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Voices in the Void:

The Silent Healthcare Crisis in
Disorders of Consciousness



Map the Systems 2023

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INTRODUCTION

01

Returning voices and autonomy to unresponsive patients

EXECUTIVE SUMMARY



The right to communicate, or which includes the **freedom of opinion and expression without distinction of language**, is a **fundamental universal human right** (McLeod, 2018). Unfortunately, patients struggling with disorders of consciousness are often unresponsive and incapable of physically communicating, isolating them from principles of medical beneficence, personal autonomy and the right to communicate with others.

Disorders of consciousness are not restricted to brain injuries. Often, end-of-life care for palliative patients involves deeply sedating patients to the point of unconsciousness in an attempt to alleviate suffering (Takla, et al., 2021). There are different levels of consciousness (Table 1). **The patients' wellbeing and autonomy are transferred to proxy health care or physicians who must make healthcare decisions on behalf of the patients** (Crane et al., 2005; Cavalieri, 2001).

Previously, there were no methods to communicate with these patients. Thankfully, **advancements in technology have unlocked novel brain imaging methods that allow physicians to potentially communicate with patients** (Tamburrini and Mattia, 2001); thus, the fundamental human right for communication no longer should be ignored.

The purpose of our project is to examine the complicated and complex systems involved with the implementation and feasibility of using brain imaging techniques for communication. Challenges encompass spiritual, ethical, legal, medical, societal and personal perspectives.

	Minimally Conscious State (MCS)	Vegetative State (VS)	Coma
Eye opening	Spontaneous	Spontaneous	None
Movement & Behaviour	Recognise, reach, hold objects. Environmentally contingent behaviors not attributable to reflexive action (e.g. smiling, vocalizations, head shake, attempt to speak when asked question).	Reflexive (e.g. attempts to speak randomly) Preserved physiological functions (cardiac, sleep/wake, respiratory)	No verbal or motor responses
Responses to pain	Localisation (can identify where the pain is coming from then prevent it from happening again)	Withdrawal (pull arm away)	Tensing but no withdrawal
Awakeness	Awake	Awake	Not Awake
Awareness	Some awareness	Not aware	Not aware
Volitional motor behavior	Some	None	None

Table 1. A Look at Varying States of Consciousness from Highest Level of Consciousness to Lowest.

INTRODUCTION

02

MOTIVATION AND POSITIONALITY



We are a team of two undergraduate students enrolled at the University of British Columbia (UBC) who are part of the Consciousness Lab. Both of us have experience interacting with patients who struggle with varying levels of disorders of consciousness. One of our teammates volunteers at Burnaby Hospice and interacts with unresponsive palliative patients on a weekly basis. We acknowledge that, even with our experiences, our work is shaped by our specific subject positions and perspectives. Appendix B elaborated on each out of motivations and subject positions.

One limitation of our research is the limited sample size in our survey. This is due to the lack of access to healthcare professionals and family and friends who are currently treating or caring for patients with disorders of consciousness. The sensitivity of this subject is a barrier to open communication.



Literature
Reviews



Interviews and
Discussions



Anonymous
Surveys

RESEARCH METHODOLOGY



Our team conducted an extensive literature review of government publications, current health protocols all over the world, academic journals, media articles and non-fiction writing to gain a better understanding of:

1

Current healthcare protocols surrounding care of patients with disorders of consciousness

2

Advancements in technology that may allow for communication with these patients

3

Sentiments of healthcare professionals, family and friends, legal entities and other governmental entities

4

The barriers and challenges surrounding the implementation of such care

We conferred with neuroscientists studying consciousness and interviewed nurses working in palliative wards and hospitals, as well as family and friends of patients with disorders of consciousness.

Additionally, we also conducted an anonymous, online survey regarding attitudes of family and friends of patients, as well as healthcare professionals, towards implementing possible care.

"Consciousness poses the most baffling problems in the science of the mind. There is nothing that we know more intimately than conscious experience, but there is nothing that is harder to explain."

David Chalmers

CHALLENGE LANDSCAPE

03

CHALLENGE LANDSCAPE



Disorders of consciousness include coma, vegetative state (also known as unresponsive wakefulness syndrome) and minimally conscious states (Table 1). 15-20% of patients with these conditions have a cognitive-motor dissociation (Silverberg, 2023), which means that they have some awareness that cannot be seen behaviourally due to a brain-body disconnect. However, despite the variability between these conditions, most of these disorders tend to get lumped into a "vegetative state" (Owen, 2019).

At present, there is not sufficient interest or funding towards this issue, and the patients' fundamental rights to communication are often ignored in favor of treatment protocols that treat underlying symptoms and conditions. There is a lack of healthcare understanding and protocol for dealing with patients of such disorders, leading to several problems that contribute to this silent healthcare crisis. We have outlined several main challenges associated with just starting the conversation.

1

Improper diagnostic and prognostic tools for disorders of consciousness

2

Ethical and legal issues associated with the patients' inability to consent

3

Lack of research for these conditions and for the technological advancements in this area

4

Financial implications and labor allocations for providing tools for communication

STAKEHOLDERS AND IMPACTS



Our systems-based approach to this problem has led us to uncover the complex relationships between various stakeholders and systematic consequences that result in this healthcare crisis. Our key stakeholders are governments and the legal system, patients, friends and family of patients, healthcare professionals, educational institutions, and researchers. The concept map in Appendix D identifies the interconnected relationship between resources, roles and relationships between stakeholders and effects.

Some important stakeholder insights are:

- Two-layered barriers to research - accessibility of patients and lack of funding for researchers
- Lack of clear definitions and protocols for how to proceed with such patients by educational and health-care institutions
- Lack of dissemination of information to the general public due to lack of communication between journalists, governments and institutions.
- Having reliable and mentally-capable surrogates of patients' will is important
- Having health-care professionals and caregivers who are willing to work on patients' condition progressively after diagnosis are important

Challenge Landscape

04

ROOT CAUSES



1

Improper Diagnostic and Prognostic Tools for Disorders of Consciousness

Misdiagnosis is common for disorders of consciousness, with 40% of patients being misdiagnosed (Monti et al., 2010). Out of these, 15-20% patients have cognitive motor disassociation, having preserved/impaired consciousness but no physical response to show for it. Locked-in-syndrome patients, who have completely intact consciousness but cannot move at all, tend to be lumped into the same category as well (Chua, 2021). Furthermore, 2 in 3 patients in a vegetative state will transition to a minimally conscious state within 6 months (Silverberg, 2023). Since there is no follow-up protocol for these disorders to check for brain activity, most healthcare providers would not know that a change in consciousness has occurred. Most patients end up being unaccounted for despite having some level of consciousness.

2

Ethical Issues Related to Patients' Treatment and Inability to Consent

There is a large stigma associated with disorders of consciousness, being treated as “undignified conditions akin to death” (Chua, 2021). Patients have been either prematurely discharged or they have been diagnosed as “permanent vegetative state” (Chua, 2021). Although this term has been changed to “chronic vegetative state” (Chua, 2021), suggesting better prognosis, it is still difficult to systematically implement changes within laws and healthcare institutions. This means that family members may have been forced to pull the plug or make decisions on their behalf, being under the assumption that there is no recovery or awareness. However, the large percentage of misdiagnosis suggests that this is not the case with disorders of consciousness.

In 2018, the American Academy of Neurology did propose significant revisions to the treatment and care of such patients (Giacino et al., 2018), however, there is still stigma regarding this topic. Further, similar actions have not even been considered in other countries. It seems that such patients are still not being treated as humans worthy of care (Chua, 2021). Rather than being treated as disabled patients subject to disability laws, these patients are being segregated from friends and family (Chua, 2021), decreasing their chances of recovery. However, healthcare is expensive for such patients, especially when it is not clear when they will recover. Hence, it is difficult for these individuals to be considered under the American Disability Act as they need to meet certain conditions (Chua, 2021), which they cannot prove due to being unable to communicate. Beyond America, no Act even exists. This is also a straining and mentally arduous process for friends and family, who have to be responsible for the will of someone else (Appendix C). This information is not accurately disseminated across all stakeholders via journalism either.

Challenge Landscape

05

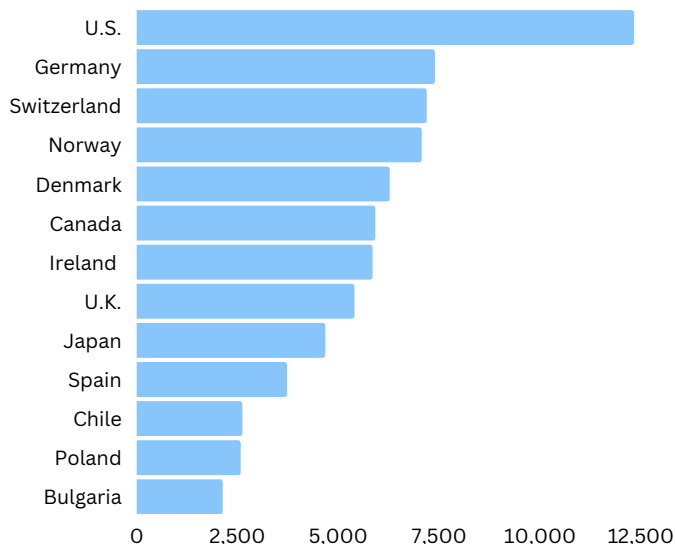
3

Barriers to Research for Disorders of Consciousness

Within the research communities, despite many papers being published about some states of consciousness, there is no clear definition of what would constitute conscious awareness for patients of disorders of consciousness. There was a “Curing Coma Campaign”, consisting of a group of professionals that formed a “Scientific Advisory Council” to oversee improvements to healthcare practices (Provencio et al., 2020). This campaign has made promising first steps in trying to facilitate change, however, there is still a lack of implementation of these recommendations. Not only is this expensive to implement, there are logistical issues that prevent this from being systematic changes. Furthermore, through a research lens, there is still no governing body synthesizing existing research to create a protocol specific to communication with such patients.

It is difficult to conduct research on such patients due to many barriers to research. Current neuroimaging techniques are expensive and time-consuming, so it is difficult to receive funding (Owen, 2019) to conduct intensive studies with a large sample of patients. Moreover, patients themselves tend to have barriers that do not allow them to participate in such studies or methodologies. Patients may reside in rural places where they do not have access to such equipment, or have health barriers that prevent them from participating in studies with certain equipment.

Per Capita Health Care Spending in Select Organisation for Economic Co-operation and Development (OECD) Countries in 2021



4

Financial implications and labor allocations for providing tools for communication

Another notable challenge is finding financial and labor allocation for providing this healthcare service. The per capita healthcare spending for many Organisation for Economic Co-operation and Development (OECD) countries (Health Resources, 2023) is already quite high. Providing a voice for those who are unresponsive may have further financial implications on the healthcare system.

Additionally, nurses and many other healthcare professionals already experience high workloads. As a result, it may be difficult to allocate resources for this service (Miller and Hemberg, 2022).

SOLUTIONS LANDSCAPE

06

CURRENT HEALTHCARE PRACTICES

Current treatment protocols for non-responsive patients include assessments of response to physical stimulation, neurological assessments and defined treatments for any physical symptoms (Huffman and Stern, 2003). EEG may be used to diagnose unremitting complex partial or atonic seizures or the extent of the brain damage. Ongoing nursing management involves implementing frameworks of care that prevent further complication and managing the underlying cause of unconsciousness (Geraghty, 2005).

Unfortunately, management of care does not involve active assessment of patient conscious levels or attempts to “communicate” with the patient about their needs or experience. There is no standard test of awareness and data on prognosis is limited, which raises ethical dilemmas like a lack of ability to consent and lack of self-autonomy (Wade, 2001). The quality of care may also be compromised due to lack of communication.

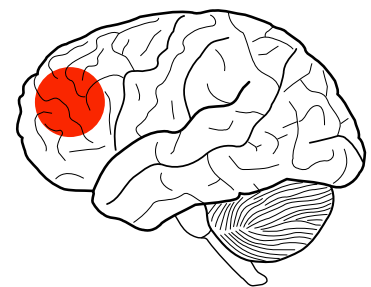
Furthermore, we did not find any active protocols, amendments or movements towards giving these patients back their voice. Instead, one medical professional that we interviewed stated that while two-way communication is not possible, they alleviate lack of communication by speaking to patients about the care they receive since studies have presented electrophysiological evidence of preserved hearing at end-of-life and in unresponsive patients (Blundon, et al., 2020). This is an attempt to bridge the gap and restore the patients’ basic human right to communication. In 2020, the first Coma Campaign scientific advisory council meeting was held to also discuss potential solutions (Provencio, et al., 2020).

POTENTIAL SOLUTIONS THANKS TO TECHNOLOGICAL ADVANCEMENTS

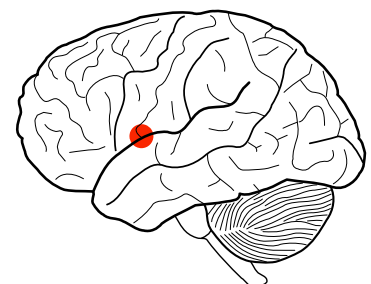
A more detailed search of literature uncovered that this may not be the only solution. Recent technological advances suggest that brain imaging techniques can be used to communicate with unresponsive patients. Brain activity, like BOLD activity with functional magnetic resonance imaging (fMRI) and evoked potentials with electroencephalogram (EEG), can be correlated with “yes” or “no” answers to investigate the patient’s internal dialogue or ability to perceive the environment (Owen et al., 2008;). Samuel and Kitzinger (2013) also presented research that supports using fMRI data to give vegetative patients back their voice.

Same Task (Imagine Yourself Playing Tennis):

Average for healthy patients:



Average for unresponsive patients:



POTENTIAL FMRI ACTIVITY

SOLUTIONS LANDSCAPE

07

fMRI can be used to determine conscious state and make decisions on whether life-sustaining treatment should be withdrawn (Skene et al., 2009). These results appear to be reproducible. Monti et al., (2010) conducted fMRI brain scans of fifty-four vegetative state and minimally conscious state patients using the same experimental paradigm as Dr. Owen found significant brain activity in four vegetative state patients and one minimally conscious state patient. Using fMRI to constantly evaluate the conscious state of all non-responsive, vegetative state or minimally conscious state patient may be a solution, but there is a high-cost attached. In the fiscal year 2020 to 2021, the average cost per scan was \$819 in Canada (Private Imaging Facilities, 2023).

A more cost-effective brain imaging tool currently under investigation is the use of EEG to determine conscious states and to “communicate” with patients. There is a surprising lack of research using this novel technique. Preliminary research has shown some motor cognition (Cruse et al., 2011) and auditory cognition (Blundon et al., 2020), however, due to the low spatial resolution of EEG, there is not enough data yet.

At a glance



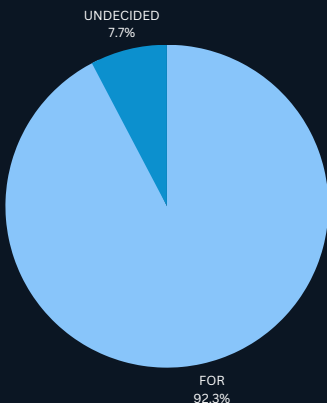
9

Healthcare professionals



4

Family and Friends



INPUT FROM HEALTHCARE PROFESSIONALS AND FAMILY/FRIENDS OF PATIENTS



We interviewed **9** medical professionals, and found that 8 interviewees supported the use of EEG, fMRI or other brain imaging techniques to communicate or better understand patients in vegetative or comatose states. 1 medical expert was neither in favor or not in favor, as they would like to see more robust results and more brain imaging studies that show replicability of previous findings. 8 of the medical professionals believe anything that could potentially aid in the care and improve communication between healthcare providers and patients would be beneficial. A psychologist we interviewed supported the use of brain imaging techniques, as they believe that it would allow for potentially better care of patients and may result in a more positive prognosis. Although the general sentiment is positive, concerns were raised on (1) the feasibility of this method, (2) whether there are sufficient labour resources to implement in patient care, and (3) the ethical implications of using this method for communication.

For a more personal perspective, we interviewed 4 family members. They expressed that they would appreciate the effort and would use these services if they are available. Currently, many family members use positive language with patients in an attempt to aid recovery – a technique recommended by medical professionals and found to be implemented often by family and friends in qualitative surveys that we found during our literature searches (Boegle, et al., 2022).

LEVERS OF CHANGE

08

LEVERS OF CHANGE



When examining the silent health crisis of disorders of consciousness, we recognise the importance of systematic changes to solve the root problems that result in the poor care of these patients. Addressing this issue will require critical analysis of the root causes and current solutions to synthesize feasible levers of change. Working with government organizations, educational institutions, healthcare professionals and families of patients is crucial. Such a multi-pronged, multifaceted approach will ensure sustainable improvements for the treatment of patients with disorders of consciousness. Thus, we suggest the following three opportunities for change, which might result in systematic changes needed to address the healthcare crisis for disorders of consciousness.

Opportunity 1

Synthesizing multiple technologies to attempt communication in patients.

We have identified a lack of cohesive research in the field to be a root cause of this issue. This opportunity can be pursued by research and educational institutions. Our proposed opportunity is to use multiple technologies in conjunction, rather than individually, to attempt communication in patients. Luauté et al (2018) suggests that electrodermal activity can be used as a marker for emotional consciousness. Perhaps an electroencephalogram can be used in conjunction with an electrodermograph to measure consciousness. Using both in conjunction will allow researchers to see consistent and reliable data. Compared to previous studies, we recommend utilizing separate scenarios as well, activating different brain networks rather than being limited to visuospatial or motor imagery tasks. Using these scenarios, we can ask participants yes/no scenarios, and ask them to imagine a) for yes, and b) for no, allowing communication. From previous research (Blundon et al., 2020; Cruse et al., 2008), it seems like using one methodology isn't enough, so using multiple technologies can allow greater accuracy in research.

Opportunity 2

Enforcing more empathetic healthcare practises.

Patients tend to get left to their own devices when in hospitals, although 40% of patients get misdiagnosed despite having some level of awareness (Monti et al., 2010). Research has shown that patients of disorders of consciousness respond favorably to familiar faces or voices (Owen et al., 2008). Further, anecdotes from family members and hospital staff suggests that building a rapport with patients by talking to them in this state helps with recovery (Steere, 2015). Some patients remember their interactions while in coma, since hearing is the last to go (Blundon et al., 2020;), so talking to these patients with empathy and care may be a beneficial healthcare practice. Furthermore, many patients transition from coma or vegetative state to minimally conscious over time (Silverberg, 2023). However, since healthcare staff do not regularly check up on these patients (Chua, 2021), we won't know of changes to states of consciousness. Treating these patients humanely, even if they appear unresponsive, with regular diagnostic tests, can aid in faster recovery. Even if complete recovery is not possible, these techniques can at least allow for some level of awareness to return.

LEVERS OF CHANGE

09

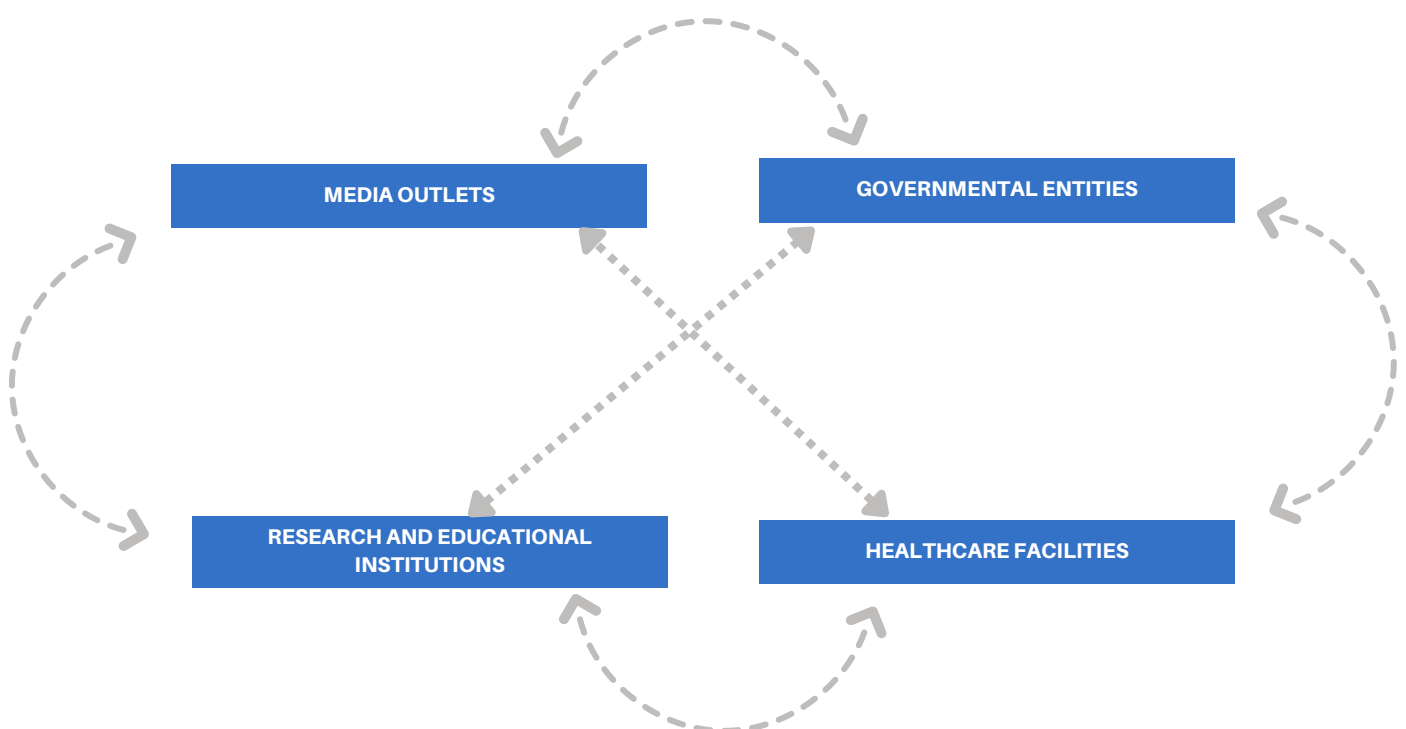
Opportunity 3

Disseminating accurate scientific information to the public for greater awareness of this issue.

Public perception of those in "vegetative states" appears to be more negative than positive (Kondziella, et al., 2019). There is also an opportunity to disseminate inaccurate scientific information and spread awareness of this gap in healthcare. It's vital that more journalists and media outlets bring attention to this issue and also emphasize that not all patients are the same, and that all patients deserve to have their fundamental human rights met.

Positive journalism and activism about this issue may allow for greater pressure for institutions to allocate greater grants for future research and maintain optimal care for these patients at hospitals. It may also lead to more support groups for family and friends who are involved in the care of these patients, as they require support as well. Researchers have found that a high prevalence of caregiver burnout amongst those providing and managing care for patients in minimally conscious states (Goseri, et al., 2012).

MAJOR INSTITUTIONS INVOLVED IN THE CHANGE



KEY INSIGHTS AND REFLECTIONS

10

KEY INSIGHTS AND REFLECTIONS



Starting this project, we each considered this project through a scientific and research perspective rather than looking at the topic through the lens of a system. However, as we unpacked the causes, stakeholders and impacts, we realized that this system is so much more complex than we initially thought. Our visual maps analyzing roles, resources and relationships made us realize the interconnectedness of all stakeholders within our system, and their respective impact.

Our research found that there are many systematic barriers that fail patients with disorders of consciousness. Patients need to be considered with humanity; all stakeholders need to start improvements by acknowledging the crisis and holding empathy towards patients. Change can only happen when each individual is considered.

FUTURE DIRECTIONS



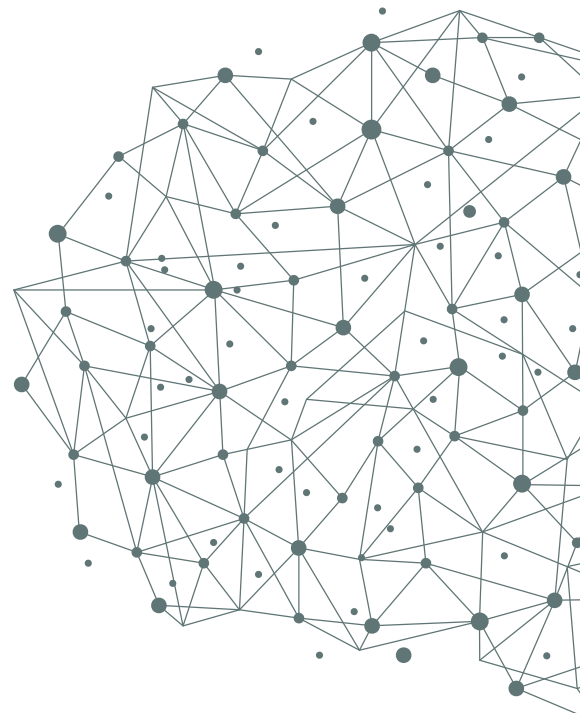
Future directions in this area could include more research into the feasibility of using EEG or fMRI to communicate with patients with disorders of consciousness. While preliminary studies have shown success, additional studies that replicate previous studies and show reproducibility in results will further garner attention from the public and also solidify this technique as a way to communicate with these patients.

There should also be more journalism to disseminate inaccurate information and decrease stigma associated with disorders of consciousness. More effort should be placed into drawing attention to this void in healthcare in an effort to bridge this gap.

Attempts should be made to develop universal protocols for not only diagnosing disorders of consciousness, but also implement protocols for communication.

On our part, further research will include:

- Getting a larger sample size to gather public sentiment on this issue
- Speaking with health authorities to understanding the steps needed to bring this issue to the right governing bodies



TERMINOLOGY



EEG: An encephalogram is a portable, structural neuroimaging device that measures electrical activity in the brain, using electrodes attached to a cap. An event-related potential is a specific measurement calculated using an EEG, to localise brain activity related to specific cognitive events or stimuli.

fMRI: Functional magnetic resonance imaging is a functional neuroimaging device that measures the blood flow to the brain. Using fMRI while completing specific cognitive tasks, researchers can correlate blood flow in a specific region to a specific function.

Hidden healthcare crisis: This is a hidden healthcare crisis because these patients are not being heard or considered by stakeholders that directly interact with them, or the general public. While researching this topic, we have found seldom journalism articles or media campaigns to advocate for this issue beyond research articles. Even within laws, only the USA had a disability act that could even be considered (despite its limitations), but other countries failed to advocate for this issue within the legal system.

Consciousness: This is a state clinically characterised by possessing both qualities of awareness, and qualities of wakefulness (Owen et al., 2006). By wakefulness, we mean states of being able to complete physiological functions, spontaneous eye opening, and reflexive movements including withdrawal from pain. By awareness, we mean states that include intentional actions, voluntary behaviour and clear cognitive/thought patterns.

Disorders of Consciousness: These are states where consciousness (wakefulness and awareness) are impaired. There are three disorders of consciousness, namely, minimally conscious, vegetative (clinically known as unresponsive wakefulness syndrome), and coma states. Minimally conscious state is when there is wakefulness and some level of awareness. Vegetative state is when there is no awareness but intact wakefulness. Coma state is when there is no wakefulness or awareness.

Diagnostic tools: A set of tools used to diagnose for diseases/disorders. For disorders of consciousness, behavioural testing methods are typically used through neuropsychological testing. However, new experimental diagnostic tools for disorders of consciousness include neuroimaging methods as well, usually fMRI.

Prognostic tools: These are tools used to determine the course of a disease, i.e., improvements or deterioration of disease. There are currently no known, utilised prognostic tools for disorders of consciousness.

APPENDIX B

POSITIONALITY & MOTIVATION



AAKANKSHA SAHU



I have personal motivation for this topic, with my grandmother being in a vegetative state for a few months before her death, after a stroke. In such a condition, she received immense support and care from family and healthcare professionals due to a collectivistic culture in India. However, I did notice a stigma of people around her talking about her negatively as if she was not really there. Knowing now that hearing is the last to go, I wonder if she could have recovered if there was more positive talk around her. Personally, I always felt like I could talk to her even if her movements were only “reflexive”. I wish I could know how aware she was in her state. Knowing this would have given our family more consolation and a sense of control about this situation.

CHRISTY OI TING KWOK



I am personally obsessed with understanding how consciousness forms in functional connectivity, which is part of the brain imaging tools used to communicate with patients. I am a Master’s Candidate in the Neuroscience graduate program.

My first encounter with disorders of consciousness is with my grandmother, who was unresponsive during end-of-life care. While palliative nurses at the hospitals and family members tried to provide her comfort by speaking with her, I often wondered whether it would be possible for a two-way conversation to occur with the technological advancements.

Since then, I work closely with unresponsive patients at a hospice once a week and provide hands-on care. I have seen first-hand how frustrating life can be for unresponsive patients, and many express their frustration with aggression or despair. I believe that further research into this field and area can greatly improve the quality of patient care although there appears to be limited research and interest currently due to the challenges we have outlined above.



APPENDIX B

CERTIFICATE FOR THE COURSE ON RESEARCH ETHICS BASED ON THE TRI-COUNCIL POLICY STATEMENT: ETHICAL CONDUCT FOR RESEARCH INVOLVING HUMANS



AAKANKSHA SAHU



CHRISTY OI TING KWOK



APPENDIX C

NOTABLE PARTS OF INTERVIEW

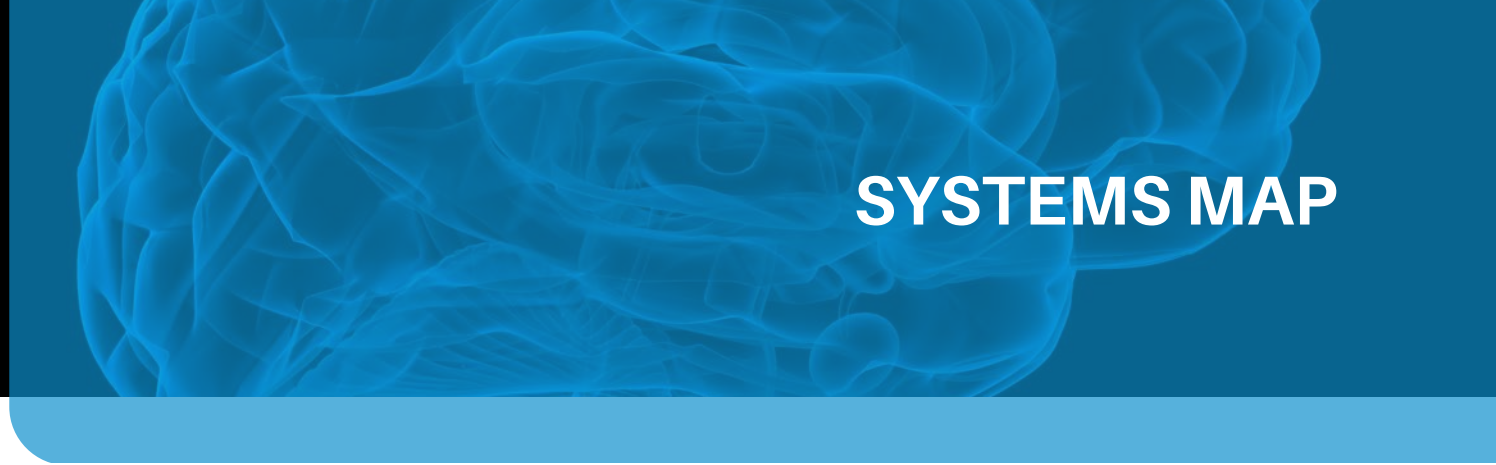


Interviewee	Notable Points
Palliative care nurse working at a hospital	<ul style="list-style-type: none">• Difficult to provide care to unresponsive patients and there are no protocols in place on how to communicate or care for such patients• Best thing to do is to talk to them when doing rounds in a room -- using positive talk, as the hearing is the last to go• It would be nice to have a way to communicate with patients, but it would be difficult due to lack of resources and staff available -- nurses already have high workloads and may not be able to provide additional support
Family of patient who is currently unresponsive	<ul style="list-style-type: none">• Some days are difficult, especially when you don't know if [they] can understand or are there with you. These techniques could give us a slither of hope that [they] are here still here
Psychologist	<ul style="list-style-type: none">• Believe that it "may allow for potentially better care of patient and head towards a path of recovery/healing"• "I would want someone to try to talk to me and would try"• In regards to mental health: "psychological services are hard to provide without the client being able to communicate fully. Unless the patient was capable of a full conversation, then it would not be useful for psychiatric services"• Positive sentiment towards "[helping] with consenting and just general autonomy"
Family of a patient who had a disorder of consciousness	<ul style="list-style-type: none">• Communication is a fundamental human right, and if there is a way to not ignore this problem anymore, it should be explored

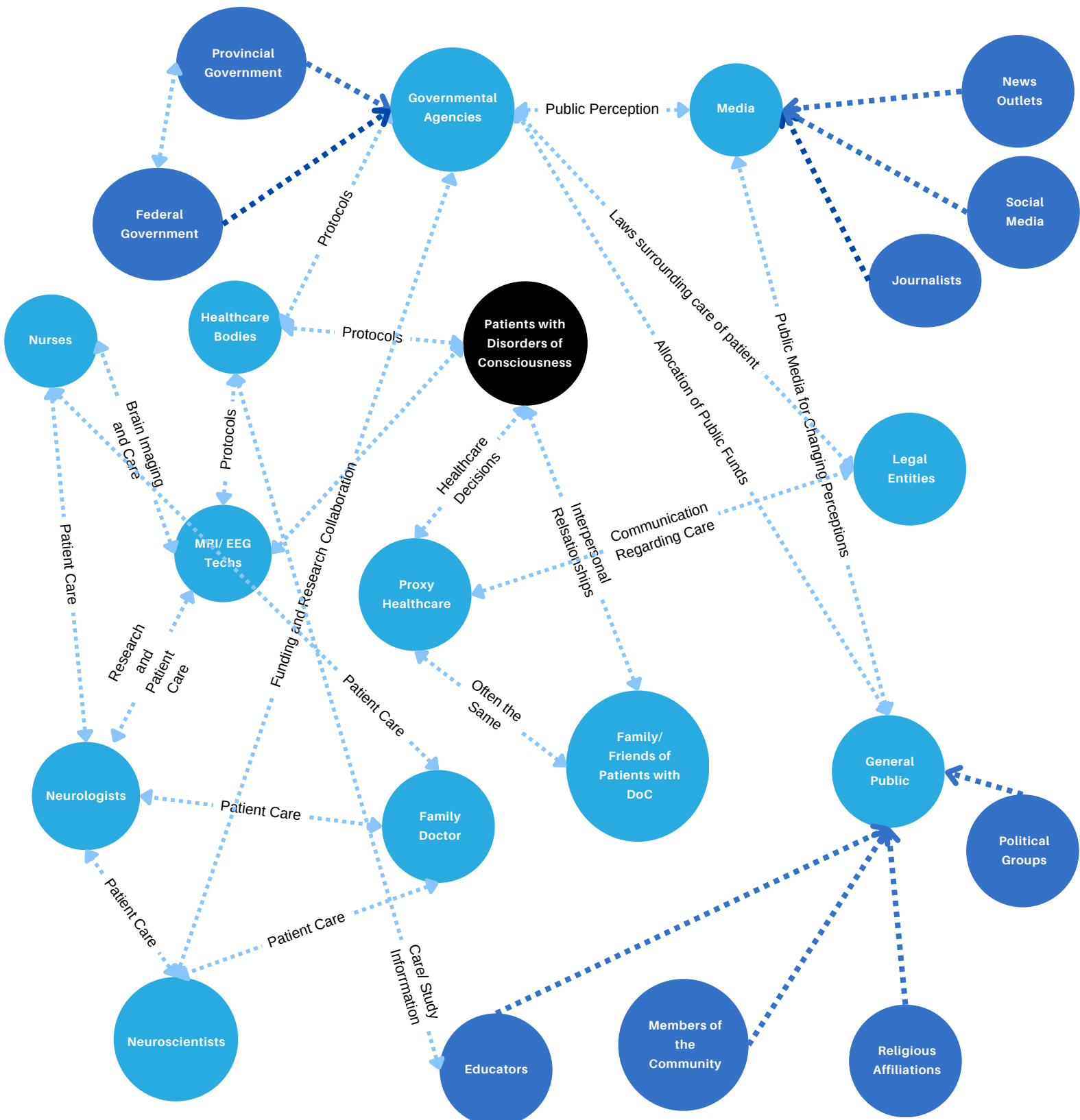
APPENDIX D

CHALLENGES AND STAKEHOLDER DIAGRAM





SYSTEMS MAP



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