



# Voices in the Void:

## The Silent Healthcare Crisis in Disorders of Consciousness

### THE PROBLEM:

Patients with disorders of consciousness (DoC) are often treated with little regard. While physical symptoms are treated, no effort is put into communicating with these patients or restoring their personal autonomy.

This is a violation of a fundamental human right (McLeod, 2018). The inability to communicate isolates these patients from principles of medical beneficence, personal autonomy and the right to communicate and socialize with others.



### WHAT IS A DISORDER OF CONSCIOUSNESS?

A disorder of consciousness (DoC) is a medical condition where a patient's level of consciousness is significantly altered or impaired. This is usually separated into three different categories:

- Coma
- Vegetative State
- Minimall Conscious State

Patients with DoC tend to have suffered a traumatic brain injury or may be receiving end-of-life care, which can often include terminal sedation (Takla et al., 2021).

Technological advancements have provided us with insight on how to communicate with these patients and restore their ability to communicate using "brain power". It provides them with the ability to retain personal autonomy and to socialize with others.



DoC patients are not treated with a level of care worthy of humans. They are unable to communicate their needs, have autonomy, or be involved in the treatment process.

### EVENTS

- High rate of misdiagnosis of DoC patients (40%)
- Patients inability to communicate or make decisions about treatment plans.
- Stigma segregates patients and influences detrimental decisions to be made on their behalf.
- Lack of funds for healthcare for patients.
- Lack of research in this area or protocols for change.

### PATTERNS OF BEHAVIOUR

- Lack of funding to facilitate research or allow for appropriate treatment.
- Require organisation between many stakeholders to acknowledge the problem and implement.
- Lack of communication between professionals in this field and other stakeholders.
- Lack of awareness of this issue in media.
- Lack of disability laws in most countries that could allow patients of DoC to be considered

### SYSTEMATIC STRUCTURE

- Common misconception that DoC have no consciousness. Stigma akin to "death".
- Disconnect between family and friends vs. healthcare staff with hopes for recovery.
- Assumption that recovery is impossible.

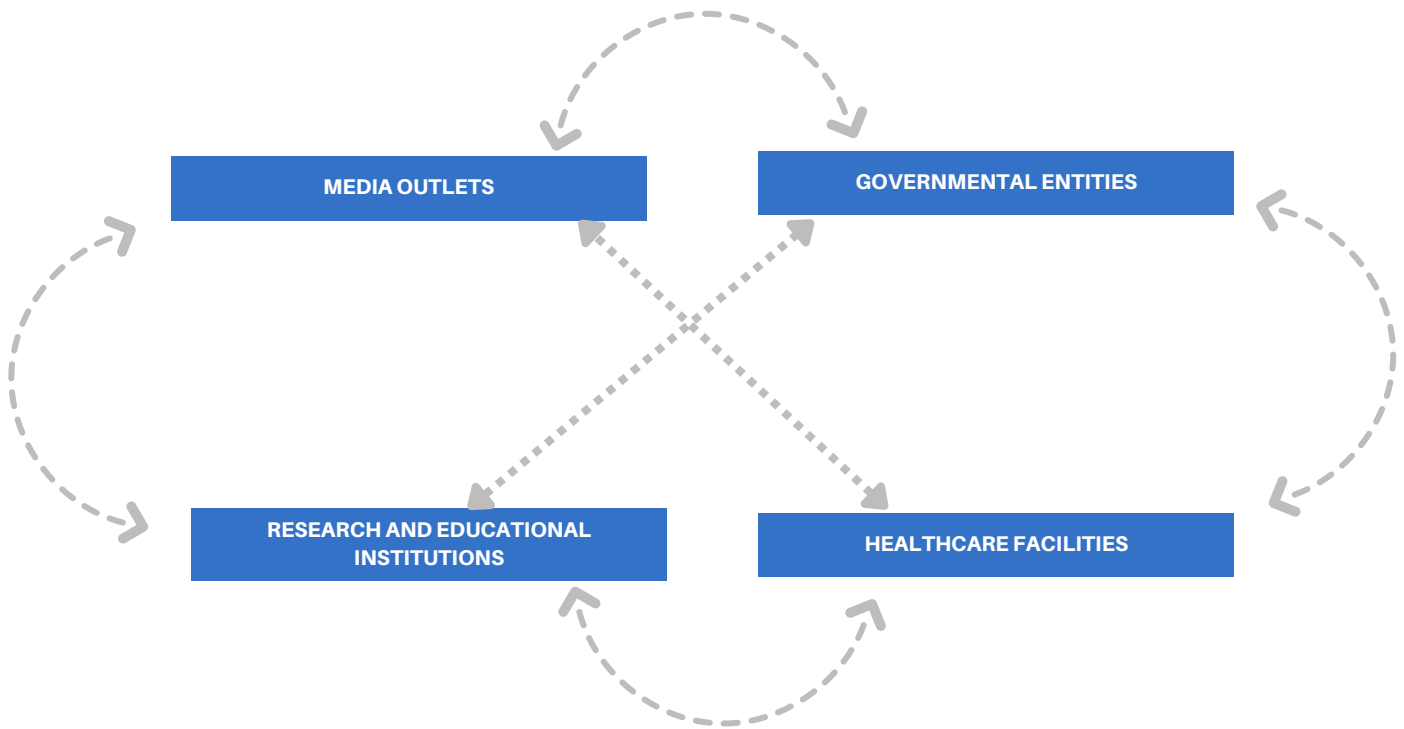
### MENTAL MODELS

# CHALLENGES AND STAKEHOLDER MAP



# SOLUTIONS LANDSCAPE AND LEVERS OF CHANGE

External entities and governmental entities work together to influence public perception of the problem. By raising awareness, additional funding can go into consciousness research in order to develop a robust research and treatment protocol for these patients. The different entities responsible for levers of change include:



On a patient care level, there are several other factors that are involved with different healthcare professionals.

## Level 1: Detection and Diagnosis

Stakeholders involved: Neurologists, radiologists and healthcare professionals who treat the underlying conditions, patients and their families and friends

## Level 2: Prognosis

Stakeholders involved: Neurologists and healthcare professionals responsible for prognosis, patients and families involved in future treatment decisions, health insurance companies

## Level 3: Treatment Planning

Stakeholders involved: Neurosurgeons responsible for invasive procedures, rehabilitation specialists, proxy for healthcare decisions

## Level 4: Treatment Monitoring

Stakeholders involved: Researchers, healthcare professionals, healthcare agencies

## Level 5: Research

Stakeholders involved: Researchers and funding agencies involved

# SYSTEMS MAP: PUTTING IT ALL TOGETHER

