An investigation into the perceptions and representations of brain injuries among third-level psychology students and the general public

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Abstract

Aims: While some brain injury survivors are symptom-free, some experience a range of problems for years and beyond. One identified consequence of this includes how a survivor is perceived. Therefore, this study aimed to qualitatively explore the perceptions and representations of brain injuries.

Methods: 119 participants completed an adapted version of the perceptions and representations of mental illnesses questionnaire which qualitatively explored their knowledge and acceptance of brain injuries. The participants were recruited as either undergraduate psychology students (n=44) or from the general population (n=75).

Results: A thematic analysis identified (i) psychological awareness and (ii) attitudes towards the healthcare system and the treatment of brain injuries as the two main themes. No differences in regard to depth of knowledge about brain injuries nor acceptance towards brain injuries were found between either population category. Empathy towards brain injury survivors mirrored each other in both category populations.

Discussion: Analysis of these results suggest that participants had a significant awareness of brain injuries especially demonstrated by the subtheme of emotional awareness in which participants expressed compassion and empathy towards brain injury survivors.

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An investigation into the perceptions and representations of brain injuries among third-level psychology students and the general public

Introduction

Types of brain damage

The study of human brain damage provides two key purposes: firstly, it increases our overall understanding of the healthy brain and secondly, it serves as a basis of understanding new treatments of brain disorders and brain damage. There are six main causes of brain damage: brain tumors, cerebrovascular disorders, closed-head injuries, infections of the brain, neurotoxins and genetic factors (Pinel, 2011). While some people are symptom-free others can experience problems for years (Pinel, 2011). Furthermore, these difficulties can express through headaches, fatigue, depression, irritability and memory problems. These difficulties experienced also depend on which area of the brain is damaged thus not everyone who has suffered a brain injury is the same ("Types of brain injury", 2019).

A variety of brain injuries will be discussed throughout this paper. Acquired Brain Injury (ABI) refers to all types of brain injuries such as brain damage since birth, disease and accidents ("Types of brain injury", 2019). ABI occurs due to diseases such as stroke, tumour, aneurysm or infection whereas, Traumatic Brain Injury (TBI) occurs due to external force such as falls or accidents (McKinney, 2004). The effects of a TBI can vary widely depending on where the damage was caused. TBI is caused by a trauma to the head resulting in injury, a brief period of unconsciousness may be followed which can last between fifteen minutes to six hours and can be accompanied by amnesia for up to twenty-four hours ("Traumatic brain injury", 2019). The effects of ABI vary from disease to disease. For example, people may experience memory problems, difficulty taking in information, storing it and retrieving it

("Memory problems", 2019). Another common effect of brain damage is behavioural problems and these can vary greatly from impulsiveness, irritability to aggression ("Behavioural effects", 2019). The term brain injury covers a broad range of severities due to the complexity of the brain itself.

Effects of brain damage

A reoccurring theme of a profound 'loss of self' is found among brain injury survivors (Landua & Hisset, 2008). A qualitative analysis was carried out by Nochi (1998) examining what ignites this overwhelming sense of 'loss of self'. It was found that people with a TBI find it difficult to comprehend what has happened to them and as a result don't know what they can and cannot do to address it. Secondly, a common theme among TBI survivors was comparing themselves to who they were before they had sustained their TBI. Finally, their sense of self is threatened by the labels they feel society puts on them. Evaluating what causes emotional distress in brain injury survivors can possibly give insight into improving treatment and rehabilitation programmes to better enable an individual's recovery. (Sherer et al. 2015). A brain injury can change how a person thinks, feels and behaves as well as their physical abilities ("Behavioural effects", 2019). Children and teens with TBI are often more impulsive, have less social awareness and externalize behavioural issues especially following severe TBI. (Tlustos et al., 2016). This study also highlights how this cohort tends to have poor social cognitive skills such as difficulty in solving social problems. Such difficulties can place individuals in a vulnerable position for risk of peer rejection and victimization. It is evident that there is a clear lack of understanding in relation to brain injuries as to why and how peoples personality suddenly changes. Injury to the brain changes the biological state of the organism and can cause temporary or permanent changes in emotional and motivational responses. A consequence of this can lead to personality disturbances in individuals who have sustained a TBI. Prigatano (1992) detailed a clear lack

of understanding regarding behavioural changes that can occur in individuals after suffering a TBI. In particular, a need for a classification system regarding irritability and anger has been suggested through the format of behavioural based definitions and measurements.

It is well known that brain damage can result in significant personality changes (Headway). However, personality changes include the individual's overall well-being and mental health. Post-stroke depression is one of the most common psychiatric complications after suffering a stroke and occurs between 33% to 40% of those affected (Klinedinst, Clark & Dunbar, 2013). Symptoms of minor depression require at least two of five symptoms which can include; depressed mood, lack of interest in previously enjoyable activities and changes in patterns of sleep and eating ("DSM-5", 2019). Although, identifying symptoms of depression in stroke survivors has been difficult due to complications associated with the disease. It is particularly difficult to recognize depressive symptoms as post stroke depressive symptoms can often be missed or mistakenly attributed to another condition leading to it being untreated (Klinedinst, Clark & Dunbar, 2013). Therefore, this results in stroke survivors subsequently being deprived of sufficient help due to a lack of awareness and knowledge surrounding the effects of brain disorders and brain damage.

Perceptions of Traumatic Brain Injury's

Traumatic Brain Injury (TBI) is a leading cause of death and disabilities in the United States (Vanderploeg, Belanger, Curtiss, Bowles & Cooper, 2019). As stated, brain damage can occur through several causes. TBI is an acute injury and shares chronic symptoms such as Alzheimer's disease. TBI Impairment can have long-lasting effects on both the individual and family members. (Florain & Katz, 1991). The manifestations of TBI's can differ from person to person such as behavioural changes, personality alterations, physical changes and

common disruptions of roles in relationships (Florian & Katz, 1991). Unexpected changes in an individual's cognitions and behaviours can contribute to negative attitudes towards individuals who have brain injuries (Florain & Katz, 1991). These negative social perceptions of TBI can be passed down by generations of stigma associated with mental illness and other illnesses linked with loss of control and irrationality. Therefore, this can be viewed as a less acceptable disability compared to other disabilities. (Safilios-Rothschild, 1982). There is a general consensus between researchers and clinicians that relatives of brain injury survivors experience a heightened level of stress as a result of their loved ones injury and its consequences. Leathern et al. (1996 examined stress levels of partners and parents of individuals who had suffered a head injury. This study found that role changes such as sudden responsibility as a caregiver, the different challenges associated with this new found relationship and any health problems, added to the stress experienced by the caregiver. Both the partner and parent group experienced a moderate level of stress and role change in regard to relationship boundaries. Interestingly, partners had reported a slightly higher increased level of stress and role change than the parents. Few studies can be found that directly examine the perceptions of brain injuries which appears to result in a significant lack of knowledge when it comes to treating and caring for individuals with brain injuries. However, Kosciulek (1994) examined cluster groups of family members caring for a relative or partner who had suffered a head injury. This study interestingly focused on the coping strategies such as having a positive outlook regarding the family and seeking advice from a doctor which family members use to enable themselves to manage the consequences of caring for people with head injuries. This is one of very few studies that provide solution-focused insights into how carers of this nature can cope better.

Misconceptions of brain injuries

McClure (2011) showed that misconceptions of brain injuries occur when people misattribute the actions of people with brain injuries. These showed two key features; firstly, the absence of a visible injury to the individual and secondly, the tendency to compare TBI survivors with their pre-injury self. These two processes resulted in the failure of the public to attribute any problematic behaviours to the individuals injury. Therefore, by understanding the common misattributes regarding brain injury it would provide greater awareness of how to address these misconceptions. Poritz et al., (2019) identified the presence of self-stigma within brain injury survivors. Specifically, TBI survivors have displayed self-stigma which refers to an awareness of negative attitudes, behaviours and stereotypes that are related to the individual's condition. This has been shown to cause mental and physical health challenges in regard to their recovery. Self-stigma was associated with a lack of community participation. Furthermore, emotional difficulties were found to have a direct relation to community participation. Deaton (1986) stated that the issue of head trauma rehabilitation is still in its infancy regarding how to treat head injuries. By understanding the recovery process, it may lead to the overall perception of brain injury sufferers to be more accepting and positive when it comes to returning to their previous life. Recovery after suffering a brain injury can take up to two years for the majority of survivors. However, in some patients further recovery can take between five to ten years later. Gathering information regarding the long-term effects of brain injuries can often be hindered by low rates of follow-up (Fleminger & Ponsford, 2005).

Rationale

This study aims to qualitatively explore the differences between psychology students and the general public perceptions of brain injuries through thematic analysis. Psychology students should already know the causes and effects of brain damage based on what they have covered in their degree. De Iorio, Nolan & Teague (2017) it was found that factsheets and personal stories are effective in increasing knowledge surrounding the effects of brain injuries. In this study, it was also stated that among the general population there is a lack of knowledge of TBI's. Some studies have stated the common misconceptions of brain injuries however, only few studies have found solutions for misconceptions of brain injuries which leaves a gap for further research. Further research is needed especially why there is lack of knowledge regarding brain injuries. A better understanding of brain injuries should improve the overall perception of brain injuries.

Research Aims, Objectives and Hypothesis

The aim of this study is to investigate the perceptions of brain injuries between third-level psychology students and the general public. This will help to understand whether or not education can influence people's perceptions of brain injuries. The objectives of this study aimed to improve our understanding of the perceptions of brain injuries among these two groups. A better understanding of negative stigmas associated with brain injuries will help to compare third-level psychology students who have knowledge of brain damage and the general public. The results should provide an insight into whether or not education of brain injuries can influence someone's perception of brain injuries.

Based on existing literature it was hypothesized that –

Hypothesis 1 - It is hypothesized that third-level psychology students would be more informed regarding brain injuries and therefore have a more positive and accepting attitude concerning individuals with brain injuries compared to the general public.

Hypothesis 2 - It is hypothesized that third-level psychology students would have a more positive and accepting perception of individuals with brain injuries

Hypothesis 3 – It is hypothesized that the current sample will exhibit a psychological awareness of brain injuries through emotional awareness of the main theme.

Methods

Participants

In this present study, a between-subjects design was used and participants were recruited through stratified random sampling. Two groups were identified using demographic information that was provided at the beginning of the questionnaire through asking participant's to provide information about their level of education and occupation. This enabled the researcher to divide participants into two groups; psychology students and the general public. The questionnaire was made available through an online questionnaire using a Google Docs format and also, online platforms such as Facebook groups for example Survey Circle for psychology research participants. A total of 119 participants took part in the study. Eighty-three females and thirty-three males and two who identified as 'prefer not to say'. The groups were divided based on the participants occupation, a total of forty-three psychology students and seventy-five general public participants took part. The age range varied between 18 and 62 years of age. One participant had a primary school level of education, eighteen participants had a secondary school level of education and ninety-nine had third-level education.

Materials and Measures

Participations were recruited using online platforms such as Facebook and it was shared to the general population and Survey Circle for psychology research participants to obtain the psychology student group. The proposed number of participants was 100 in the hopes for 50 general public participants and 50 psychology students participants. The Perceptions and Representations of Mental Illness questionnaire from (Durand-Zaleski, Scott, Rouillon & Leboyer, 2012) were replicated to create the Perceptions and Representations of Brain Injuries questionnaire. Questions were replicated and changed to suit the research question; an investigation into the perceptions and representations of brain injuries among

third-level psychology students and the general public and was shared via an online survey on Google Docs. A demographic section (Identifying information) was included that gained information regarding a variety of demographic aspects of the participants such as age, gender, and occupation. The nine core areas consisted of (knowledge of the causes of brain injuries, presupposed origins of brain injuries, evaluation of perceived social handicap, familiarity with brain disorders, feelings towards people with brain injuries, acceptance level of disease, image patterns of care and the medical community, information and communication of brain injuries, opinion of research in the field of brain disorders/ brain injuries). There were several different types of questions throughout the questionnaire such as open-ended and descriptive questions. An example of an open ended question asked in the questionnaire was copied and changed from the original mental illness questionnaire; "What are all the words, adjectives, verbs, phrases and images that come to mind when you hear the phrase 'mentally ill people?" to "What are all the words, adjectives, verbs, phrases and images that come to mind when you hear the phrase 'brain injury?'" An example of how another style of questioning was changed to a descriptive question that was originally asked by "Would you work with someone who had... (a) Schizophrenia, (b) Bipolar Disorder and (c) Autism" by choosing from the options 'Yes happily', 'Yes if I had to' or 'Absolutely not'. This was then subsequently changed to "Would you work with someone who had... (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury" by choosing from the options 'Yes happily', 'Yes if I had to' or 'Absolutely not'.

Design

A qualitative, grounded theory research design was employed using a thematic analysis approach with the aim of the design of the study to become more systematic as the study went on (Flick, 2018). A between-subjects design was used with participants by being assigned through stratified sampling and assigned to one of two groups.

Procedure

The questionnaire was distributed online via Google Docs through Facebook and open to the general population and it was also shared to Survey Circle for psychology research participants. Upon opening the Google Docs form, the first page provided a project information sheet which described the project title, objectives of the study, what will happen if they choose to participate, risks and benefits of the study, confidently, contact information. Followed by the consent form in which each participant had to tick two boxes (i) I agree that I have read the information sheet provided and (ii) I agree that I am participating in a research study investigating third-level psychology students and the general public's perceptions of brain injuries. The demographic section followed the introduction and consent section and included gender, age, occupation, level of education and what are the words, adjectives verbs, phrases, and images that come to mind when you hear the phrase "brain injury"? and whether or not the participant understood the difference between a psychiatrist, psychologist, and neurologist. Section A, "The knowledge of brain injuries" was presented. Here, participants were asked questions based on their knowledge of brain disorders and brain injuries; (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury. Question four asked participants to rate their level of knowledge of six brain disorders; Traumatic Brain Injury, Acquired Brain Injury, Concussion, Stroke, Brain Tumour, and Aneurysm and were given three options; (a) You know the name and are able to describe it, (b) You the know name without being able to describe it and (c) You have never heard of this illness. Question five asked specific questions on each individual illness; (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury. Section B, "Presupposed origins of brain injuries" was presented. Here, participants were asked to answer the question "In your opinion, what are the factors that contribute to brain injuries?" and were given the option to provide multiple answers. This question was asked separately for each brain disorders; (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury.

Section C, "Evaluation of perceived handicap" was presented. Here, participants were asked to indicate their level of agreement for each brain disorder; (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury from (agree, disagree and I do not know). Section D, "Familiarity of brain disorders/ brain injuries experiences that respondents have" was presented. Under this section participants were asked questions in relation to their understanding of brain disorders and brain injuries by being asked "Have you or have you ever been diagnosed with a brain disorder/ brain injury?" and "Has anyone close to you ever suffered from a brain injury?" and finally, if the participant had been diagnosed with a brain disorder or brain injury, they were asked to describe what disorder or injury caused it. Section E, "Feelings towards people with brain disorders/ brain injuries" was presented. The first question allowed for the participant to write their own response in relation to their top three reactions to someone close to them being diagnosed with a brain disorder or brain injury. Participants were given options to choose their top three; compassion, distrust, embarrassment/ discomfort, curiosity, shame, fear, guilt, rejection, helplessness, sadness, anxiety, anger.

Section F, "Acceptance level of disease" was presented. Under this section participants were asked questions in relation to three brain disorders; (a) Stroke, (b) Epilepsy and (c) Traumatic Brain Injury. Participants were asked to rate their response to each question by answering; (Yes happily, Yes if I had to and Absolutely not) to three questions; "Would you work with someone who had...", "Would you be ok to be in the same class with someone who had..." and "Would you accept to live under the same roof as a loved if s/he had...". Section G, "Image patterns of care and the medical community" was presented. Here, participants were asked "Do you believe in the effectiveness of existing treatments currently?" and were given the option of four responses; (Yes a lot, Yes a little, No not really and Not at all). Secondly, in this section participants were asked "If you know someone with a brain injury, do you think they were diagnosed sufficiently early or too late?" and were

given three options; (They are diagnosed early enough to be supported from the beginning, They are diagnosed too late, because often confused with other problems and You do not know). Section H, "Information and communication about brain injuries" was presented. Under this section, participants were asked "If you became ill and suffered a brain injury, who would you talk to?" and were given multiple choice answers to choose from, Secondly, participants were asked "Do you think you are too informed, adequately informed or not informed enough about brain injuries by...", (The media, Your doctor or The medical community). Section I, "Opinions of research in the field of brain disorders/ brain injuries" was presented. Here, participants were asked "Do you think the research in the field of brain disorders/ brain injuries in Ireland is..." and were given four options to choose from; (Very effective, Rather effective, Not really effective, Not at all effective and You do not know). Secondly, participants were asked "According to you, should brain disorders/ brain injury research constitute a public health priority?" and were given four options to choose from; (Yes definitely, Yes to some extent, Not really and Not at all).

Finally, participants were given the chance to offer thoughts or feelings that they would like to communicate to the researcher whilst completing the survey.

Results

Thematic Analysis

A total of 119 participants took part in the study. The gender breakdown was eighty-three females, thirty-four males and two individuals identified as 'prefer not to say'. The age range varied from 18 years old to 62 years old. Participants were divided into two groups for analysis, 44 third-level psychology students and 75 general public participants. Level of education was identified; 1 participant had only a primary school level of education, 18 participants had a secondary school level of education and 100 participants had third level education.

Table 1.Sociodemographic information of the sample

Variable	Total $(n = 119)$		
Gender	Male	(n = 34) (28.6%)	
	Female	(n =83) (69.7%)	
	Prefer not to say	(n=2)(1.7%)	
Age	18 – 24	76	
	25 - 34	18	
	35 - 44	11	
	45 - 54	6	
	55 - 62	7	
Occupation	Third level psychology	(n =44) (37%)	
	student		
	General public	(n = 75) (63%)	
Level of education	Primary school level of	(n=1)(0.8%)	
	education		
	Secondary school level of	(n = 18) (15.1%)	
	education		
	Third level education	(n = 100) (84%)	

Several themes emerged throughout the data. Two significant themes were established; "The psychological awareness of brain injuries" and "Attitudes towards the healthcare system and the treatment of brain injuries".

- "The psychological awareness of brain injuries" demonstrated the knowledge of brain injuries among both psychology students and the general public and in addition the emotional reactions to brain injuries.
- 2. "Attitudes towards the healthcare system and the treatment of brain injuries" established two subthemes; attitudes towards the management of the healthcare system along with how change should be carried out was identified. In addition, attitudes towards brain injuries in relation to the acceptance of brain injuries were identified.

Theme 1: The psychological awareness of brain injuries

The psychological awareness of brain injuries was identified as a significant theme, it emerged consistently throughout the data. Within this theme, two subthemes have surfaced (1) Knowledge of brain injuries and (2) Emotional reactions to brain injuries. It was evident throughout the data that participants aspired to learn more about brain injuries after completing the questionnaire, this was especially evident by question (21) which asked participants "Whilst completing this questionnaire did you have any thoughts or feelings you would like to communicate to the researcher?" This reoccurring theme occurred more often in the general public group, however, this could be due to the variance group ratio between psychology students (44) and the general public (75).

In the first subtheme, participants highlighted the issue of feeling a significant lack of knowledge of brain injuries whilst completing the questionnaire; "I think how much you think you know changes when faced with questions." And a consistent theme emerged of a desire to learn more about brain injuries. The second subtheme gave insight into participants

perception of brain injuries. This captured the negative emotional effect of completing the questionnaire and being faced with upsetting questions.

Knowledge of brain injuries

Participants were assessed on their knowledge of brain injuries and were presented with twelve illnesses, regarding brain disorders or brain injuries. Participants were presented with; Traumatic brain injury, Acquired brain injury, Concussion, Stroke, Brain tumors, Aneurysm, Hypoxia and Anoxia, Alzheimer's disease, Meningitis, Epilepsy, Encephalitis and, Multiple Sclerosis. Followed by three options to choose from based on their level of knowledge of each specific disease which ranged from (a) I know the name of the disease and can describe it to (c) Never heard of the illness. Stroke received the highest amount of responses (106) in relation to knowing the name of the disease and being able to describe it. Alzheimer's disease received the second highest amount of responses (105) and concussion received the third highest amount of responses (101) in this category. Interestingly, when asked, "If you have had a loved one with a brain disorder, which of these disorders have they had?" Alzheimer's disease appeared the most, followed by stroke, epilepsy and concussion. This could explain why there is such a high number of responses for stroke, Alzheimer's disease, and concussion as participants would have significant experience with these illnesses, therefore the participant would be more familiar with naming and describing the disease. The lowest response for this section, assessing the participant's knowledge of brain injuries multiple sclerosis (43) and hypoxia and anoxia (24). Despite multiple sclerosis and hypoxia and anoxia having the lowest responses for knowing the name of illness and being able to describe it, the volume of responses was significantly low compared to the volume of responses in regard to knowledge of brain disorders and brain injuries. This coincided with the responses given to the question that asked if a loved one had a brain disorder and to voice which disorder if so, multiple sclerosis had a low response rate (8) and hypoxia and anoxia

had one of the lowest responses with only participant choosing it as an option. As a result, the lack of knowledge of brain injuries can be attributed to lack of personal experience and engagement with brain disorders.

Emotional reactions to brain injuries

The majority of participants expressed negative emotional reactions to several of the questions. In particular in question (21) participants expressed feelings of sadness, discomfort, and anxiety towards the topics raised throughout the questionnaire. In this particular question, sadness, anxiety and discomfort were the most reoccurring themes. Participants were also asked if a loved one were to suffer from a brain injury, what would be their top three reactions. Compassion, sadness ,and curiosity were the top three words mentioned by participants. The three top-ranked words most commonly used together were; compassion, sadness, curiosity (24), compassion, sadness, anxiety (9) and compassion, sadness, fear (8) (See table 2.) Compassion is a reoccurring theme and remains at the highest ranked response for this particular question. Despite a possible lack of knowledge for some brain disorders and brain injuries, the consensus for the majority of participants is compassion. Interestingly, the issues raised during the questionnaire such as traumatic brain injury ignited an emotional awareness to the severity of the condition; "It's clear the words traumatic brain injury give of a shock factor that would make you believe they need help and can't work etc."

Theme 2: Attitudes towards the healthcare system and the treatment of brain injuries

In addition, a second significant theme emerged. Attitudes towards brain injuries reoccurred several times throughout the data in two ways; participants expressed concern regarding the healthcare system and how people with brain injuries are diagnosed and treated. In this first subtheme, participants reiterated a lack of trust in the healthcare system; "I think that GP's should be more informed on this topic and the variety of symptoms that may occur that indicate brain injuries/disease." 42.9% of participants stated that they knew someone who had a brain injury and they believe they were diagnosed too late, due to other confusion with other symptoms. The majority of participants expressed a substantial concern for a lack of understanding to correctly diagnose brain disorders within the healthcare system, often due to misunderstanding symptoms; "While it is necessary to rule out severe brain injury in initial diagnoses in A&E following a TBI, I do believe being told to just rest is not good enough". In the second subtheme, the acceptance of brain injuries emerged as another reoccurring theme. It was portrayed by participants that there is a lack of knowledge and several misconceptions in relation to brain injuries, therefore leading to a negative attitude towards brain injuries; "The general public has many misconceptions about what a brain injury entails, and awareness could be much better spread." Participants were assessed on their acceptance level of disease in relation to three brain disorders; stroke, epilepsy, and traumatic brain injury. The majority of participants were accepting of each disorder in each instance, however, a minority of participants chose otherwise.

Attitudes towards the management of the healthcare system

The majority of participants expressed concern surrounding the healthcare system and the treatment of individuals suffering from a brain injury. The main concerns were in regard to General Practitioners lack of awareness and lack of knowledge when diagnosing and treating people and the medical community disregarding neurological symptoms leading to a

late diagnosis and distress for both the patients and loved ones of patients. Throughout the data, it is consistently understood that participants have an overall lack of trust in GP's to appropriately help individuals suffering from a neurological condition; "GPs should be more informed regarding brain injuries." And "Being diagnosed with any illness is traumatic for any patient. Ireland definitely needs to improve their aftercare and put a focus on support following on from treatments." There is a significant reoccurring theme that participants want a change within the medical community, specifically with General Practitioners. Participants were asked at what level do they believe drug treatments and therapies such as physiotherapy and speech therapy are effective for the treatment of brain injuries. Physiotherapy and speech therapy had the highest response with 94 participants choosing 'Yes a lot' in response to its effectiveness. Participants rated drug treatments significantly lower with only 47 participants choosing 'Yes a lot'.

Acceptance of Brain Injuries

Participants were assessed on their level of acceptance of disease in regard to work, school or college and home life. The majority of participants were accepting and responded positively towards all three disorders; stroke, epilepsy, and traumatic brain injury.

Participants were asked "Would you work with someone who had...?" in relation to all three disorders and diseases. Overall the majority of responses were similar for each one, stroke was the highest with 112 responses, epilepsy had 111 responses and traumatic brain injury had 108 responses. Participants were further examined on their acceptance of three disorders and diseases based on their acceptance to be in the same classroom as someone who suffered from a stroke, epilepsy and traumatic brain injury. This particular question had the lowest level of negative, unaccepting responses with only 1 yes if I had to response for stroke, 4 responses for yes if I had to in regard to epilepsy and 2 responses for traumatic brain injury. No participant chose 'absolutely not' for this question in relation to the acceptance of brain

injuries in the classroom. The final question for acceptance of disease and brain injuries focused on the individual's comfortability surrounding living with an individual who had either a stroke, epilepsy ,and traumatic brain injury. Once more there was an overwhelmingly positive response towards the acceptance of all three disorders and there was no response given for absolutely not in relation to feeling comfortable being under the same roof as someone who had each of these disorders. Overall, there was a significant acceptance of brain disorders in regard to work, in the classroom and home life.

The psychological awareness of brain injuries reoccurred more frequently and had a more substantial response compared to attitudes towards the healthcare system and the treatment of brain injuries. The overall consensus towards the healthcare system was a lack of knowledge and research within the medical community especially in regards to General Practitioners; "I think that GPs should be more informed on this topic and the variety of symptoms that may occur that indicate brain injury's/disease. There was not substantial evidence that third-level psychology students showed a better understanding of brain injuries despite additional knowledge of neurological disorders from their studies. However, psychology students did show a better understanding of brain disorders and brain injuries, however it was not a substantial increase in knowledge compared to the general public group. Despite this, psychology students were slightly more accepting of brain injuries than the general public, although there was an imbalance between the two groups, especially among psychology students as only 44 psychology students took part in the study, whereas 75 participants took part within the general public group. Therefore, this is an important limitation to take into account when analysing the current sample. Furthermore, it is important to discuss how participants acquired knowledge surrounding neurological disorders and brain injuries, in question nine participants were asked if they had a loved one who had suffered from a brain disorder, to provide information regarding what specific disorder it was.

Alzheimer's disease, stroke ,and epilepsy had the highest response for question nine, this coincided with question four which examined participants knowledge of brain injuries and how well participants could describe each disorder, Alzheimer's disease, stroke and concussion had the highest response. Therefore, it would suggest that personal experience with a specific brain disorder increases knowledge of that specific disorder.

 Table 2.

 Themes, subthemes, code, and quotations for the current sample.

k you	
know, changes when faced with	
questions." (3)	
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71)	
rmed	
et of	
(21)	
7	
ain	
s fault	
they	
spects	
ssible	
everity	
illness	
mprove	
us on	

			- "I think that GPs	should be more
			informed on this	topic and the
			variety of sympto	oms that may
			occur that indicat	e brain
			injury's/disease."	'(11)
			- "It should be taug	ght in schools or
			at least more in n	nedia, such as
			infomercials so it	is not a taboo
			subject that peop	le are afraid to
			talk about." (29)	
			- "Delay in diagno	sis." (73)
	'Acceptance of	Yes happily		
	brain injuries'	(1,018)		
		Yes if I had		
		to (48)		
		Absolutely		
		not (5)		
1	1	1		

^{*}Note: Code represents the frequency of occurrence. In the quotation section, the number represents the participant's identification.

Discussion

This study set out to investigate perceptions and representations of brain injuries among third-level psychology students and the general public. There were nine core areas examined in the study which explored knowledge and attitudes in regards to brain injuries. The study specifically focused on identifying the current samples knowledge of brain injuries in relation to the two groups as it was hypothesized that psychology students would hold more knowledge regarding brain disorders and brain injuries compared to the general public who have not studied neurology or neuropsychology. The second hypothesis focused on the attitudes towards individuals who have a brain disorder and/or brain injury, however specifically focusing on psychology students. The third hypothesis examined the subthemes of psychological awareness of brain injuries, specifically emotional awareness of brain injuries.

Hypothesis 1 - It is hypothesized that third-level psychology students would be more informed regarding brain injuries - this hypothesis was not supported due to several reasons. Thematic analysis of the data indicated there was no difference in knowledge of brain injuries among third level psychology students. A potential reason for a lack of difference between each group category regarding this hypothesis may be due to the unequal numbers between each. There was a significant imbalance between the groups as the general public acquired a larger sample size of 75 participants and psychology students only comprised of 44 participants. However, within this study it was found that individuals who had a loved one who had suffered from a brain disorder and/or brain injury knew a substantial amount about the specific disorder that had affected someone they knew thus, had an increased level of knowledge depending on the disease. Therefore, this significantly impacted the reliability of the data collected and did not give an objective interpretation of the current sample

Hypothesis 2 - It is hypothesized that third-level psychology students would have a more positive and accepting perception of individuals with brain injuries compared to the general public – this was not supported.

A positive pattern emerged in regard to brain injuries. These findings support the existing literature such as Chan, Mak & Lam (2018) which found that positive attitudes towards mental illness can lead to a sense of community leading to a higher level of empowerment and can help to improve personal recovery from mental illness. It was hypothesized that individuals who are more informed about brain disorders would have a better perception of brain disorders. There was no significant difference of patterns between either group due to the shortage of psychology student participants in proportion to the general public participants. Therefore the hypothesis could not be supported. In addition, several other aspects of the demographic information affected the outcome of the study yet again. The overall gender ratio of 34:83 presented an uneven gender assessment. Furthermore, the age range for both psychology students and the general public were mainly comprised of 18 – 24-year-old participants thus, inadequate representation of gender differences was presented. Due to the lack of existing research into the area of perceptions of brain injuries, it is difficult to know whether or not gender differences would impact the individual's perceptions of brain injuries. However, the questionnaire used was originally based on perceptions and representations of mental illness and had an almost equal gender ratio, thus the aim for this study was to achieve the same (Durand-Zaleski, Scott, Rouillon & Leboyer, 2012).

Hypothesis 3 - It is hypothesized that the current sample will exhibit a psychological awareness of brain injuries through emotional awareness of the main theme – this was supported.

In a study carried out by (De Iorio, Nolan & Teague (2017) it was found that personal stories from brain injury survivors had a greater impact on individuals and were better able to recall the information of each story. Based on the existing literature, it was hypothesized that both groups would experience a level of psychological awareness surrounding brain injuries. It emerged that both groups expressed an emotional awareness of brain injuries and displayed a desire and need to understand brain injuries more. A reoccurring theme was compassion for brain injury survivors and was a predictor for emotional awareness. The demonstration of compassion is consistent with the hypothesis and proves that individuals exhibit an emotional awareness of individuals with brain injuries. Specifically in relation to demonstrating empathy. Empathy can be described as a concept of using cognitive and emotional domains (Hojat et al., 2002).

The subtheme, emotional reactions to brain injuries was the most reoccurring theme. It was evident within the current sample that the majority of participants demonstrated empathy whilst completing the questionnaire, specifically in relation to question 11 which examined participants acceptance of brain injuries in particular in regard to stroke, epilepsy, and traumatic brain injury. Compassion occurred a total of 96 times and emerged to be the main theme. In the current sample of 119 participants, the main findings suggest that there is a lack of research in the area of perception and attitudes towards brain injuries. Third level psychology students should have covered neurology in their studies, which would have included several of the disorders mentioned, the results did not convey any advantage in answering factual questions on brain disorders or expressing additional compassion or

emotional awareness towards people with brain injuries. There was a slight increase in knowledge of brain disorders within the psychology student sample, however, it was not substantial enough to support the hypothesis.

Limitations

Within the current sample, there was a number of implications in relation to current research and future research. The majority of rehabilitation treatment for individuals who have suffered a traumatic brain injury is in relation to cognitive, social and behavioural aspects of the disability and a positive social-interactive feature of treatment has proven to help improve social obstacles after suffering a brain injury (Ylvisaker, Turkstra & Coelho, 2005). Therefore based on previous literature, a positive social environment influences an individual's social improvement whilst recovering from a brain injury. Despite this, there is an insufficient amount of literature based on perceptions of brain injuries.

Within the current sample, there were several limitations that affected the outcome of the study. The main limitation within the demographic information was the lack of third level psychology students compared to the general public sample. In addition, gender and age imbalance affected the current sample. A limitation that was expressed to the researcher by participants was the layout of the questionnaire itself and the restrictive form of questioning.

Demographic information

Occupation – In the current sample participants were divided into two groups, third level psychology students (n = 44) and the general public (n = 75), there was a significant disproportion between each group thus, resulted in an insufficient representation of third level psychology students. It was hypothesized that psychology students would have advanced knowledge of brain injuries and therefore have a more accepting attitude towards brain injuries. This was not achieved due to the lack of psychology students compared to the general public.

Gender – The target sample for the current study was 100 responses with a 50:50 ratio for gender. Thirty-four males, eighty-three females and two individuals identified as 'prefer not to say' took part in the study. In a study carried out by (Durand-Zaleski, Scott, Rouillon

& Leboyer, 2012) there was an almost even gender balance, the sample was 52% female and 48% male which rounded up to be a more appropriate sample size. However, in this current study, the target sample for gender was not achieved.

Age – The majority of participants were aged between eighteen and twenty-four. The age range of the current sample was not evenly distributed.

Layout of the questionnaire

It was clearly stated by several participants that the layout of the questions was often confusing or questions could have been asked in a more general sense. The majority of the questions were based on three specific brain disorders; stroke, epilepsy and traumatic brain injury which are all distinctly different conditions and have varying levels of severity. Several participants expressed their concern over how certain questions were asked especially in regard to rating scales such as 'agree' and disagree' as each disorder varies in severity therefore, participants felt they were restricted in regard to answering such questions.

Strengths

Despite the lack of psychology student participants compared to the general public group, the study had several strengths. The use of thematic analysis provided a voice for participants to express how they feel about brain injuries. This consequently added to the knowledge of people's perception of brain injuries. Hypothesis one examined psychology students level of knowledge of brain injuries compared to the general public and there was no difference in terms of level of knowledge between third level psychology students and the general public. Hypothesis two examined psychology students attitudes towards brain injuries compared to the general public. Once more, there was no difference between the groups. However, hypothesis three found that both groups expressed compassion, sadness, curiosity and anxiety

towards people with brain injuries. Hence, these results demonstrate how one could carry out qualitative research in relation to this topic.

Conclusion

Brain disorders and brain injuries are generally misunderstood by both society and the medical community. The study of neurology and neuropsychology is constantly evolving and new diseases are being discovered continuously. However whilst completing this study it was evident that the majority of participants feel there is a need for further research and resources for brain injury survivors and the families of those affected by brain injuries.

Existing literature surrounding perceptions of brain injuries was rather inconclusive due to insufficient data. For example, traumatic brain injuries have a profound effect on the cognitive, physical and emotional functioning of an individual and relatives of the individual have reported changes in personality which ultimately puts a strain on the relationship (Rosenberg, Dethier, Kessels, Westbrook & McDonald, 2015). A better understanding of how brain damage affects someone would, in turn, help the people around the individual understand their difficulties more.

The study set out to better understand third-level psychology students perception of brain injuries compared to the general public's perception of brain injuries. It was hypothesized that psychology students would have a better understanding of brain injuries due to their knowledge they would have retained from their studies, however, the findings do not support the hypothesis due to the lack of psychology students that took part in the study. Nevertheless, it remains unclear if knowledge of brain injuries can improve perceptions of brain injuries due to the lack of existing literature. The implications of this study suggest further research into the area of neuropsychology and the effects of brain injuries as it was heavily evident from the data collected that participants were willing to learn more about brain injuries. Despite hypothesis one being unsupported, the variation in group sizes may have had an effect on the outcome of the results. Therefore, the results of this study should be

interpreted with caution. The most prevalent theme identified in this study was the psychological awareness of brain injuries and specifically the subtheme emotional reactions to brain injuries as it consistently emerged a great deal of compassion for individuals suffering from a brain injury and/or brain disorder. It was also evident that participants felt sad and anxious whilst completing the questionnaire due to imagining a loved one ever suffering from a brain injury. Due to the lack of research, it was unclear if the results of this study correlated with the existing literature. However this study, provided a platform for individuals to voice their concern towards the lack of awareness and knowledge surrounding brain injuries. It also highlighted concerns regarding the medical communities treatment of brain disorders and brain injuries. The implications of this study suggest further research into the effects of brain injuries on both the individual and the families affected. It also suggests further research into brain injuries and more awareness surrounding brain injuries for the general public.

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Appendix 1: Project Information Sheet

Information Sheet

Study Title: To Investigate Third-Level Psychology Students and The General Public's Perception of Brain Injury's.

My name is Hannah Farrell and I am an undergraduate Psychology student conducting research at The National College of Ireland under the supervision of Dr April Hargreaves.

Objectives of this study:

This study aims to investigate two groups of individuals in relation to their perceptions of brain injuries. Third-level students and the general public will be examined in relation to how they perceive individuals who have acquired a brain injury.

What will happen if I volunteer:

This research study is voluntary, and you will only participate if you wish to do so. If you do decide to take part in this research study, the first thing you will be asked to do is give some background information such as age, gender and whether you are a third-level student or the general public. You will then be asked to rate a series of questions in relation to your perception of brain injuries. If you wish to withdraw at any point, simply close the tab on the google docs form. This will exit you from the study without saving your data. Please also be aware that once you submit your data to the study, it is saved anonymously, and can never after be identified as your data. For that reason it is not possible to withdraw your data from the study once submitted.

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Risk and Benefits of the study:

The possible risks in taking part of this study include:

Mental Health Risk (Psychological) – We will be discussing brain injuries which

may be a sensitive or triggering topic for individuals who know someone personally

who has acquired brain injury. The possible risk of taking part in this study is you

may find some of the material we will be discussing upsetting and distressing. If at

any time you find the study distressing, you have the right to finish the study and

discontinue partaking in it. There will also be contact details provided at the end of

the survey for organisations who can answer questions on acquired brain injuries.

The possible benefits in taking part in this study include:

Research and Better Understanding of Brain Injuries -. By understanding the

opinions and views of the public it can help to inform those with an acquired brain

injury, who are often misunderstood or stigmatised in society.

Confidentiality:

The online questionnaire is anonymous. The information that you provide will be

collected into an electronic database and will be stored in a password protected encrypted file

. As a result, it will not be possible to identify either you or your data from the rest of the data

pool. This affords you complete confidentiality and anonymity.

Contact Information:

Researcher: Hannah Farrell

Supervisor: Dr. April Hargreaves

Email Address: x15394626@student.ncirl.ie

Supervisor: april.hargreaves@staff.ncirl.ie

Address: Mayor Street Lower, International Financial Services Centre, Dublin

Appendix 2: Project Consent Form

Before you begin please indicate that you know what the requirements of participating entails.

Informed Consent

Please read the following statements and tick the box if you agree with the statements.

- (b) I agree that I have read the information sheet provided \Box
- (c) I agree that I am participating in a research study investigating third-level students and the general public's perception of brain injuries. □

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Appendix 3: Debriefing Sheet

Thank you for participating in this research study. If you have any further questions please contact the researchers at x15394626@student.ncirl.ie and april.hargreaves@staff.ncirl.ie

If you have been affected by anything raised in this study, there is support that you can reach out to.

Headway Ireland provide support services for individuals affected by brain injuries.

Telephone: (01) 604 0800

https://headway.ie/

Samaritan's provide support services for individuals under any emotional distress

Telephone: (01) 671 0071

https://www.samaritans.org/your-community/samaritans-ireland-scotland-and-

wales/samaritans-ireland

Appendix 4: Perceptions and representations of brain injuries questionnaire

Perceptions and representations of brain injuries

Survey

Welcome to our online questionnaire. This survey is about your perception of "brain injuries". Your opinion is important to us. We appreciate you taking the time to complete this questionnaire, it will take you about ten minutes.

identifying information

- Gender
- Age
- Occupation psychology student or general public
- Level of education

Question 1

What are all words, adjectives, verbs, phrases and images that come to mind when you hear the phrase "brain injury"?

Question 2

What are all words, adjectives, phrases and images that come to mind when mentioning "people with a brain injury"?

Question 3

Do you know the difference between a psychiatrist, psychologist and neurologist ?

- Yes
- No

Knowledge of the causes of brain injuries

Question 4

For each of the following illnesses, please tick one of the following options: a) you know the name and are able to describe it, b) you know the name without being able to describe it, or c) you have never heard of the illness.

[Only one answer possible per line]

	I know the name	I know the name of	
DANDON	of this disease,	this disease, but I	I never heard of this
RANDOM	and I'm able to	am not able to	disease
	describe	describe	
aumatic Brain Injury			
cquired Brain Injury			
Concussion			
Stroke			
Brain Tumour			
Aneurysm			
Hypoxia or Anoxia			
Stroke			
Alzheimer's disease			
Meningitis			
Epilepsy			
Encephalitis			
Multiple Sclerosis			

Here is a series of statements about three brain conditions. Indicate for each whether you agree or disagree with each of these statements.

Stroke..

Epilepsy..

Traumatic brain injury..

[Only one answer possible per line]

Stroke	Agree	Disagree	l do not know
Is Contagious			
Worsens with time			
Can be diagnosed early			
Is a disease with which one can live normally,			
with treatments			
Involves lifelong treatment			
Is a hereditary disease			
Is a disease like any other			
Causes motor disabilities			
Expresses in young adults			

Epilepsy	Agree	Disagree	I do not know
Is Contagious			
Worsens with time			
Can be diagnosed early			
Is a disease with which one can live			
normally, with treatments			
Involves lifelong treatment			
Is a hereditary disease			
Is a disease like any other			
Causes motor disabilities			
Expresses in young adults			
Traumatic brain injury	Agree	Disagree	I do not know
Is Contagious			
Worsens with time			
Can be diagnosed early			
Is a disease with which one can live			
normally, with treatments			
Involves lifelong treatment			
Is a hereditary disease			
Is a disease like any other			
Causes motor disabilities			
Expresses in young adults			

Presupposed origins of brain injuries

Question 6

In your opinion, what are the factors that contribute to brain injuries...?

[Multiple answers possible by column]

	Stroke	Epilepsy	Traumatic Brain Injury
Genetic factors			
Food			
The conditions of life (living			
environment, lifestyle, etc.)			
age			
The sex of the individual			
Psychological or emotional shock			
Drug or alcohol			
Other (specify)			
You do not know			

Evaluation of perceived social handicap

Question 7

Here is a series of statements about <u>people with brain injuries.</u> Indicate for each whether you agree or disagree with each of these statements.

A person with
Stroke
Epilepsy
Traumatic Brain Injury

[Only one answer possible per line]

RANDOM	Agree	Disagree	I do not know
Is able to resume responsibility of a family			
Must follow treatments that leave them numbed			
Can not live with a partner			
Can not live in society, must be isolated			
needs to be assisted in his/her life everyday			
Can not hold down a job			
Represents a danger to herself (accidents, memory			
loss)			
Often Represents a danger to others (anger,			
impulsiveness)			

Familiarity with brain disorders/ brain injuries experience that respondents have Question 8

Are you or have you ever been diagnosed with a brain disorder/ brain injury?

[Only one answer possible]

- •Yes, I am or have been suffering from a brain disorder
- No, I am not and have never been diagnosed with a brain disorder

Question 8a

Has anyone close to you ever suffered from a brain injury? (family, spouse, friends, colleagues ...)

[Only one answer possible]

- •Yes, someone close to me is or has been suffering from a brain injury
- No, no one close to me is or has been suffering from a brain injury

Question 9

If you have had a loved one with a brain disorder, which of these disorders have they had?

[Multiple answers possible]

- Traumatic Brain Injury
- Alzheimer's disease
- Epilepsy
- Concussion
- Meningitis
- Hypoxia or Anoxia
- Stroke
- Multiple Sclerosis
- Other (specify)
- You do not know

'Feelings towards people with brain disorders/brain injury

Reaction		In third place
Compassion		
Distrust		
Embarrassment / discomfort		
Curiosity		
Shame		
Fear		
Guilt		
Rejection		
Helplessness		
Sadness		
Anxiety		
Anger		
Indifference		

Question 10

If you learned that someone close (a family member, neighbour, spouse, friend ...) was suffering from a brain disorder/brain injury, what would your reaction be?

[Up to three possible answers]

Acceptance level of disease

Question 11

Would you work with someone who had...

[Only one answer possible]

RANDOM	Yes happily	Yes if I had to	Absolutely not
Stroke ?			
Epilepsy ?			
Traumatic Brain Injury ?			

Question 12

Would you be ok to be in the same class with someone who had \dots

[Only one answer possible]

RANDOM	Yes happily	Yes if I had to	Absolutely not
Stroke?			
Epilepsy?			
Traumatic Brain Injury?			

Would you accept to live under the same roof as a loved one if s/he had ...

[Only one answer possible per line]

RANDOM	Yes happily	Yes if I had to	Absolutely not
Stroke?			
Epilepsy?			
Traumatic Brain Injury?			

Image patterns of care and the medical community

Question 14

Do you believe in the effectiveness of existing treatments currently ?

[Only one answer possible per line]

Treatment	Yes a lot	Yes, a	No, not really	Not at all
Drug treatments				
Physio therapy/Occupational				
therapy/Speech therapy?				

If you know someone with a brain injury, do you think they were diagnosed sufficiently early or too late ?

[Only one answer possible]

- They are diagnosed early enough to be supported from the beginning
- They are diagnosed too late, because often confused with other problems
- You do not know

Information and communication about brain injuries

Question 16

If you became ill and suffered a brain injury, who would you talk to?

[Multiple answers possible]

A family member

An association that helps people with brain injuries

A boss

A colleague

A specialist

A stranger on the Internet, in forums that talk about the

subject

Your doctor

Your friends

Do you think you are too informed, adequately informed or not informed enough about brain injuries by ...

[Only one answer possible per line]

	too	sufficiently	
RANDOM	informed	informed	Not informed enough
The Media			
V 1 (
Your doctor			
The medical			
community			

Opinion of Research in the field of brain disorders/brain injuries

Question 18

Do you think the research in the field of brain disorder/brain injuries in Ireland ${\bf r}$

is ...

- Very effective
- rather effective
- Not really effective
- Not at all effective
- You do not know

According to you, should brain disorders/ brain injury research constitute a public health priority ?

[Only one answer possible]

- Yes definitely
- Yes, to some extent
- Not really
- Not at all

Question 20

Whilst completing this questionnaire did you have any thoughts or feelings that you would like to communicate to the researcher? Please detail them below.

Appendix 5: Question 20 data

N/A - very interesting research project!

Q20 - Whilst completing this questionnaire did you have any thoughts or feelings that you would like to communicate to the research? Please detail them below. N/A I think how much you think you know changes when faced with questions Being diagnosed with any illness is traumatic for any patient. Ireland definitely needs to improve their after care and put focus on support following on from treatments. More research is needed in these indefinite (to an extent) areas around pharmacology and neuroplasticity Needs to be a bigger conversation about BI and How people are treated post BI Those with brain injuries may not display any different to others in the community The general public have many misconceptions about what a brain injury entails, and awareness could be much better spread. I think that GP should be more informed on this topic and the variety of symptoms that may occur that indicate brain injurys/diseases. Would like to know more on this I'd just like to highlight that I am not currently a student of psychology but I have a psychology degree nope In relation to some forms of TBI, particularly concussion (as it is not visible by MRI - unless in cases of contusion), I think that researchers and workers within the medical community need to be more aware. While it is necessary to rule out severe brain injury in initial diagnoses in A&E following a TBI, I do believe being told to "just rest" is not good enough. In my case, I've had two concussions during my life and was advised to rest as much as possible in order to promote my recovery. However, I was not told about all the other symptoms I would begin to As concussion is not visible, there are a whole cluster of symptoms which are generally recognised under an umbrella term "post concussion syndrome", although little is known about the injury/disorder I believe that more research needs to be done on this to effectively determine, monitor, and treat the cognitive deficits, physical symptoms, fatigue, and which can occur weeks following initial injury; and Some of the answers where not broad enough as most brain injuries are like a rainbow i.e many different spectrums Diagnosis of a stroke took over 6 months. It was only suggested after multiple test. It took far to long and support from hospitals for the patient was very limited within the hospital. I wish I knew more about brain injuries and treatments. Its stigmatized and the affect of that is that I too feel some discomfort in regards to it

Just felt really sad and very anxious thinking about it especially because I think stroke/epilepsy/traumatic brain injury are never the sufferer's fault but it happened to them and they have to potentially characteristics.