to specialized post-acute care, which can enhance

recovery at the individual level and reduce the long-term economic burden on society.

Conclusions

Improvements in survival after severe acute brain injury and growing efforts to decrease early WOLST have increased the number of patients with DoC. COPIC has identified gaps in knowledge and areas of scientific exploration of the efficacy and impact of bedside interventions related to DoC. Urgent action and funding to address gaps and support research to improve the care in DoC are required. Recommended actions include the following: (1) development of systematic DoC education and curriculum for clinicians; (2) standardization of bedside assessment tools and protocols; (3) optimization of the timing of DoC care interventions through global multicenter research initiatives; (4) implementation of technology and leveraging of large data sets to promote precision medicine for assessment and treatment interventions; (5) examination of the efficacy of rehabilitation interventions; and (6) development of avenues to improve surrogate engagement and support and incorporate familial, cultural, and religious beliefs of families of patients with DoC. These action-steps will require collaboration of interdisciplinary experts, organizations and funding opportunities.

The successful bedside care of patients with DoC necessitates an interdisciplinary collaboration that integrates the diverse expertise of neurologists, rehabilitation specialists, neuropsychologists, ethicists, health care advocates, policy makers, and funders. Such collaboration is essential to achieve the call to action listed in this article. Fostering a comprehensive approach and collaboration that combines clinical insights, ethical considerations, and innovative research, we can achieve these goals, advance knowledge, optimize care, and improve outcomes for patients with DoC and their families.

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Acknowledgements

Curing Coma Collaborators: Sachin Agarwal, Venkatesh Aiyagari, Yama Akbari, Fawaz Al-Mufti, Asher Albertson, Sheila Alexander, Anne Alexandrov, Ayham Alkhachroum, Moshagan Amiri, Brian Appavu, Hugo Ardaillon, Charlene Aubinet, Meron Awraris Gebrewold, Marc Ayounb, Rafael Badenes, Mary Kay Bader, Neeraj Badjiata, Ram Balu, Brooke Barlow, Megan Barra, Rachel Beekman, Ettore Beghi, Andreas Bender, Erta Beqiri, Tracey Berlin, Federico Bilotta, Thomas Bleck, Yelena Bodien, Varina Boerwinkle, Melanie Boly, Alexandra Bonnel, Luca Brazzi, Emery Brown, Sebina Bulic, Eder Caceres, Adrian Caceres, Tullio Cafero, Elizabeth Carroll, Emilio G Cediel, Sherry Chou, Giuseppe Citerio, Jan Claassen, Chad Condie, Alfredo Conti, Katie Cosmas, Paolo Costa, Claire Creutzfeldt, Neha Dangayach, Mario Dauri, Derek Debicki, Michael DeGeorgia, Caroline Der-Nigoghossian, Masoom Desai, Rajat Dhar, Michael Diringer, Karin Diseren, Emily Durr, Brian Edlow, Ari Ercole, Anna Estraneo, Guido Falcone, Salia Farrokh, Adam Ferguson, Davinia Fernandez-Espejo, Ericka Fink, Joseph Fins, Brandon Foreman, Federico Franchi, Jennifer Frontera, Rishi Ganesan, Nicolas Gaspard, Ahmeh Ghavam, Joseph Giacino, Christie Gibbons, Emily Gilmore, Chavie Glustein, Olivia Gosseries, Theresa Green, David Greer, Mary Guanci, Deepak Gupta, Cecil Hahn, Ryan Hakim, Flora Hammond, Daniel F Hanley, Ahmed Hassan, Raimund Helbok, Claude Hemphill, Arthur Henrique Galvão Bruno Da Cunha, H.E. Hinson, Karen Hirsch, Sarah Hocker, Peter Hu, Xiao Hu, Theresa Human, David Hwang, Judy Illes, Matthew Jaffa, Michael L. James, Anna Janas, Susan Johnson, Jane Johr, Morgan Jones, Ralf J Jox, Atul Kalanuria, Emanuela Keller, Lori Kennedy, Megan Kennelly, Maggie Keogh, Jenn Kim, Keri Kim, Hannah Kirsch, Matthew Kirschen, Nerissa Ko, Daniel Kondziella, Natalie Kreitzer, Julie Kromm, Abhay Kumar, Pedro Kurtz, Steven Laureys, Thomas Lawson, Nicolas Lejeune, Ariane Lewis, John Liang, Geoffrey Ling, Sarah Livesay, Jacques Luauté, Andrea Luppi, Jennifer MacDonald, Craig Maddux, Dea Mahanes, Sherif Mahmoud, Shraddha Mainali, Nelson Maldonado, Rennan Martins Ribeiro, Luciana Mascia, Errikos Maslias, Marcello Massimini, Rohan Mathur, Stephan Mayer, Victoria McCredie, Molly McNett, Jorge Mejia-Mantilla, Michael Mendoza, David Menon, Geert Meyfroidt, Julio Mijangos, Dick Moberg, Asma Moheet, Erika Molteni, Elisa Montalenti, Martin Monti, Chris Morrison, Susanne Muehlschlegel, Marina Munar, Brooke Murtaugh, Lionel Naccache, Masao Nagayama, Emerson Nairon, Thomas Nakagawa, Andrea Naldi, Ganesalingam Narenthiran, Girija Natarajan, Esther Nemetsky, Virginia Newcombe, Niklas Nielsen, Naomi Niznick, Filipa Noronha-Falcão, Paul Nyquist, Katherine O'Brien, DaiWai Olson, Marwan Othman, Berno Overbeek, Adrian Owen, Llewellyn Padayachy, Mehrnaz Pajoumand, Soojin Park, Lindsey Patton, Melissa Pergakis, Heidi Perry, Len Polizzotto, Nader Pouratian, Marilyn Price Spivack, Lara Prisco, Javier Provencio, Francesco Puglises, Louis Puybasset, Chethan Rao, Lindsay Rasmussen, Verena Rass, Frank Rasulo, Bappaditya Ray, Michael Reznik, Zaccaria Ricci, Risa Richardson, Cassia Righy Shinotsuka, Chiara Robba, Courtney Robertson, Benjamin Rohaut, John Rolston, Stefano Romagnoli, Mario Rosanova, Eric Rosenthal, Shaun Rowe, Michael Rubin, Mary Beth Russell, Gisele Sampaio Silva, Leandro Sanz, Simone Sarasso, Aarti Sarwal, Nicolas Schiff, Caroline Schnakers, David Seder, Vishank Arun Shah, Amy Shapiro-Rosenbaum, Angela Shapshak, Kartavya Sharma, Kumar Ajay Sharma, Tarek Sharshar, Lori Shutter, Jacobo Sitt, Beth Slomine, Keaton Smetana, Peter Smielewski, Wade Smith, Beth Solomine, Emmanuel Stamatakis, Alexis Steinberg, Robert Stevens, Jose Suarez, Gene Sung, Bethany Sussman, Shaurya Taran, Anna Teresa Mazzeo, Aurore Thibaut, David Thompson, Zachary Threlkeld, Lorenzo Tinti, Daniel Toker, Michel Torbey, Jenna Tosto, Stephen Trevick, Georgia Tsaousi, Alexis Turgeon, Lynne Turner Stokes, Andrew Udy, Panos Varelas, Paul Vespa, Walter Videtta, Henning Voss, Ford Vox, Michaela Waak, Amy Wagner, Sarah Wahlster, Mark Wainwright, Jennifer Weaver, John Whyte, Briana Witherspoon, Aleksandra (Sasha) Yakhkind, Susan Yeager, Michael Young, Sahar Zafar, Ross Zafonte, Darin Zahuranec, Chris Zammit, Bei Zhang, Wendy Ziai, Lara Zimmerman, Elizabeth Zink. The authors would like to acknowledge and thank the CCC Executive Committee and CCC members contributing to date. The authors specifically thank the CCC Scientific Steering Committee for their support in development and submission of this manuscript.

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BM: conceptualization (lead), writing the "Introduction" (lead), reviewing/editing (lead), preparation for submission (lead); DMO: writing "Timing of interventions" section (lead), reviewing/editing (supporting); NB: reviewing/editing (supporting); AL: writing "Religion and culture in DoC care" section (lead); reviewing/editing (supporting); VA: reviewing/editing (supporting);

KS: writing "Assessment and monitoring" section (lead), reviewing/editing (supporting); CJC: writing "Family communication and engagement" section (lead), reviewing/editing (supporting); GJF: writing "Use of technology" section (lead); AS-R: writing "Transitions from acute to post-acute care" section (lead); EKZ and JIS: writing "Systems of care for DoC" section (co-leads); GSS: writing "Clinical expertise" section (lead), reviewing/editing (supporting).

Source of Support

No funding was provided for the development and completion of this article.

Conflict of interest

The authors do not have any conflicts of interests to disclose related to the content within this article.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Received: 16 May 2024 Accepted: 22 August 2024

Published online: 21 October 2024

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