

**Square Pegs in Round Holes: An Ethnography  
Investigating the Relationship between Identity,  
Acquired Brain Injury and Rehabilitation.**

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## Declaration

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

Signed ..... Tim Banks ..... (candidate)      Date ..... 30.03.17 .....

### STATEMENT 1

This thesis is being submitted in partial fulfilment of the requirements for the degree of PhD.

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### STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by giving explicit references. The views expressed are my own.

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## **Dedication**

I dedicate this thesis to my Uncle John. Without his incredible thoughtfulness and kind generosity, none of this would have been possible. May you rest in peace. I also dedicate this thesis to my parents, Frank and Pamela Banks who always believed in me. Finally, I dedicate this thesis to my family; my wonderful wife Carly who has always been there for me and my beautiful children, Arlo and Romy who inspire me every day. I hope to have done you all proud and I love you all very much.

## **Abstract**

This thesis is an ethnography which explores acquired brain injury (ABI) survivor experiences of rehabilitation and compares these experiences with an analysis of discourses of ABI, as well as the social and organisational arrangements of rehabilitation services.

Acquired brain injury interacts with the health care setting in complex ways. Many of the usual markers in which the individual might be interpreted as a patient such as assessing symptoms, the method of diagnosis, how the progress of the patient is viewed and the actual act of getting better are immensely complicated and, at times, even contradictory in this setting. Very often, these markers become negotiated. When the understanding of these different interactions between actors is contested, (e.g. when there is a disagreement between professional, family member and patient as to what a symptom might be or what a goal to work towards might be) this can become problematic.

The ultimate objective is to use the study's findings to inform ABI services and potentially enable better provision. Health care professionals work tirelessly in difficult environments, with increasing workloads and often with scarce resources. Research that specifically engages with the interactions within the health care setting will aid understanding of good practice and help prioritise the importance given to parts of the service which are currently under-represented.

This research also aims to make a contribution to the sociology of biomedicine, healthcare organisation and work which investigates the body, identity and disability, particularly hidden disabilities.

The practical implications of this research would inform decision makers of the extent to which identity work and participation underpins the success of the overall rehabilitation process.

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## Chapter One: Square Pegs in Round Holes

### *Introduction - What's the problem?*

This thesis began life as a question; a concern that I could not leave alone when I became Day Centre Manager of HeadStart, a charity assisting people affected by acquired brain injury (ABI.) I found myself responsible for triaging patients and was involved in making decisions which determined who gained access to our service, who might have to wait and who was declined a place altogether. It was put to me that as a charity with limited resources, we were unable to have an open door policy and careful management of space had to be considered. However, I felt unsure that the way in which I confronted this sometimes impossible task was fair and correct.

An important aspect I became uncomfortable with was the criteria that were in place in order to determine whether an individual's attendance would be deemed 'appropriate'. These criteria consisted of factors such as length of time post-injury, geographical location, whether the brain injury is the primary difficulty for the individual and so on. Certain signs and symptoms, such as a recent history of physical violence or drug abuse, would mean that the patient would probably be deemed inappropriate to attend and would therefore not be given a place. It transpired that the initial criteria for suitability were loosely based on a model set out by the community brain injury team, a specialist unit based in the main part of the rehabilitation hospital where we were also located and a team with which we had strong ties.

HeadStart, without having the constraints of being part of the NHS, were able to take individuals on a case-by-case basis, extending geographical areas and bending the rules as to what constitutes a brain injury as we saw fit when we felt it would benefit the individual in question. Alternatively, without any statutory obligation to intervene, if an individual appeared to be potentially too problematic, we could signpost the person elsewhere. These assumptions could be based on predictions as to how the individual might engage with others in the group, whether the amount of time needed to be dedicated to them could be accommodated, or whether it was felt that they could be relied upon to attend such a limited resource regularly enough to warrant them being allocated a place. The very issues that might determine a person being granted a place are the very issues that someone with acquired brain injury might face. This inevitably led to the Day Centre, the major component of the charity, being shaped by the attitudes and subjective values of me, the Day Centre Manager, even if I could hide behind the selection criteria in place as I saw fit. As the number

of participants attending reached saturation I felt increasingly pressured to make 'objective decisions' as to who accessed the service depending on these fluid criteria which could be interpreted both to the benefit and the detriment of the patient. With no obvious pathway in terms of leaving the service, the various projects were becoming fuller as the need and waiting list grew.

Through my role with HeadStart, I worked closely with healthcare professionals, particularly those working in neuro-rehabilitation. It became apparent through working with healthcare professionals that they were experiencing many of the same difficulties and being forced to make similar decisions to me. They too had issues with waiting lists as well as feeling pressure to move existing patients onwards. Not only did they have to determine who gained access to the medical domain, but they also had to make problematic interpretations of what constitutes 'wellness' and success in terms of recovery. It seemed that there could often be differences across departments and between professionals, family members and patients when it came to deciding the best course of action. Some wanted discharge; others felt there was more that could be done in hospital. Family members suggested certain behaviours had changed whilst patients claimed that there was nothing wrong with them. Without definitive absolutes in terms of what to do next, this only muddied the waters further.

I started to question whether what I was doing regarding selection was right and the reassurances I was getting did not seem to get to the core of the issue. This led me to consider two meetings that really exemplified my concerns. These were goal-planning meetings that had taken place amongst healthcare professionals, social services, the patients, family members and myself. The purpose of these meetings is to try to determine goals that constitute progress with the ultimate aim in most circumstances being a discharge from any further medical intervention. The meetings are in two halves with the first half being used to discuss progress and goals between professionals and the second half used to transfer this information to the patient and family members who only join the meeting for this component. This is the opportunity for patients and family members to contribute their own thoughts and ideas. The first patient was a mother in her late 30's who had received a traumatic brain injury when her horse had kicked her. She was living back with her parents. The discussion turned to future goals and it was decided by everyone present that she had made a recovery sufficient that the community brain injury team (CBIT) no longer needed to be involved. She was accessing HeadStart, had a strong social support network at home and had taken up hobbies with a view to starting voluntary work in the near future. All of these are deemed positive indicators of a good outcome after ABI. However, the patient's parents, who had been strong

supporters of the work done by CBIT, were known to have concerns with the idea that interventions would stop altogether. Therefore, it was decided that when the patient and her parents entered the meeting they would be told that she would be put onto a 'sleeping file' where the patient would still have access to services but it would be their responsibility to request them. When the patient arrived, this was deemed satisfactory for all concerned.

The second meeting concerned an individual who lived alone. He had considerable mental health difficulties and was known to be a very high suicide risk. He had been registered blind, a result from a previous suicide attempt, an overdose, in his early 20's. He was now in his late 40's and had received an ABI after falling down a flight of stairs. He was in the process of going through a difficult divorce which he was having trouble fully understanding due to a combination of memory loss, a lack of understanding and a predisposition to oppose institutions such as the law, the banking system and some elements of organised medicine. His attendance at CBIT meetings was very sporadic. When he was in a cycle of attending, he would do so regularly but during bouts of depression, he would miss all services and appointments for weeks, if not months, at a time. During a particularly long period where he had not participated or responded to phone calls and two letters, the procedure in place for events like this, it was decided by CBIT that they had no other option but to discharge him. They were not able to offer any service if he was unprepared to access them. It was agreed by all concerned that there was nothing more they could do and this was the right course of action.

These are two separate meetings amongst many but they serve to highlight the somewhat counter-intuitive, contradictory organisational system which may actually penalise patients. The woman who is well supported elsewhere remains part of the system whilst the man who, perhaps by the very effects that could be attributed to an ABI, misses out. These two meetings, alongside my own role in the process, led me to ask:

Why does it seem that resources used to assist individuals with ABI are organised in such a way that those that appear to need the most support are the ones who may not be able to gain access or remain in the system?

Could the objective framework for constituting 'patient' in the medical discourse be problematic and even incomplete when it comes to defining acquired brain injury and what it is to be ill?

The health care professionals and the staff at HeadStart were very hardworking, caring individuals but the organisational procedures that they followed seemed to constrict available options. This in turn acted to renegotiate the cultural norms in terms of what it was to be 'ill' or 'well'; a 'patient' in need of care or a 'person' fit for discharge. Somehow decisions were being made that we all agreed were correct but at the same time might equally not seem common sensical. Critically, were the very difficulties experienced by individuals following ABI adding to their exclusion from the rehabilitation process?

With 'objective' measures beginning to seem problematic but safely embedded in the discourse, I decided that I wanted to explore the conditions of possibility underpinning this situation and what the impacts might be. Specifically, I wanted to understand how the process and procedures in place are interacted with by the actors involved in order to configure the ABI patient, much in the way I had been doing when deciding who was to gain access and who would miss out. I wanted to know how this is accomplished, by whom and what the impact of this is for the success of the rehabilitation process. I also wanted to know what the consequences might be for patients after their interaction with the clinical domain was over. Whilst I previously mainly worked alongside the community brain injury team, I felt that in order to understand this fully, it would be necessary to trace the journey back further. This meant it would be necessary to go back to the neuro-acute wards and the rehabilitation hospital.

### ***The scale of the problem***

According to the charity Headway UK, in 2013-14, nearly 350,000 people were admitted to hospital in the UK with some form of acquired brain injury. This is roughly 566 per 100,000 of the population. Of course, this does not include those who did not access the medical setting. For 90% of those admitted, they will go on to make a full recovery, but for the 10% who do not, the ABI has the potential to cause life-changing effects not just to the person with the injury but very often to friends and family members as well (Headway UK 2016).

Acquired brain injury (ABI) could be neatly categorised as an injury to the brain that has taken place since birth. However, this is a collective term for a whole range of different potential combinations of symptoms and causes of injury. It is considerably messier than this and what it is to have an ABI can be redefined according to the need of the person or the particular organisation categorising it. For example, the charity Headway UK describes acquired brain injury as a term which, "*covers all*

*situations in which brain injury has occurred since birth and includes traumatic brain injury as well as tumour, stroke, brain haemorrhage and encephalitis, to name a few,”* (Headway UK 2016). This definition groups together illnesses which have similarities in terms of expected effects common as a result of them. In the medical domain, at an operational level, it is messier still. For example, a ward or a community brain injury team may have a written definition of the type of stroke that it will accept and the sort that it will not, defined by the part of the brain effected or the nuanced, expected outcomes that different types of strokes might produce and therefore the likelihood of available resources making a valid contribution to recovery. In real terms, the diagnosis can be quite fluid with the patient only being categorised or re-categorised after they have been admitted to a neuro-ward or community brain injury team, arriving there when they fit no other medical diagnostic category.

Many of the effects of ABI are well documented and would probably be anticipated by a lay audience. Issues such as memory loss or poor mobility are almost synonymous with what people may think of when asked to consider possible signs and symptoms of ABI. However, whilst significant issues, these are just some after-effects that a patient might experience whilst some patients may not suffer these at all. Other difficulties may include impulsiveness, lack of confidence, compromised judgment, frustration, anxiety, anger management issues, poor attention, lack of taste and smell, sexual dysfunction, slurred speech, problems with self-awareness and poor flexibility in their thinking. These issues were purposefully given in list form to highlight both the extent and the variation of problems which could be attributed to a brain injury. It is far from exhaustive. What the list cannot do is begin to explore how each difficulty might be experienced by the individual both in relation to each other and to the wider society that the individual interacts with. Each symptom can carry differing significance for the individual depending on their personality, lifestyle, prior experiences, their environment and their hopes and expectations both before and after the injury. Whilst it is of course possible to read the list and, to an extent, imagine what some of those issues might mean if they happened to oneself, to experience difficulties after brain injury, to understand how these difficulties might manifest themselves both in combination with each other and by interacting with other aspects of the individuals life-world, is a truly different reading of the list altogether.

The most common ways to acquire a brain injury is through a trauma such as a road traffic accident, lack of oxygen, infection, poisoning or a brain tumour (Ownsworth 2014). Many of these incidents might mean that the ABI is just a part of a wider insult to the body which also needs addressing.

Immediately following an acquired brain injury, particularly a severe ABI, it is probable that the person is in a life-threatening position. However, advances in medical technologies, knowledge and techniques means that increasingly, if the patient survives the initial insult to the brain, they can expect to live to a similar life expectancy to what they might have prior to their injury (Stewart 2014). What this inevitably means is that some patients will go on to live but with lifelong, chronic conditions. This brings its own unique set of issues and challenges that need to be addressed.

In terms of treatment and rehabilitation, pathways are almost as varied and nuanced as the symptoms described above. As well as neuro-consultants, doctors and nurses, in order to deal with these different needs, there are a large variety of different specialties and therapists that work with patients to a greater or lesser extent. This can include speech and language therapists, physiotherapists, psychologists, occupational therapists and dieticians to name just a few. In addition, there might also be a community brain injury team which can work with survivors for several years after they have left the hospital. A typical pathway, if such a thing exists, might involve the neuro-acute ward, neuro-rehabilitation in a specialist hospital, and discharge with or without ongoing support from an appropriate community brain injury team. Duration of stay in hospital could be a matter of days but could also be weeks, months or even, in rare cases, years.

The above, highly simplified pathway may not be deemed applicable for some. This might be due to the nature of the injuries, where the patient lives, whether beds are available, or if the brain injury was actually picked up in the first place.<sup>1</sup> In many instances, the patient has been known to self-discharge and simply leave the hospital. There can be issues in terms of coverage of specific services. For example, the rehabilitation hospital may cover a whole geographical region whilst the community brain injury team only covers part of it. This means that an individual may have very similar needs to a person in the bed next to him, but, unlike his neighbour, is ineligible for the next part of rehabilitation. Others may not be diagnosed with an ABI until many years after the event. Some are considered unsuitable for certain stages of rehabilitation and a large part of this thesis is interested in the decisions and rationales behind determining movement between these various

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<sup>1</sup> Sometimes the injuries to the body are so severe that these are treated first, on a different ward, and the ABI does not get categorised until much later. In other circumstances, outcomes of the ABI are not immediately obvious and only become recognisable when the individual themselves experiences difficulties and seeks assistance for them. As described later, one patient I spoke to only knew there was something wrong when he tried to use the computer when returning to work and could no longer do so. Other aspects to his life were perfectly normal and had he not used the computer at work, it may have been many more days or weeks until the injury was recognised.

stages of rehabilitation, particularly when it comes to analysing why one patient may 'pass' (Garfinkel 1967) to the next stage and another may not.

Increasingly, media and public attention has been turned towards concepts of good and bad patient. Additionally there is an increased moral agenda circulated by a health care discourse that invites us to look after ourselves, manage our own care, to select and use services appropriately and only turn to medical care when we cannot help ourselves (Choose Well 2016). This has major implications for an individual's identity and sense of self. You cannot just choose to be a patient. This has to be legitimated by an 'other', namely 'experts', from within the healthcare system. The agenda dictates that the label 'patient' is only bestowed when all other avenues explored have failed. This is accomplished through significant work on the part of the individual who feels there is a problem and interaction with the healthcare setting. It often requires this individual to perform certain subtle, and not so subtle, behaviours which makes them recognisable as 'patient'. Garfinkel calls this "*passing*" (Garfinkel 1967 pg.118). This allows the individual to be understood as legitimate. As this thesis explores, the need to be seen as legitimate in order to pass into, and remain in, the category of patient has never been so important (Hillman 2014). The relationship between patient and healthcare professional is a complex and intricate set of arrangements which are necessary for it to be successful. They require certain performances and negotiations on both sides.

I consider a loose interpretation of the sick role (Parsons 1951) as a construct for understanding these performances. It is used as a useful heuristic device to provide a framework for considering the obligations that patients are expected to adhere to in order to be perceived as legitimate and worthy of help. Despite the sick role being problematic, as will be discussed in the next chapter, societal expectations of what it is to be ill, make it necessary for the individual to at least acknowledge them. The importance of interpreting and performing patient in line with these obligations cannot be underestimated. To a greater or lesser extent, these obligations must be performed in order to be deemed legitimate by professionals, family members and society more generally (Goffman 1959). They need to 'do patient' (Garfinkel 1967). If configured (Latimer 1997) as legitimate, the patient is absolved, to a point, from social responsibilities. They are not expected to contribute to society to the same level and extent as others. They are given emotional and financial support, particularly in their attempts to fulfil the above obligations. To not be configured as legitimate can be a devastating blow to the patient and they can be castigated for their supposed failed attempts to be configured as such. But what if the very reason that the person looks to be regarded as patient (such as receiving an acquired brain injury) has restricted their capacity to

perform their role? The thesis that follows explores this issue, also showing that an additional irony for the ABI patient is that the individual may not be seeking a configuration of patient and in doing so, problematising the situation yet further as there is no suitable configuration in which they can belong. I show that the obligations; the rules of the sick role which overarch what it is to 'do patient' can be deeply problematic for the ABI patient.

### ***This thesis***

This thesis is an examination of the interaction between patients diagnosed with acquired brain injury and the medical setting designed to assist them. It shows a 'lack of fit' (Goffman 1966) between the biomedical discourse and performance of patient. This examination includes how this issue is met and challenged by the main actors involved, most notably healthcare professionals and patients. I show how it becomes necessary for familiar concepts such as 'patient', 'illness' and 'wellness' to become more flexible and negotiated in order to meet this challenge. This gives wider scope to allow the individual with ABI to be 'legitimated' allowing them to fulfil their obligations and 'perform patient' successfully whilst simultaneously assisting the professional to do 'good medicine' (Goffman 1959; Dingwall and Murphy 1983; Latimer 1997). I demonstrate strategies and practices in play that are used to accomplish these performances by all parties involved. This includes the professional configuration of the patient, the organisation of the everyday in the healthcare setting, 'moving the goal posts' and the importance of the 'patient willingness to try;' the performance being a sufficient marker of what it is to 'do patient'.

I show how the concept of ABI can be configured differently by the actors involved considering the various artefacts that are used to accomplish this (Mol 2002). I argue that the differing interpretations are manageable when the framework used to conceptualise patient, illness and wellness is flexible enough to incorporate these differing accounts to ensure there is still 'fit'. As long as the patient maintains some form of recognisable and manageable 'performance of patient' then it is acceptable. The flexibility of the framework is largely controlled by the professional.

However, when the configuration of ABI impacts on what it is to 'do patient' it can make the legitimisation of patient problematic and unstable. I examine how and when this negotiation cannot be agreed; when the patient cannot be made to 'fit' it might ultimately lead to 'disposal' (Berg 1992; Latimer 1997) from the setting. Overarching all of this, I consider the wider implications of these

performances and actions, both for the treatment of the patient but also how this interacts with the patients understanding of a sense of self and their relationship with ABI throughout.

This investigation was conducted by undertaking an ethnography, primarily based on a neuro acute ward in a large university teaching hospital, two neuro wards of a rehabilitation hospital and at classes run by a community brain injury team, also at the rehabilitation hospital. The teaching hospital was a large, purpose built hospital, built in the 1970's but being constantly upgraded and extended. The rehabilitation hospital on the other hand was under continual threat of closure, destined to be merged with other regional hospitals in the area.<sup>2</sup>

The purpose of observations was to capture the day-to-day, micro-interactions which are so crucial in configuring ABI. It is not the formal diagnosis but the small conversations in the corridor or at the bedside, interpretations of a certain comment by a patient or response to a family request which form 'accounts' (Garfinkel 1967) making up an individual's brain injury. These observations were complimented with 14 interviews with patients and healthcare professionals that took place during the observations. These allowed for context and a richer exploration of the observational work whilst also allowing for data collected to be cross-referenced. It also gave insights to interpretations of events which were at times at odds with my own understandings.

### ***Thesis outline***

#### **Chapter Two: Positioning the research**

In chapter two, I set out the analytical framework drawn upon in the study, reviewing the literature which underpins the research within a wider context. In particular, I examine the key theories that underpin my theoretical framework, explaining how they are operationalised for interpreting the data, including theoretical tropes drawn from the work of Parsons, Goffman, Garfinkel and Latimer.

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<sup>2</sup> As a result, there had been little investment in the infrastructure for several years. The building itself was a listed building; a country house originally a convalescence home for wounded soldiers during the First World War. It was constantly being patched up in order to remain in working order though staff and patients alike had to become used to regular issues such as faulty doors, lights and even leaks. During fieldwork, the latest date for closure was moved on by three years meaning staff were hopeful that there may now be more investment due to a little more stability.

Specifically, I elaborate theories of identity, the organisation of healthcare, medicalisation and the role of the patient and consider how these come together to construct the medical world that the individual with ABI is required to negotiate. I conclude by reflecting upon how these different, and sometimes potentially competing, theories have been brought together in the analysis of the data in this thesis, exploring my own epistemological position in the process.

### **Chapter Three: Methods**

Having positioned the research within a sociological theoretical framework, the methods used in order to undertake this project are presented. In chapter three, I tackle several key issues. Firstly, the chapter considers the role of NHS ethics in placing the researcher within the setting. I consider how the process positions the researcher and promotes a distinct understanding of research. Whilst it was a fairly straightforward process to gain ethical approval for this study, the reality of research is distinctly messier. I also pay particular attention to an issue that could all too easily be overlooked as mundane, the act of gaining access. In particular, I provide a reflexive discussion as to how my previous position as an employee associated to the field led to my attempting 're-impression management' in order to be understood differently, with limited success. I then give a detailed account of my choices of methods, explaining how they were carried out as well as the reasons for which they were advantageous. A discussion of analysis concludes the chapter, explaining how analysis was tightly interwoven into, not only data collection practices, but through every aspect of the research process, even including gaining access and applying for ethical approval initially.

### ***Empirical chapters***

The first two empirical chapters (chapters four and five) are largely interested in the movements of professionals. Chapter six examines organisational practices and the significant role this plays in understanding the relationship between ABI and 'doing patient'. Chapters seven and eight then move the conversation back to examine the space from the perspective of patients, closely considering how they configure ABI and the consequences of this. Inevitably, the various actors are closely intertwined, symbiotically shaped by the actions of each other. Therefore, it would be foolish not to account for this within the chapters by ignoring the implication of the one actor until their designated chapter. The chapters are only set out with the professional or patient as the main focus point for ease of reading.

#### **Chapter Four: When is a patient a patient, when is a professional professional?**

In the first findings chapter, I discuss how the patient is 'configured'. Using the multi-disciplinary team (MDT) meeting as a starting point, the chapter presents an in-depth account as to how configuring of patients is accomplished and the reasons why it is considered necessary. I explore how, in some instances, configuring can be both advantageous and encouraged by the patient whilst at other times it can be to their detriment. I consider how concepts such as expertise come into play and how social accounts can be brought in and out of focus depending on the fit.

In an arena which is organised to accomplish the moving of the patient from a category of 'illness' to one of 'wellness', I argue that by configuring the patient, the professionals are doing 'good medicine'. It is necessary to position the patient in this way to prevent them from becoming stuck within the medical setting. Considerable work is sometimes undertaken to ensure the patient 'fits' and those that do not are disposed of. This allows throughput of beds and for a negotiable concept of wellness to be established (Allen 2015).

#### **Chapter Five: Medicalisation vs. De – Medicalisation**

Configuration of 'patient' by healthcare professionals can be significantly influenced by the biomedical lens in which illness is understood. To understand illness, the issues must be 'legible' in the medical domain (Atkinson 2005.) The person must be medicalised in order for the issues being discussed to be a site of illness. They can then be isolated, worked on and fixed, also allowing the patient to be legitimised. In instances where the patient is not medicalised (or when they are de-medicalised) legitimacy can be taken away from them. This leaves the individual in a precarious position. This chapter considers how medicalisation and de-medicalisation as a process is accomplished in more detail. I discuss how it interacts to assist the individual to perform patient successfully. I consider how medicalisation is bound up in the social, brought in and out of focus and used in conjunction with other categories in order to 'read the patient,' marking them as appropriate or not.

I go on to consider how medicalising the patient can be problematic for the individual's identity causing a site of conflict between professionals, patients and family. Finally, using a case study of two patients, I demonstrate how the principles of medicalisation and de-medicalisation can play a key role in configuring the individual, influencing the trajectory of the patient narrative both in the

sense of configuring the patient and the options made available to them in the rehabilitation process.

### **Chapter Six: Organisation of the ward**

In order to understand the significance of the interactions and movements that take place between actors when configuring identity in ABI, it is imperative that the spaces in which it takes place are considered. The ward is not a space without meaning, symbolism or power. It is itself a core component in the discourse of creating and sustaining identities. It is interpreted and configured by the actors involved in order to make sense of themselves, often using the 'other' and the space as reference points. Additionally, the organisation of the ward plays a significant role for understanding interactions between the various actors who inhabit the space. The ward acts as a form of surveillance (Armstrong 1995; Foucault 1978), an organiser that encourages actions to be performed in a particular way. The very way that the space is utilised and interpreted reinforces the cultural practices and expectations of those involved.

This chapter explores the organising practices in detail beginning by considering how the ward is set out ergonomically. The everyday practices that make up life on the ward are then mapped onto this. In particular, I analyse how daily life is carried out in response to the organisation which takes place; *"how ward daily life is like normal life but at the same time isn't"* (field notes). I consider how the world which the patient inhabits becomes inverted and subverted; a site where the private becomes public. I also show how the rituals and rhythms on the ward, act to discipline patients.

### **Chapter Seven: ABI: What does the patient think?**

Chapter seven is the first chapter to take patients as the primary focus. I begin to consider how patients 'respond' to the medical discourse and organisational practices in which they are expected to 'fit'. I consider how the patient often uses different cultural artefacts to produce different 'accounts' (Garfinkel 1967) to understand ABI and their own relationship with it. This chapter looks in depth at the tools that are used to configure their own ABI such as experiences, technologies, concepts of wellness, the hidden nature of disability and comparisons with other patients.

I explore how the concept of wellness, being fluid and subjective and by being interpreted with different tools, can have the potential to configure an 'alternative' ABI. Through 'performance'

(Goffman 1959) of 'patient', I consider how this can exist symbiotically within a medical discourse, even complement it, but if there is an irreconcilable difference, it becomes a site of conflict.

### **Chapter Eight: Are they moving the goal posts or playing a different game? Patient experiences in the medical setting**

In this chapter, I particularly consider how the organising principles of the healthcare setting might impact on the patient. I explore how patients reinterpret the setting as part of their own understanding, configuration and performance of ABI. I discuss how the patient looks to make sense of themselves within this alternative world and how they carry out the everyday against the organisational rituals and practices. In particular, I consider how patients interact with other patients in order to make sense and accomplish identity. I then discuss how this is interpreted on the ward. I also consider the role played by the relationship between staff and patients in the patient understanding of self; how the invitation to the backstage can play an important role in creating and sustaining relationships yet the staff are the significant actors when it comes to who gains access to this space with the power largely held with the professional.

Fundamentally, I argue that the patient is not a passive object, to be acted on and to. There is a great deal of agency going on here. Patients, by reinterpreting themselves, technologies and rhythms within the setting, construct their own meaning and display identity that cuts through the rituals of the healthcare setting. This plays a fundamental role in the performance of self after ABI.

### **Chapter Nine: Conclusion/ Implications**

In this final chapter, I conclude by reiterating the findings from the previous chapters. Returning to the obligations of the sick role, I reflect on the seeming 'lack of fit' between acquired brain injury, performance of 'patient' and biomedical discourse. In particular, I re-emphasise the various strategies employed by the major actors involved in order to address this issue. Finally I consider the implications of brain injury rehabilitation being organised in this way, reflecting on how the systematic, organisational procedures act to shape the experiences of the patient as well as contributing to the possible exclusion of those most in need.

The following chapter will now set out a theoretical framework in order to position the research in a wider academic context. It will also provide a review of existing academic literature in order to position the research.

## Chapter Two: Positioning the Research

### *Introduction*

Having provided an overview of the thesis, this chapter now sets out the analytical framework drawn upon in the study, reviewing the literature which underpins it and positions the research within a wider context.

The overarching aim of this study is to investigate how acquired brain injury (ABI) is configured through the discourses, processes, practices, performances and representations put into play in medical settings focussed on the diagnosis, treatment and rehabilitation of people identified as having an ABI. The objective is to explore the (possibly) unintended consequences of these as 'ordering' (Latimer 2000) practices, particularly the 'classifying' (Jeffery 1979; Becker 1993) processes through which patients are 'sorted out' (Bowker and Star 2000). My concern is to illuminate the unintended consequences of these practices and processes from the patients' rather than the staffs' perspectives. As discussed earlier, my experience as an actor in this domain was as someone who tried to act in the patients best interests. I was troubled by how patients were positioned by the very forms of organisation through which they were assessed and their needs identified. The thesis precisely set out, therefore, to examine this clinical world through an alignment with patients' worlds. As such, it does not set out to understand how practitioners' practices and processes for organising and classifying patients are situated by complex political and socio-cultural logics (Mol 2002) or agendas (Latimer 2001), as important as these matters are. I leave this for another study.

In order to interpret and understand the rationale for and possible unintended consequences of the ordering and classifying processes through which patients are categorised, I draw upon the work of Goffman (1955; 1959; 1961; 1963) particularly his observations of identity-work, notions of 'performance' and the dramaturgical analogy. The data is also examined considering ethnomethodological (Garfinkel 1967) understandings of how worlds are organised through the methods and occasions that members draw upon to make sense of, and account for, how and when they do things, including the categorisation practices through which illness is configured and patients are classified. Here, I am particularly concerned with how encounters between persons are conducted and organised, but also with the specific technologies and other materials that are drawn upon to help order these worlds.

The clinical domain with which I am concerned can, therefore, be understood in terms of power, surveillance and resistance – aspects of everyday life implicit to the work of Goffman and Garfinkel. Here, I pay particular attention to the work of Latimer (1997; 2000; 2001; 2004), discussing how some patients' characteristics and behaviours are medicalised as 'clinical' needs, while others are not. Against this, I consider Parsons' (1951) theory of the 'sick role' as an overarching trope for understanding the everyday practices through which some persons are distinguished and positioned as legitimate ABI patients, while others are not.

The chapter begins by considering several key theories employed in the thesis. I explore the contributions of the theorists, address criticisms of their approach where necessary, and provide a more detailed explanation as to how they are understood and are being operationalised. I particularly dedicate time to these ideas here as they are the foundations of my research approach as well as how I have analysed the data. I then move on to apply these theories, alongside others, in exploring particular concepts important in this study. This includes theoretical interpretations surrounding identity, the organisation of healthcare, medicalisation and the role of the patient before considering how these come together to construct the medical world that the individual with ABI is required to negotiate. I conclude by considering how the different, sometimes potentially competing, theories have been brought together to be operationalised in the analysis of the data in this thesis, exploring my own epistemological position in the process.

### ***Parsons and the sick role***

A vital theoretical underpinning of this thesis is a reengagement with some of the key principles of the 'sick role', developed from the original work of Parsons. As a structural functionalist, Parsons, in his seminal work *The Social System* (1951), interpreted society as made up of a series of systems which acted to ensure equilibrium, a balance in society. Each sub-system in a given society - such as education, religion, the law and the family – has a function and, in doing so, produced an operational, harmonious society, the total of which was greater than the sum of its parts. Perhaps the most influential part of this work is the sick role and the system of medicine. This theory explores how sickness is a form of social deviance, something morally undesirable, with the function of the medical profession to sort out the legitimately deviant from the shams and cheats, that is, those people trying to get out of the responsibilities of their role in society (e.g. employee or parent). It is worth making clear from the outset that these principles are not to be taken literally as

a description of practice in a medical site, nor are they meant to limit interpretations of actions and behaviours of the actors involved in this study to these basic principles.

I am aware that Parsons' structural-functionalist systems theory is problematic and does not sit well with Goffman and particularly the ethnomethodologists' position that organisation is the accomplishment of its members (Garfinkel 1967). However, I do think that there are some elements of the sick role as a description of a social process that are useful in relation to the specificities to the effects of brain injury on a person's capacity to 'pass' (Goffman 1963) as, or 'do' (Garfinkel 1967), patient. Rather I use it as a device to help describe some elements underpinning the 'ideal' relationship between clinical staff and their patients.

For Parsons (1951), the sick role sets out a series of rights and obligations for returning ill persons to a state of health (the normative and ideal state according to Parsons) through, what Garfinkel (1967) might regard as moral forms, which the patient must adhere to. These obligations are as follows. Firstly, the person in the sick role needs to be helpless and in need of help. The helplessness during sickness should not be the fault of the patient. If the patient *is* responsible, then they can be partially exonerated providing that they cannot recover by their own efforts exclusively. Secondly, the person has technical incompetence regarding knowledge of the best course of treatment by which they can be returned to a state of normality. They must be prepared to seek specialised assistance for this as they, as the layperson, would not have the technical capabilities to do so alone. Thirdly, they are emotionally involved in this change of state and wish for there to be change. The emotional involvement bound up in the sick role means that the sickness cannot be accepted. It must be seen to disrupt 'normalcy' and therefore be acted upon. Finally, the patient must actually recover or at least move into a position where they are understood to no longer require medical assistance (Parsons 1951). In exchange for fulfilling these obligations, the patient is exempt from 'normal' social obligations (Williams 2005). While categorised as medically sick they can withdraw, albeit temporarily, from the obligations they are required to fulfil in their other roles as part of a functioning society. In contemporary medical encounters, I argue that this contract also fulfils a vital part of organising legitimacy in terms of gaining access to financial, as well as medical, emotional and social support.

Criticism of Parsons' theory of the sick role as an accurate commentary of contemporary medical organisation is well established and far reaching (Freidson 1970; Gallagher 1976; Freund et al. 2003; Williams 2005). In fact, it has been contested to such a degree that by the 1980s, the theory was

almost disregarded altogether in medical sociological debate. It was considered over reliant on the contract being consensual (Williams 2005). It assumes that the patient is a passive recipient of care and comfortably assumes the position of patient with neither input nor protest. It does not account for experiences which may be influenced by age, class or gender, thereby failing to take into account the differing power dynamics and interpretations of behaviours of these demographics which influence the medical encounter (Nettleton 2013). Its relevance in a changed medical paradigm is also in question. For example, Bury (1997) argues that increasing choice, the marketisation of healthcare and patient empowerment all serve to ensure the disappearance of the sick role in acute illness. I argue against this last point, as I shall come onto shortly.

Perhaps the most cited criticism of Parsons is that the sick role fails to address the differing aspects of chronic illness (Freund et al. 2003). In a contemporary society, there is an increasing shift away from acute illness to one of chronic, lifelong conditions as the main staple of medical care. Therefore, there is difficulty in maintaining the argument that illness, as *social* deviance, is a disruption to normative values, the maintenance of which relies upon the persons returning to full health, as a process that ensures a harmonious, smooth running society. Given the exacerbation of chronic illness in a society with an ageing population, it would be difficult to maintain the argument that illness was exclusively to be regarded as a deviance in this instance (Williams 2005; Freund et al. 2003). More pertinent here, acquired brain injury would also come under this category and this thesis will show how problematic the lack of 'fit' can be.

Parsons (1975) did take some, rather non-committal, steps to make a defence of his claims, in light of these criticisms. He suggested that illness should not exclusively be confined to the category of deviant behaviour, though it was maintained that its connected negative connotations must always be considered. He later also conceded that the patient-doctor interaction is a two-way process, though still asymmetrical given the specialist expertise and position of power that the doctor has over the sick person (Williams 2005). Whilst this defence is not always considered particularly robust, the findings in this thesis do lend some credibility to both these claims, exploring both the moral linkages to ill health as well as the differential power relationship which governs the interaction between the various actors involved.

To a greater or lesser extent, how we consider the merits of Parsons' sick role in its initial iteration is a moot point. I do not intend for the sick role to be an explanatory account for the actions I describe from observations. When taken literally, the obligations are highly problematic and it would be

difficult to argue that they were a definitive reflection of either the modern patient or the medical encounter. However, the sick role can act as a framework, a heuristic device, for exploring the relationship between the performance of the sick person and both medical discourse and societal expectations more generally. The sick role can contribute by forming a backdrop, a loose understanding of what is expected of the patient by both the professionals and the patients themselves. As the descriptions of the relations between doctors and patients, and the demand for patients to be able (to some extent) to 'do' patient and fit in, as I will show, it is particularly apposite in the context of analysing problems arising from ABI in fulfilment of the obligations for patients to conduct themselves in relation to these as shared moral understandings and expectations. It is not the obligations in themselves that are important but the 'doing of' patient by the actors involved, using them as a frame of reference, which is important (Garfinkel 1967). The sick role is not being used here to explain the function of medicine for the wider social system. It is being held up as a set of understandings embedded within medical discourse, which arrange and operate distinctions of around how patient legitimacy is instituted, or not. Whilst Bury (1997) argues that we are soon to see the disappearance of the sick role, I argue that this thesis will show it is still very much alive and well. It is merely manifesting itself in more subtle forms. Specifically, individuals need to address the obligations of the sick role in order to be recognised as 'patient' in a domain which is increasingly squeezed in terms of resources.

More advanced knowledge, technologies and expertise has meant that populations are living longer and surviving diseases which they previously would not resulting in chronic illness and multiple ailments being common place within the medical setting. Despite this, it seems that healthcare organisation and discourse has not deviated too far from the traditional pathway of trying to move the patient through the system from being categorised as 'ill' to that of 'well' or at least 'disposable' (see Latimer 2000). Therefore, patients still need to be considered as legitimate and appropriate in order to 'fit' the medical setting. By interpreting Parsons' sick role in this more pragmatic way to investigate contemporary practices as in this research, further understandings can be made as to how 'fit' can be accomplished and when it is considered unsuccessful.

### ***Goffman, Garfinkel and performance***

A second theoretical underpinning used in this thesis is the observations of Erving Goffman (1959; 1961; 1963) over identity-work, particularly 'passing', as an effect of interactions. Considered to be within the realm of social interactionism, a position he never considered himself (Psathas 1996), his

approach can be described as making sense of how the social through exploration of subtle, micro-interactions between actors. I choose the word 'actors' with purpose as a fundamental analogy used throughout this thesis is the dramaturgical analogy (Goffman 1959). Using the everyday as a 'stage', Goffman argues that the actions of individuals constitute performance. As I go on to show, with particularly high stakes, such as notions of legitimacy and the identification of the patient as belonging or not to a clinical category, being in play here, the medical site is full of multi-level performances with many actors involved.

Of particular interest in this thesis is Goffman's (1959) discussion of 'front' and 'back' stages, in which he describes how a particular public performance is carried out in the front stage, while the back stage allows for a different, perhaps more private enactment of self. The front stage performance is essential to maintain separation between the different actors involved, e.g. the doctor and the patient, to ensure boundaries are adhered to. When in the front stage, the individual is performing their role within the definitions and expectations of the setting. In the case of a neuro-consultant, for example, this might traditionally mean adopting a formal, authoritative presence with the best intentions of the patient and hospital at the forefront of all perceived actions. When backstage, this person is able to allow this performance to drop, presenting a different aspect of identity. In the case of the consultant, this may be the site where the presentation of self shows frustration at the bureaucratic nature of the hospital or suspicion of the non-compliant patient. As this thesis will show, it is not in the interest of the actor to be seen in the back stage performance if that individual wants to be taken seriously or perhaps professionally, in their particular role (Goffman 1959) but nevertheless is a necessary and important expression of identity for other reasons.

The notion of these different stages is of particular interest in this thesis because in an environment as intense, but often as blurred, as ABI rehabilitation, there can be crossover between the front and the back stage. Through various, nuanced, social interactions, individuals can be invited to the back stage at times and in circumstances that they might not do otherwise. For example, long standing patients may view, or even receive invitation to, the back stage where the professional shows their frustration at the organisation of the hospital setting. As this thesis shows, this crossing is good for both the professional and the patient but the power that animates such movement clearly rests with the professional. As I examine in the following chapter, I too felt privileged enough to be given access to the different stages and was struck by both the relationship and interplay between the two as well as the importance they played in the organisation of the setting.

'Identity-work' (Goffman 1959) is thus a concept which is fundamental to this thesis. Taking this notion of performance further, I consider identity as a social construction, arising out of interactions between persons. In the case of this study, this could be between professionals, between patients or between patients and professionals. The identity-work and shared meaning making through these interactions are vital for the various actors involved to manage their performances and reaffirm particular identities. This may be the hierarchical structure of the professional discourse or the work accomplished by patients in both their configuration of 'patient' or potential performances that purposefully position themselves outside the medical realm. Of particular interest here, is how this identity-work has the potential to unravel and be contested when the complex social conventions necessary for this work, are reinterpreted.

There are several criticisms levelled at the work of Goffman in terms of its practical applications. He has been criticised for describing examples from a society that is outdated, even at the time they were written. Whilst this may be the case (many examples are certainly dated now), I argue that it is not the examples themselves that are important but the concepts involved, such as those already described, providing useful tools for analysing and understanding motivations within contemporary sites. In fact, despite this criticism, I argue that Goffman is still one of the most accessible and relevant bodies of work for understanding interaction at the micro, fine-grain level. On this note, Goffman has been criticised for focussing with too much emphasis on small group interactions. Alongside this, his work is considered inconsistent and too subjective (Psathas 1996). To criticise Goffman for these is to fundamentally miss the point of his work. As I discuss in the next chapter, we construct our imaginary, our interpretation of the world, largely through small group interaction and through highly subjective means, so this should not be a concern when using the same method as a mode of analysis here. Goffman, like the data presented in this thesis, was not attempting to produce high-level conceptual theory that can be applied at a societal level. His observations are a set of descriptions and interpretations of specific aspects of interactions as 'social processes', from often very unique environments and if this analysis can fulfil a function and be applicable elsewhere, then this is also a useful contribution. Moreover, important to this analysis are how 'infractions' (Goffman 1967) where patients do not conform or provide a performance which is in keeping with the expected performance of patient, are interpreted – as an effect of their ABI or of something else. An important part of this study is to explore how moments of infraction are managed and interpreted, particularly by professionals.

Intertwined with Goffman and the notion of performance and 'identity-work', I also consider the contributions of Garfinkel (1967). This thesis is an examination of the mundane, the ordinary goings on of medical sites and how meaning is made from these micro-interactions. I explore how 'order' (Garfinkel 1967) arises from the expectations, performances and repetitions of practices along recognised routes and how these constitute and embed particular agendas. 'Accounts' are formed from the actors involved in order to make sense of these practices and to provide consistency and justification for the practices they carry out (Garfinkel 1967). Of particular interest is how this ordering takes place along 'moral' grounds. As I discuss shortly, patients are positioned and configured by considering how much they can be trusted to perform their 'role' against every day, taken for granted expectations.

The term 'passing' is used throughout the study. Goffman uses the term to mean to successfully disguise a particular stigma (1963). In this instance, it might be to use strategies to hide deficits or potentially embarrassing outcomes that an ABI has created e.g. incontinence. Whilst a study considering those with an ABI outside of the medical setting may find this interpretation of the term particularly helpful, in this instance, I also consider the more subtle use of the term employed by Garfinkel. For Garfinkel, 'passing' is more bound up in legitimacy. To 'pass' is where a specific performance is considered successful. In this study, that is largely the individual being able to 'pass' as a legitimate patient. 'Passing' as an effect of 'doing' patient successfully plays a crucial role in the ordering, organising and management of the healthcare setting.

### ***Latimer and 'configuring the patient'***

The final theoretical underpinning to draw special attention to is the work of Latimer (1997; 1999; 2000; 2004; 2013a). This research draws on a range of concepts that Latimer explores to make sense of identity and organisation at the micro-interactional level within the medical domain. Latimer describes how patients are 'figured' by healthcare professionals in order for them to be categorised in particular ways (Latimer 1997). This is accomplished through a range of complex, interrelated encounters, processes and relationships. For example, in her study of nurses' conduct within an acute medical setting, the organisation of beds on the ward can be determined by types of care required (high dependency, discharge, etc.). Whilst this appears to assist with organisational practices, when the allocation of staff is mapped onto this system, it produces hierarchies of value or 'classes'. When junior staff are given patients determined to require less complicated assistance,

there is, as Latimer puts it, “*a grading of forms of care*” (Latimer 1997 pg.172). These tasks are more to do with everyday functioning – e.g. feeding, dressing – and constituted as basic, rather than as medical and technical tasks, those that require training and that help the nurse to perform herself as professional. Latimer (1997) refers to this as the ‘constituting of classes’. This social process, in turn, begins to figure the individual into corresponding categories. This figuring work is also largely accomplished through everyday interaction. The bringing in of ‘the medical’ (e.g. scores, measures, scans), is combined with social considerations, such as an individual’s capacity to interact with the setting and ‘do’ patient appropriately, to hold them on medical rather than social grounds.

When dealing with increasingly complex, co-morbid chronic illness, organisation becomes more challenging accordingly. The purpose of configuring patients, according to Latimer (1997, 2001), is to accomplish this organising work, allocating (often scarce) resources, whilst also (re)producing societal and professional expectations. This figuring work is very much bound up in legitimacy. However, whilst we may consider the categories of legitimacy as the shifting the figure constituted between the status of ‘patient’ (worthy of assistance) and ‘person’ (fit for discharge), Latimer argues that the process through which these “*medical moves*” are made:

*“...can be better understood through considering nurse-patient relations as interactive and that contexts are defined by a number of different actors, including the patients themselves.”*  
(Latimer 1997 pp. 162-163.)

This ‘configuring’ work is accomplished in the everyday practices and interactions of all actors involved. As this study shows, it is the fine grain, nuanced understandings, interpretations and everyday interactions that play such a vital role in configuring and reconfiguring individuals as legitimate patients, or not. As part of the configuring work, Latimer (1999) discusses the importance to the patient of being judged to be “*response-able*”. Put simply, this concept is the work undertaken by staff where they are looking for the patient to respond in the interaction in a way befitting a patient so they can be categorised on medical grounds, even “*at the subordination of their selfhood*” (Latimer 1999). The patient must perform ‘patient’ in a manner which helps enact them as still of moral worth. As this thesis shows, when the very diagnosis that leads to admission inhibits possibilities for reading the social and giving a performance that can pass, it can lead to even greater difficulties in categorising and configuring in a reliable way, and necessitate complex negotiations between patients, professionals and family members.

The individual has to learn to perform and 'do patient'. People who are not regarded as doing so are potentially eligible for what Latimer terms 'disposal' (Latimer 2001). Whilst all patients are eventually 'disposed' of, those who are not deemed 'response-able' may meet with this outcome quicker. This is the final key concept I use from Latimer which I feel requires specific consideration here. Disposal is not a new concept to medical sociology (Berg 1992) but it is the specific extension of the concept by Latimer which offers a unique and important insight and it is largely in this way which I employ the term 'disposal' in this study. Berg developed the notion of 'disposal' to mean that the patient is able to be moved on from the particular situation they are in. A 'route' has been found for the patient, even that the diagnosis may need to be engineered to fit the route. This might mean when the individual enters a clinical setting, a diagnosis is formed not just based on their clinical problems, but in relation to how they can be made to fit with organisational criteria. In this instance, the diagnosis leads to 'disposal' because the patient is able to be moved on to the specific discipline or treatment option that the diagnosis requires. The patient has been 'solved' (Berg 1992). Likewise, 'disposal' might mean discharge from the setting altogether. Whilst this is an important, relevant and applicable understanding of the term, Latimer takes this further. Here, the term is employed in a more subtle capacity, to consider 'disposal' as disposable of practitioners' moral obligations to, and their accountability for, patients in their care, by their re-categorisation as inappropriate to the medical realm, including reinterpretation of their symptoms and needs, and as a consequence their diagnosis. To put it another way, a patient that is 'stuck' under their care, one that cannot be shifted from patient back to person and so moved through the system, is refigured as inappropriate by reworking their diagnosis (Latimer 1997): what gets disposed of is healthcare professional's 'moral responsibility' for them. Under these circumstances, they can be refigured as for example "geriatric confused crumbles", 'bedblockers', and 'social' rather than medical. As chapter four shows, when this happens, the responsibility falls back onto the patient who is then held accountable for their actions. Sufficient 'moves' (Latimer 1997) have been made to ensure that the individual is no longer deemed as being the moral responsibility of the healthcare setting. This is particularly relevant here. When the diagnosis, symptoms and potential recovery is as complex, nuanced and varied as it is in ABI, 'disposal' in this way is a vital tool used by professionals to accomplish organisation.

Although the work of Latimer that I draw upon focuses mainly on older people in acute medicine, there is significant crossover here. 'Chronic' and complex health and social needs as threatening to the smooth organisation of the healthcare system, the ways that the clinic can change the status of people as 'full persons' (Latimer 1999) and patient's lack of capacity to feel in control to influence

such change, are features of both care of older people and of people with ABI. As a response, a challenge to legitimation is often experienced by both groups.

I have discussed the key theoretical ideas and concepts used throughout this thesis. These underpin my interpretation of the analysis throughout. I now bring in other theories, in combination with those described above, in order to explore some more key concepts relevant to this study. In doing so, I show how I intend to operationalise its use in framing interpretation of the data generated in this study.

### ***Identity***

As discussed, the performance of 'good patient', is vital in order to be successful both in gaining access to and regarded as legitimate in the rehabilitation setting (Latimer 1999). Ironically, ABI can be particularly unsuitable at allowing this performance thus creating blurred differentiations between the expectations and realities of what it is to 'do patient' in this domain. The various performances are closely intertwined with understandings of identity. To consider this fully, it is important to understand how the concept of identity is understood. Is it a thing? Is it performed? Is it a constant or is it a fluid, ever-changing product of interaction? This will now be explored before returning to consider how it is applied in this thesis.

Identity is the individual's source of meaning and experience (Castells 2003). It is the vital component which allows actors in a given society to understand each other, interact and function. Therefore it can be assumed that to lose, or be unsure of one's identity, is to lose a sense of meaning. When reflecting on the importance of identity it is vital to consider how it might be assigned and who is able to do the assigning. A common message played out in popular culture from avenues such as advertising is that identity is a definitive thing that can be consumed and used by the individual for their own ends (Bauman 2004). We are led to believe that we can select and deselect identity through the changing of our outward appearance or cultural practices which will in turn display a particular, recognisable identity. This concept, however, suggests that we are free, unconstrained to select these identities as we choose. The assumption of choice can be problematic. It suggests that the presentation given by the individual will be interpreted and validated by their audience not only whole-heartedly and without question, but in a vacuum without prior assumptions of the individual being present. One may feel that they are free to make choices to

display an identity as they see fit yet this identity has already been influenced by preconceived ideas that the individual may have as well as ideas others have of the individual (Bourdieu 2010).

Many perceived identities may be inaccessible to some as societal assumptions and expectations may prevent access. The role of employee after an ABI may be an example of this. An identity can only be convincingly assigned when it is validated by an 'other' (Goffman 1963). It is impossible to assign oneself a role and communicate it successfully if the intended audience does not accept that label. Often there may be a power differential between the actors involved in the interaction which influences the success of the identity-work on display. Identity-work therefore has the potential to be a stratifying tool (Bauman 2004). As this thesis shows, the identity of 'patient' in the healthcare setting cannot be assigned by the individual or their family member. Part of the contract, going back to Parsons' sick role, is that this label is given by the professional. This can be quite a formal agreement often employing technologies such as forms, admittance to the medical setting and prescription medication being used as evidence that the label has been applied (Mol 2002). In other circumstances, validation of an identity may not manifest itself in large structural organisational practices but in the subtle interpretation of interactions which take place (Bourdieu 2010).

As identity is a 'fuzzy' concept, it is considered in this study not as a product but as a process. Not only this, it is a process which is in a state of constant flux (Bauman 2004). If it were possible to capture a picture of identity, one of the many facets that made it up will already have changed in some respect. Identity is an ever changing, fluid set of conceptualisations which are constantly being evaluated and re-evaluated. Interaction plays a crucial part in this. This is as much a sub-conscious process as it is a conscious one with interactions changing and developing through experiences of interaction (Goffman 1959; Bauman 2004). We may be called upon to consider our identity at different times and in varying circumstances. For example, we become very aware of our own identity when facets of what might constitute it are at odds with the majority around us (Munro 1999). For example, we might become very aware of our nationality during a sport event, particularly if we are in the minority. Overall, however we are able to allow the process of identity to continue without major concern.

Though academic literature differs on the name, interpretation and function, there is a consensus that identity can be performed through actions concerned with the individual and is more in relation to the collective (Goffman 1959; Mead 1967; Jenkins 2008). These take a variety of analytical forms and the significance of how the two relate to each other is contestable. Mead discusses these terms

as the 'I' and the 'me'. For Mead, identity and self is a social process. The self was the social aspect in the process where an individual would interact and be influenced by collective ideas and interactions. These would in turn be internalised to form the 'I'. Whilst the 'me' was the organisation of the attitudes of others, the 'I' was the internalised result (Mead 1967). Goffman and the display of identity as a performance and the notion of the front and back stage have already received attention (Goffman 1959). In this thesis, I do not consider one performance as any more or less trustworthy or valid than the other. These are both accounts which are equally as important (Atkinson 1995). Both the internalised 'real' person and the public performance are not only intrinsically linked but are both fundamentally shaped by the social (Jenkins 2008). As Jenkins puts it:

*If identity is a necessary pre-requisite for social life, the reverse is also true. Individual identity – embodied in selfhood is not meaningful in isolation from the social world in other people. Individuals are unique and variable, but selfhood is thoroughly socially constructed: in the processes of primary and subsequent socialisation, and in the ongoing processes of social interaction with which individuals define and redefine themselves and others throughout their lives. (Jenkins 2008 p.20)*

The internalised set of values is not natural or organic but a series of micro-processes made up from continual interactions which have influenced these attitudes through socialisation. As the process of socialisation continues, the internalised set of values will change also. The public performance would be on display, constantly being tested in terms of validation. As the role is validated (or not), this is then considered (or not) by the individual in their concept of identity. This is a fluid, non-stop process where the social identity is forever evolving; both being shaped and shaping the internalised concept of self.

If the culmination of this process is internalised then it can be a lot more difficult to disregard or re-configure (Castells 2003). The identity, such as the traditionally patriarchal position of breadwinner, is now more than a superficial part of the self; it is now embodied. Illness or disability can remove this embodied role which can be so fundamentally bound up in interpretation of self that to lose it is to lose oneself (Charmaz 1987). It has the potential to affect the individual, fundamentally shifting self-identity and the position from which identity-work is performed (Goffman 1959). At its most severe, this sense of loss of identity can in turn lead to a loss of desire to carry on living (Becker

1999). This is how bound up it is with what it is to be human and understanding this fundamental relationship is essential for the rehabilitation process.

### ***Healthcare organisation of illness in the career of the patient***

The second concept worthy of examination is the organisation of healthcare in shaping and determining the relationship between disease, illness, the individual and society. The domination of a biomedical discourse is increasingly being challenged by other practices (Engel 1977). Other models to address illness are increasingly being sought out either in place of, or alongside biomedicine as the individual is becoming increasingly aware of other practices. For example a patient might be sceptical of a system tightly bound up in profit making institutions such as pharmaceutical companies (Eisenberg and et al. 1998). The assumption that best practice follows a reductionist, mechanistic, scientific grounding where the healthcare professional knows best, interprets the symptoms and prescribes the appropriate course of action for recovery is less universally accepted. It is contestable as to whether this form of biomedical endeavour is, or has ever been, an accurate representation of what goes on in healthcare settings in the first place (Berg 1992; Becker 1993; Pearce 1993) and an important concept considered in this research is the manner in which this paradigm is interacted with, considered and negotiated by the various actors involved. As I go on to show, there are many other factors that go into this sequential model. Biomedical discourse is presented as a highly routinised, scientific, deductive practice which organises patients according to illness and disease. However, studies indicate that many other aspects – most notably social, environmental and financial aspects (Berg 1992; Reyes-Ortiz 1996) – are fundamental to the organisational process. For example, in a study of mental illness, it was found that diagnoses of patients with a mental illness rose when there were finances available to treat them (Estroff 1993). As Berg states:

*“Scientists are practical reasoners who, in the process of knowledge-construction, interweave cognitive, social and material elements on an ad-hoc, opportunistic basis,”*  
(Berg 1992 pg.152).

Routes, as in potential medical pathways, are extremely important here. The patient, who may have been given a diagnosis of mental illness, was given this route as and when it was necessary and able to be given. Hospital staff often have to be pragmatic rather than scientific (Berg 1992). These routes

are influenced by the outcomes of this pragmatism and different routes exist in different hospitals. This thesis shows that ABI is certainly no different to this.<sup>3</sup>

More modern conventions, such as the use of technology (e.g. internet) to allow the patient to determine their own illness is arguably changing the doctor-patient relationship, so often the traditional bedrock of how medicine is organised. For example patients are increasingly becoming 'lay experts', often arriving in the medical setting with some form of a self-diagnosis, seeking confirmation and access to the correct medicine (Bensing 2000; Prior 2003). This is leading to an uneasy power relationship where the practitioner is required to carry responsibility for certain actions without the same level of autonomy they once enjoyed (Chambliss 1996). This changed level of public knowledge is in keeping with an increasingly individualised position laid out by policy makers who want to put both ownership and responsibility in the hands of the individual (Dixon et al. 2010). Caution must be taken here however. This change is not universal amongst all patients. Many individuals do not necessarily want or feel they are able to take ownership of themselves in this way. The lack of clarity leads to uncertainty in terms of the basic understanding of the relationship between doctor and patient.

In this thesis, an important part of the organisation of healthcare is through the interactions between the different actors involved, a vital component given the landscape as described above. Other means have been required to negotiate the medical encounter as the traditional power relationship becomes less trustworthy. This has meant an increased importance for the performance and negotiation that makes up the relationship on both sides. As this study shows, with the professional no longer having the same tools at their disposal regarding the determination of the course of treatment, they are required to use increasingly complex practices to configure the patient. Likewise, the patient needs to negotiate their way into the healthcare system. A role of the healthcare setting is to label and legitimise illness (Grant 2011). The patient needs to 'pass' (Garfinkel 1967) to not only enter the medical setting but remain there. Regardless of this, studies show that the health care professional still retains much of the power (Chambliss 1996; Latimer 2013a). Any attempts of a mutual consideration towards the chosen healthcare solution are perhaps in name alone. Many families of ABI patients report that they have to continue to fight to be heard,

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<sup>3</sup> As chapter four shows, interpretations and importance given to particular complaints vary depending on resources available to treat them.

their views never seriously taken into consideration and this only worsens when the patient is back in the community (Coco, Tossavainen et al. 2011).

Rather than accept the notion of medicine being organised to a reductionist and wholly objective agenda, it is better to view it as a social construct, steeped in cultural meaning (Good 1993). Personal choice and experience on the part of the professional can play a major part in both diagnosis and treatment of illness. Certain doctors prefer certain practices which may differ between doctors and hospitals (Becker 1993). These routes have to be negotiated with fellow professionals and patients who may have different views. Measurable evidence may be used as evidence towards pursuing a certain practice but this is disregarded in equal measure in favour of 'instinct or tacit knowledge' when deemed correct to do so by the health care professional. In order for the professional to have legitimacy, the individual has to be configured as a medical problem and this is very much bound up in the notion of medicalisation. This is a particularly useful concept when considering the configuration of patients in ABI and therefore, particular attention will now be given to it.

### ***Defining 'Medicalisation'***

The concept of medicalisation has made an enduring contribution to sociological understandings of health, illness and the organisation of society. There is variation in how the term has come to be understood (Nye 2003) and so it is important to explore these interpretations in order to show how the concept is being operationalised here. Numerous elements and perceived consequences of medicalisation have interested different theorists and it has found itself influential in other perspectives, such as critical or feminist accounts which, in turn, provide fresh impetus into the way that it is used to inform debate (Morgan 1990; Cahill 2001; Farrell and Cacchioni 2012). It is a highly malleable concept, applicable to contemporary society even when relationships it seeks to analyse have changed considerably from those the term was originally devised. This is particularly the case in terms of the power relationship between the medical profession and on the macro-level of governance. Medicalisation also has policy implications, used to warn of potential dangers and the need to change course (Illich 1975.) More recent commentaries have questioned the extent to which medicalisation has come to dominate thinking in the manner in which it was so pessimistically prophesied by Illich viewing it more as a practice to be "*warily suspicious,*" (Nye 2003 pg.127) rather than outright opposed to.

Whilst there are multiple interpretations, at the heart of medicalisation is the argument of power of the state over the individual. Initially it was considered by Zola (1972) as the *“extension of medical jurisdiction, authority and practices into increasingly broader areas of people’s lives,”* (Clarke et al 2003 pg. 164; Rooke 2012). Medicalisation can be used to describe the desire to interfere and intervene in individual lives, the process where this happens as well as a result of doing so. This is accomplished through the complex process of increasingly understanding the social through a medical lens. As Szasz in Weindling (1986) puts it: *“medicalisation is a straightforward conversion of a social and moral problem into a disease,”* (pg.277). Aspects of life are re-configured as medical problems (Clarke 2003). They are understood in terms of the way that an action interacts with health and illness, both at the individual level and for wider society forming a fundamental role in configuring and interpreting the relationship between the individual and the issue in question.

Importantly, as a key concept for understanding actions in this thesis, this shift in positioning a social problem as a medical one legitimates intervention is only achieved in a certain way and by certain professionals with specific expertise. This overlaps with obligations of the sick role. It also reinforces the biomedical model where the individual is re-configured as a problem which needs to be ‘fixed’ on scientific, rational grounds (Armstrong 1995). More recently, it is argued that this is not a one-way process (Ballard and Elston 2005). The individual is not merely a benign object, to be acted upon. As argued in the introduction, to be a ‘patient’ requires legitimation and the individual plays their part in this process, repositioning themselves accordingly as this relationship can be symbiotically advantageous for both parties. The individual can be reframed from that of ‘bad’ to that of ‘sick’ (Conrad and Schneider 1980). Deviant actions themselves can become medicalised with responsibility then rescinded or excused (Fabrega Jr. 1993). This exoneration from blame is one of the reasons that medicalisation may be sought. As discussed, however, the configuration of ‘patient’ carries with it important symbolic rights and entitlements, but also obligations. The patient must be deferential to medical expertise and cannot opt to consider themselves or be considered differently. For example, various forms of addiction, rather than being regarded as a moral failure on the part of the individual, can be reinterpreted as a sickness. This means the sickness, rather than the individual, can be acted upon with systematic treatment. Cultural understanding of this change in position means certain culturally accepted obligations to rectify the problem. This can be through expected individual action, such as taking necessary steps to get better, or by deferring control to a wider enactment of policy, such as allowing government to control gambling and licensing laws (Morgan 1990). The concern is that state control is being increasingly extended through the use of medical authority to begin to govern all aspects of individual lives ranging from the quantities of food one

should eat, the moralising discourse of certain sports and even the amount of hours that the individual designates to sleeping. This in turn erodes civil liberties. Increasing aspects of individual lives becomes subtly shaped, influenced and even controlled by the state through this 'governmentality' (Foucault 1980). In terms of the brain, increasingly the notion of 'brain plasticity' (Pickersgill 2015) has served to begin to reinterpret the actions of the individual and the relationship this can have to the brain. As Pickersgill describes:

*"The plastic brain is framed as a dynamic network, the very nature of which is moulded through subjective experience,"* (Pickersgill 2015 pg. 879).

Consequently, for those with ABI, this can act to open up expectations but also put further personal responsibility onto the individual to ensure they are conforming to accepted practices and conventions to ensure recovery is maximised. Every behaviour and activity can be judged to be influential in ABI recovery.

The irony of this 'medicalisation of life' is that it does not decrease morbidity (Illich 1975). In fact the opposite occurs. Rather than the cost of healthcare and morbidity decreasing as innovation, knowledge and technology improves, more and more social problems become legitimated as worthy of medical consideration, therefore bringing an ever-increasing number of issues into the medical domain. Through this, state intervention also extends. Social issues such as tobacco use (Rooke 2012), phenomena associated with the life cycle such as child birth or aging (Jones et al 2010, Spence 2010) and culturally defined bodily features such as height (Rayner, Pyett et al 2010), baldness, breast size and psycho-somatic issues are all reinterpreted as medicalised problems, worthy of intrusion. As medical authority increases, so does the number of social 'problems' which enter into the medicalised label. Actions that were traditionally outside of the medical remit begin to see medical intervention as a social norm. Examples can include cosmetic issues such as blemishes of the skin and personality traits such as shyness (Scott 2006). These are re-configured as problems that need intervention and the individual feels obligated to turn to medicine to assist with this. In the example of childbirth: every aspect of the process, from the right time to conceive, through to the right foods to feed the baby can be reinterpreted into a medical issue. By making genetics visible and associated with risk, there is even a medicalised perception as to who you might want to have a child with (Latimer 2013a).

As this thesis shows, medicalisation can be more complex yet ambiguous. In the domain of 'brain injury', it can be used for establishing evidence for organic damage to the brain, which can validate certain kinds of behaviour. As I show, this can be very subtle but in doing so creates a site of crossing between medicine, psychology and the social; the psycho and the somatic.

Increasing technological developments, such as screening techniques, and corresponding knowledge have increased the reach of surveillance of the body. This has redefined the scope of medicalisation as it has furthered potential intrusion of the medical (Armstrong 1995). In addition, actors such as pharmaceutical companies have changed the landscape in terms of spheres of influence so considerably that it is necessary to reconsider this period as an entirely new term: biomedicalisation. In line with the post-modern era, Clarke et al argues that:

*"Biomedicalization is characterized by its greater organizational reach through the meso-level innovations made possible by computer and information sciences in clinical and scientific settings, including computer-based research and record-keeping. The scope of biomedicalization processes is thus much broader and includes conceptual and clinical expansions through commodification of health, the elaboration of risk and surveillance, and innovative clinical applications of drugs, diagnostic tests, and treatment procedures,"* (Clarke et al 2010 pg.52).

The 'technologies of self' (Foucault 1988) are extended and pervade increasing aspects of daily life (Clarke et al 2003.) The multi-sited, complex, multifaceted, highly technical nature of what constitutes biomedicalisation certainly corresponds to the organisation of ABI. Conrad (2005) believes that rather than see biomedicalisation as a separate entity, it is better suited as being seen as a new engine in the overall machine that is medicalisation (Conrad 2005.) In terms of the brain, Holmer Nadesan (2002) in Pickersgill (2013) suggests that:

*"...brain science promotes new regimes of surveillance, bolsters the power of already privileged groups and extends governmentality,"* (Pickersgill 2013 pg.323).

De-medicalisation (Fox 1977; Halfmann 2012; Conrad 1992) is also a concept important for this study. This is the repositioning of an issue away from the medical domain. Homosexuality is a classic example of this (Conrad 1992) when it was removed from DSM III largely due to successful lobbying from the gay liberation movement; essentially recognising that homosexuality is not a disease.

Sociologically, consideration has also been given to disability. The management of disability is sometimes viewed as if it is largely a personal or social matter requiring little medical input (De Jong and Lifchez 1983). This is a very important issue when considering ABI. As shown in chapter five, many of the anxieties and contestations between the actors involved come from conflict when negotiating when a particular symptom is medical or social.

It is also too simplistic to view medicalisation exclusively as a negative intrusion; an interference into peoples' lives which erodes civil liberties to suit the power of the state. Rather than focus subjectively on medicalisation as a negative force, I wish to regard it in the abstract. It is a process that is used, not necessarily with conscious thought but through actors' understandings of the medical site and the patient through these practices. This study examines how this affects the individual at a fine grain level. On a macro level, the erosion of civil liberty and the lack of choice may obviously seem damaging. When looking at the detail, it can be seen that the process of medicalisation, if not the consequences, can in itself be a vital empowering tool for the individual when performing 'patient'. As this thesis shows, it can help to construct identity which enables the individual to make sense of themselves. It also forms a resource from which to acquire the necessary artefacts in order gain legitimation from the medical system which relies on it. Having discussed the interaction with medicalisation in configuring 'patient', I now finish this section by considering the concept of 'doing patient' in more detail.

### ***'Doing patient'***

Whilst this has been explored already, the concept of 'doing patient' is so significant in this thesis that it deserves to be considered in more detail. Studies put forward the concept that if the patient deviates from their expected role, they become problematic and must be dealt with. As discussed, this usually means that they must be moved on or 'disposed' of (Jeffery 1979; Berg 1992; Latimer 1997; Nochi 1998). Deviation from this role is most likely to take place when there is a lack of fit between the organisation of healthcare and the individual requiring it. ABI is a typical example of this lack of fit. A role of the healthcare organisation is to ensure 'fit'. This is achieved by configuring the patient so that they are 'solvable' (Berg 1992). To be solved, like any puzzle, is for the problem to be recognised, understood and a solution to be found. As Berg (1992) explains:

*"A problem is solvable when the doctor is able to propose a disposal: a limited set of actions which she perceives to be a sufficient answer ('a prescription of aspirin, 'referral to the*

*urologist' or 'advice'). This does not necessarily imply that the patient's problem is relieved: what matters is that the physician knows what to do next."* (Berg 1992, pp.155-156).

A good way of ensuring the patient is solvable is to restrict access to the healthcare setting in the first place so that only those who are likely to be solved can enter. Access to the healthcare setting may be restricted or refused and it is up to the patient to 'pass' through enacting the performance which is expected of them (Garfinkel 1967). The sick role may carry sign equipment or cultural artefacts (Goffman 1959) which promote illness such as blood, distress, discolouration or identifiable marks on an internal scan. Without these immediate, identifiable symbols of illness, the patient may find themselves in a vulnerable position. As explored in this thesis, this distinction of 'deserving' patient can become problematic for the ABI patient. The rules of the sick role and the patient do not fit with the healthcare organisation in which they find it. As a hidden disability, the brain injury does not have the sign equipment that one would look for in an illness. In fact, many survivors, especially younger survivors, choose to carry as little signage as possible, often due to the perceived stigma attached.

The patient can be negotiated between different categories of deserving or undeserving. As I address shortly, this is not a new phenomenon. Those who are undeserving have been labelled 'rubbish' (Jeffery 1979) or 'a crock' (Becker 1993). These are individuals who fail to 'do patient' (Garfinkel 1967) by conducting themselves in patterns of behaviour that can be recognisable and interpreted to be in line with behaviours similar to that of Parsons' sick role. As already discussed, in the instance of a patient being figured like this, attempts are made to reposition them to ultimately be disposed of.

In his study of an A&E department, Jeffery (1979) describes four types of individual that made up most of the "*rubbish patients: Tramps, Drunks, Overdosed and Trivia*," (pp.95-97.) Each label was given as it broke one or more of Parson's sick role rules. The outcomes of brain injury have the potential for the survivor to be categorised in the rubbish category by healthcare professionals as well as by fellow patients. They may display symptoms which assume drunkenness or hygiene issues. Another typical definition would be that of 'trivia'. Often, following ABI, obsessional behaviour about the mundane is commonplace. The regular occurrence at the health care setting, the likely display of concern about a perceived 'trivial' ailment and the lack of ability to stick to task will all result in a lack of credibility given to the performance of 'patient'.

Becker discusses the use of the term 'crock' in his study of student doctors (Becker 1993). Again, a definition between a deserving and undeserving patient is made in relation to the sick role. The two are distinguished by a crock being "*a patient who had multiple complaints but no discernible pathology,*" (Becker 1993 p.3). Brain injury relates to this description as it can produce multiple complaints which cannot be relied upon to react to treatment in a defined and certain way meaning they are not always solvable (Berg 1992). In addition, the lack of ability to describe those ailments, due to a combination of dysarthria and the complexity of difficulties, also mean that often the patient can go misdiagnosed or misunderstood. Symptoms of brain injury can include lack of motivation, poor insight, anger management issues, frustration, lack of understanding and poor memory. Individually or in combination, these can have a devastating effect on the ability of the survivor to perform 'patient'. This may lead to frustration and a seeming lack of co-operation which can mean another of the obligations of the sick role becoming unfulfilled, "*patients should co-operate with the competent agencies in trying to get well,*" (Jeffery 1979 p.101).

Jeffery also describes 'good patient' as requiring expert intervention by healthcare professionals who are able to heal them. After brain injury, whilst considerable progress and recovery can be recognised, very few patients could be considered 100% well after injury. The lack of ability to heal the patient, alongside ailments that do not match pathology and behaviours inconsistent with the good patient are all problematic.

It is not just the healthcare professionals who perform this system of organisation. It can also be taken on as the responsibility of the patient to police each other and give each other a sense of deserving or undeserving. Patients are encouraged to organise themselves in the setting aided by the utilisation of spaces and technologies (Hillman 2007). Hillman described how sometimes the sheer lack of resources and design of the healthcare setting ensure that the experience is less than comfortable. When the furniture is basic, the magazines several years out of date and with no additional resources to distract, it could be argued that you have to be 'really' ill to want to stay. This leads to a hierarchy of illness and a distinction between the deserving and undeserving. Patients organise each other and those deemed unworthy are encouraged to remove themselves. This is also a trope examined fully in this thesis.

I finish this chapter by drawing together the differing theories and concepts that have been discussed in order to set out my own epistemological position to aid understanding as to how data has been interpreted in the following chapters.

### ***Epistemological Foundations***

Much of this study is concerned with the configuring and categorising of individuals with ABI between 'patient' and 'person', between legitimate and illegitimate in the medical setting. Whilst it is not a simple dichotomy, with many patients holding ground in both categories simultaneously, I consider these configurations as the end points on two ends of the negotiation. This thesis shows how this configuring work is attempted, negotiated and accomplished between the different actors involved. It is a fluid, ongoing process. As Latimer puts it:

*"[patients] are endlessly accomplished through drawing upon what is professionally, culturally available to them, to produce and square their accounts" (Latimer 1997 pg. 162).*

In order to attempt these distinctions, different tools (or points of reference) are necessary in order for there to be a universal recognition of when 'patienthood' is being performed (and when it is successful). The sick role plays an important part in providing the framework for this. In terms of the attempts themselves, the performance is vital here. The negotiation to determine legitimacy is bound up in the configuring work discussed by Latimer (1997; 1999). I argue that it is the interaction between them that can assist to help them work together to make a specific contribution in this study. The sick role, as by now established, is not being used as an explanation of the role of medicine and I reject the functional structuralism, where it originated, as a means of understanding society. My epistemological position is that our imaginaries are continually shifting, understood through fluid micro interactions that we use to make sense of the world, based on prior experiences, assumptions and predictions for the future. In this sense, the sick role performs the function of providing those underpinnings of prior experiences which has increased chances of being given legitimacy or not. It is the interplay between these prior experiences and the experiences of the ABI patient which can potentially cause difficulty. The work of Goffman, Garfinkel and Latimer provide tools for this research to understand conceptually how the interplay between the individuals concerned performs such a key role in producing these 'accounts'. Also, they provide a glossary of terms in which to articulate the data which I observed and interpreted, that is, they bring my data 'to life'. They allow me to consider and position this work not only in its own right but also in relation to the wider medical sociological literature.

## **Conclusion**

This chapter has provided a theoretical framework for the study showing how concepts and sociological approaches have informed the study. The contribution of the sick role was considered with the application for this study explained. Particular attention was also paid to performance as a means of displaying identity as described by Goffman, applying this to ABI. The work undertaken by Latimer, namely the attention paid to 'configuring', being 'response-able' and 'disposal' was also discussed. These debates were then contextualised against theoretical concepts surrounding identity, the organisation of healthcare and illness and the role of the patient as part of this process. The importance of medicalisation was considered, problematising the relationship this has with the biomedical model in the configuration of ABI.

In summary, my starting point for the collection and analysis of data is that acquired brain injury does not lend itself well to the sick role. Some patients are unable to rely on ABI pathology to hold them on the medical ground, instead it takes additional performances, negotiation and identity-work for people with ABI to keep being figured as legitimate patients. The problems associated with this complex set of negotiations are exacerbated and determined by the very outcomes that the ABI patient is attempting to recover from, such as insight and motivation, resulting in the potential 'disposal' of the patient as the moral responsibility of the health practitioners concerned. I concluded this chapter by bringing together the various theories and concepts to show how I interpreted and understood the data. Before going on to present the data, the methods used for this study will now be discussed.

## Chapter Three: Methods

### *Introduction*

Having established theoretical frameworks as well as positioning the research into the wider debate, I now want to turn to the methods used in this study. This project is an ethnographic investigation; participant observation complemented by semi-structured interviews and a form of discourse analysis, focussing on the technologies and practices that constitute ABI rehabilitation. In this chapter I want to accomplish several things. Firstly, I discuss what and how fieldwork was carried out both in terms of collecting data and the concurrent analysis that took place. I also acknowledge limitations of the study as well as highlighting criticisms of the ethnographic endeavour generally before providing a response.

Before any description of methods can take place however, it is vital to thoroughly consider how different components played a comprehensive role in both the manner in which data was made accessible and collected. For example, I discuss the official process for obtaining NHS ethical approval to the field site. I also give an extensive reflection on the position I held in relation to one of the field sites where I had previously been employed. Whilst this is not an attempt at auto-ethnography, reflection as to how my former position influenced my reception, my own interpretations and my understandings must be considered. It plays a key role in both shaping what data could be collected and also the epistemological lens in which said data is understood. Reflexivity here should not be considered unnecessary 'naval gazing' (Hammersley and Atkinson 2007). Rather, by recognising the relative position of self within the context of the fieldwork, I argue I was able to understand the concepts and engage with the analysis from a particularly unique position.

### *NHS ethical approval*

Before any research could take place, it was necessary for the project to be approved by an NHS ethics board as the majority of research would involve NHS sites and staff. It goes without saying that this is a vitally important part of research, particularly when working with vulnerable groups like those with ABI. Whilst the application process itself was time consuming and a little repetitive, it was not as challenging as its reputation might suggest (Reed 2007). The IRAS form, as it is known, is an electronic document numbering up to 80 pages. In completing the form, the applicant is required to fill in extensive details as to how they propose the work will be carried out. This includes a summary

of the research, details of the investigator, the purpose of the study, how it is to be carried out, who will be involved and ethical considerations including those particularly pertinent to the specific requirements of the prospective participants. As this research was working with individuals who, to use medical terminology, lacked capacity, it was necessary to provide substantial detail as to how the rights of this group would be assured, how they would be able to opt in or out of the study and even why it was necessary to include such patients in the first place. My main argument was that this is the very group of patients who are most often overlooked and not given a voice when it comes to research, often due the barriers that an exercise such as this produces. From a research point of view, they form a central part of the setting with their experiences vital to inform understanding in the study.

Overall, the process was a largely straight forward, dare I say even useful exercise. It forced ideas around objectives to be thought through as well as the more logistical aspects of the research process. Whilst being required to provide this data in advance was not always ideal, as I shall come onto shortly, it did at least ensure a platform as to what would be investigated and, perhaps just as importantly, provided a realistic expectation including what could not be accomplished.

A logistical complication to this process is that the investigator is required to obtain a relatively large amount of information prior to submitting the form to the board. This involves gaining signatures from various heads of departments from the field site. ABI did not seem to fit neatly into a category for this to be a straightforward process (perhaps an early indicator of the messy, difficult to define, relationship ABI has in the medical setting more generally.) I would be moved from neuroscience to psychology and onwards on many different occasions as the most suitable person to sign the document was sought. At times, the documents would be signed and returned only to discover that the signature was no longer correct and would need re-signing by someone else. This may sound like a trivial issue but it could mean delays of several weeks, even months on occasions.

The second issue addresses the perceived lack of cohesion for allying qualitative work into a medical epistemological framework. Though some find this to be less of an issue (Hedgecoe 2008), it seems that sometimes the structured, quantitative information required does not sit neatly in the more fluid, inductive nature of ethnographic research (Dingwall 2006; Pope and Mays 1995). I would be required to state exactly how long I would be in the field, how many participants would be recruited

and where exactly I would be carrying out the project.<sup>4</sup> Answers would often have to be speculative which was not much better than guesswork at this initial stage. Importantly, I had to be careful not to lose confidence in the ethnographic process. The form could almost force the individual to think in a structured, formulaic pattern and I was very conscious of this when I finally did enter the field. (As it transpired, I quickly found that the rhythms and organisational practices of ward life were far more alluring than the more objective stance.)

By structuring applications in this way, the process does not give room to appreciate the strengths of ethnographic fieldwork. The interpretation of the unknown through the unpicking of the everyday can only be accomplished by allowing oneself to become immersed in the setting (Garfinkel 1967; Geertz 2000). To set boundaries, quantifiable measures such as participant numbers or exact sites visited, is to miss the point entirely. Constricting the researcher, and thus the research, in this manner has the potential to shape the research. The researcher is called upon to only act upon pre-conceived assumptions. This is not to say that prior understandings should be downplayed or even ignored, if such a thing were even possible. Quite the reverse, as I will discuss shortly, an appreciation of the knowledge one has of the setting cannot be underestimated as a vital part of data generation in its own right. However, if followed to the letter in terms of mapping out methods for carrying out research, the pre-conceived ideas become a prison of sorts for the researcher. They restrict themselves and their movements to what they assumed would be useful and important therefore ignoring what they had not considered before entering the field site. By doing this, the very essence of ethnographic research and its spirit of exploration are laid to waste.

In an exploratory study such as this, where the very technologies used to configure illness (such as ward rounds, meetings and information leaflets) are under the microscope it means that sites of analysis are everywhere (Mol 2002). Even the IRAS form itself is a technology worthy of investigation (Boden et al. 2009). A vital component that emerges in the 'reading' (Latimer 2004) of the ethics process is that there is the assumption that fieldwork begins with entry to the field site. It fails to take into account how, through the questions it asks, through the information and type of information it privileges, it is already doing 'work' (Atkinson 1995; Latimer 2000; Mol 2002). It is categorising and configuring information and ways of 'doing' research which in turn can influence

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<sup>4</sup> This is not to say that the NHS ethics process was unfamiliar with ethnographic research. Those who I met at the committee meeting were perfectly accommodating to my intentions. However, the form itself was less flexible.

how the research site is viewed and configured. Measures and scores (perceived absolutes) are deemed more important than the richer contextual understandings of experiences.

Once NHS ethical approval had been obtained, this did not mean entry into the field was assured. However, it did mean a significant hurdle had been cleared. The approval in itself provided a symbol of validity and academic rigour, particularly amongst professionals who had undertaken the process themselves. I now go on to discuss the more informal part of the process, gaining access, paying particular attention to my own relationship to the setting and the participants in this process.

### **Access**

When considering the benefits and challenges of the researcher already being known in the setting, it would be too simplistic to assume that prior relationships are always clearly and universally defined. Also, focus often considers a lineal movement of change from one relationship to another e.g. from outsider to insider, or describes the difficulties of being an insider and *“trying to make the familiar strange,”* (Manney 2010 pg.94) as if the position of insider is stable. Here, the terms insider and outsider can also be likened to performances. Over the course of gaining access to the primary field site, the rehabilitation hospital, my experiences have shown that there are variations to this dichotomy.

Firstly, it became very clear that my position as insider or outsider varied significantly between and even within certain departments. Secondly, the notion that this relationship was clearly defined and stable before shifting to another static relationship also did not materialise. There was a constant movement between myself and the participants which continued to shift back and forth, as access was continually negotiated and renegotiated. In this section, I am not only meaning access to the field site, which after some time was pretty much established. By access, I also mean that I could enter the field without disturbing patients and staff in their daily activities.

It is useful to consider the notion of insider and outsider being akin to having access to the back stage and front stage discussed as part of Goffman’s dramaturgical analogy (Goffman 1959). In order to explain this further I will use examples from field notes to describe meetings with gatekeepers during the process of gaining access and how I made attempts to make changes to my impression management (Goffman 1959) in order to reposition myself. I consider the epistemological benefits

and pitfalls of attempting this before analysing what was actually achieved through my attempts at what I am calling 're-impression management'.

As discussed in the last chapter, I previously worked for the charity HeadStart working, to differing degrees, with some of the professional participants in the study. On my return to the field setting as a researcher, I felt conscious of the mixed perception between insider and outsider which others may have of me. I questioned whether there would be a natural shift in assumption now that I had a different ID badge. Several staff changes in key departments meant that there were numerous instances where I had a unique position of possibly being more aware of the goings on at the hospital than some of the potential gatekeepers, obviously counter to the usual situation where the gatekeeper is perhaps chosen based on their extensive knowledge and influence (Johnson 1990; Pope 2005). I made a decision early on that I would not attempt to assume an insider position. I felt this might lead to distrust on the part of healthcare professionals who might become frustrated that I appeared to have a sense of entitlement due to past relationships. I decided it better to relinquish power to the gatekeeper than assume it and have it taken away. For those who firmly positioned me in an outsider position, to attempt access to the backstage might potentially lead to an embarrassing and unproductive exclusion from accessing the field altogether.

### ***Re-impression management***

Changes I adopted were subtle but targeted in order to shift the perception of me amongst those who knew me. They were simple changes such as smartening up my appearance and using more formal language in correspondence. I also made sure I was punctual and attended meetings fully prepared. This 're-impression management' was attempted so that those who previously considered me an outsider might consider me serious, professional and trustworthy, ready to take up a detached, disinterested position. It would also suggest to those who considered me an insider, that I would not be taking advantage or exploiting my position. Re-impression management was a lot more difficult than anticipated with interpretations of my previous identity frequently resurfacing and becoming instrumental in interactions.

In order to gain access, I organised several meetings with key gatekeepers to various departments I wanted to study. My first meeting was with two members of the community brain injury team (CBIT). This was a department which I felt would be crucial for data collection. Additionally, it was the department with which HeadStart traditionally had the strongest support as well as having a

good informal, personal relationship so I felt that this would be a good place to start. Therefore, I was already using my position as insider to set myself up within the hospital. If I was to get support from CBIT, I could go to other departments being able to say that I had their backing for additional credibility. However, being aware of the relationship between CBIT and HeadStart, I also wanted to distance myself from my previous role in order to be taken seriously. I was concerned from an ethical perspective that by presenting myself as an extension of HeadStart, or as a close friend to CBIT, I might give the impression that I would be conducting a study which would look favourably on certain individuals or departments. I was also conscious of a desire to disassociate myself from my previous persona in order to not give the impression that I was 'playing' researcher and was not to be taken particularly seriously. I prepared fully for the meeting with a full presentation that anticipated any questions that might arise. This preparation followed guidelines and questions asked by the REC committee whilst also drawing on my own knowledge of CBIT, their approach to ABI and their relationship with patients.

Overall, the tone of the meeting was quite formal. When invited to explain my research, by having prepared notes and explanations, I had clearly surprised the staff by the seriousness in which I wanted to conduct the meeting. As a response, they seemed to change their tone accordingly, mirroring my own approach. I almost engineered the environment so I would be perceived as an impressive outsider rather than an insider asking for a favour. When I had finished, the majority of the conversation between staff was to consider how the research might be implemented. There was no question that I would not be able to have access to the department. I felt very pleased by this but kept my thanks at a respectable level so as not to belie my face-work (Goffman 1955).

On reflection, I believe that whilst my re-impression management tried to position myself to that of outsider, it was the perception of me as one of insider which ensured they had no reservations regarding assisting me. I had exploited my unique position to gain access. I had drawn on my insider knowledge to know who to request to speak to, who would be interested in my research and who would be most likely to give me access.

Buoyed by this initial meeting, I then went on to meet with the speech and language therapy team (SALT) planning to construct the tone in much the same way, hopefully leading to a similar outcome. My relationship with this team was a little different to CBIT though. I had always maintained a very professional relationship with SALT and this was reciprocated.

It was halfway through my talk that I felt that the situation was unfolding differently to my previous meeting. I was unable to find the sufficient tone to place myself. I would try to give examples to illustrate how I perceived the research to be carried out but it was often met with little or no reaction. I was unable to gauge if I was being supported or not. When I finished, I felt more nervous than in the previous meeting. Certain reservations were highlighted to me and my immediate response was to concede my position and apologise for neglecting to consider certain points they made. I kept thanking them for their advice whilst agreeing to change course in accordance with their suggestions. Not only was I remaining on the outside, I was now allowing therapists to be the expert in the research domain as well. I was unable to find my position for fear of being denied access.

When I mentioned the REC committee, I discovered that the therapists had been instructed to undertake an MSc as part of professional development and had therefore also had experience of dealing with the REC. It was not my intention to speak ill of the process but I found some initial empathy for the length of time it takes, evidenced by the therapists rolling their eyes and explaining that they understand how hard it can be. However, this avenue of establishing camaraderie was shut off as quickly as it was opened as if the REC, being part of the NHS like the SALT team, was therefore not to be criticised in front of 'an outsider'.

I was relieved when the SALT team said, albeit cautiously, that they would allow me to research with them. It was only then, during the period that we were packing up our various notes, that one of the therapists dropped their face-work for a brief moment allowing me a glancing view of the backstage. When discussing discharge practices, one of the therapists said "*...and we all have different opinions as to why they have clients on their sleeping file...which I'm not going to tell you,*" (*field notes*). As discussed previously, the sleeping file is a virtual space where individuals are placed when there will no longer be any active intervention given by CBIT, but it was felt that discharge might be a step too far. I felt this comment was very telling. Firstly, it was the first occasion that there was a slip and the backstage was revealed to me. Secondly, it showed that I was not deemed suitable for that space. The use of the words "*we all know...*" was said in a way that suggested that there was an assumption that I might share their view. However, there was then a readjustment and by saying "*which I'm not going to tell you,*" I was re-considered as not yet suitable to have access to the backstage, perhaps especially given my new position in the setting.

I had been positioned as 'outsider' by the speech and language department. By being positioned in this way, it felt that consideration was given to the research as if it were from a more detached perspective. Whilst reservations regarding certain aspects were expressed, this was also done so as if it were from an objective viewpoint. The interaction was very interesting from an epistemological position. I felt that I was given the performance of the front stage presentation (Goffman 1959) a perspective of the hospital setting that might initially be given to patients and family members. This presentation of the front stage is equally valid and as important to any that an invitation to the back stage might allow me to view.

It took a great deal of time to gain access to the actual wards. Staff working in other departments told me that ward staff were stressed and overworked. When I initially attempted to meet the ward manager, I discovered that she was on sick leave, as was her replacement, so the person covering was the ward manager from the spinal unit (now covering both units simultaneously.) Having worked at the hospital, and having already had initial meetings with senior staff, I found myself in the unique position of having more intimacy with the ward than the person introducing me.<sup>5</sup> On meeting the ward manager, she then took me onto the ward. She asked to speak to whoever was in charge so she could introduce me. There was then a rather humorous series of negotiations whilst staff organised between themselves, in front of the manager and patients, who was in charge and therefore would be best placed to speak to me. I was introduced to two nurses and it was explained that I had full clearance to research on the ward and I was to be assisted wherever possible. The ward manager then left me to explain my research further, briefing me to keep it as quick as I can. At this point, though I had not engineered it to be this way, access was perceived to have been granted and my briefing was to explain to the senior nurses as to how they might help me to recruit participants (a stipulation of ethical clearance was that recruitment was through a medical professional; which obviously has its own limitations.)

I returned a week later and met yet another nurse. After re-describing the procedure and arrangements she explained how *"the two nurses who I had been left with were unreliable, had not recruited anyone and if you want something doing, they are not the best people for the job,"* (field notes.) I took this viewpoint at face value though there was something quite telling going on here. Firstly, I was being treated as an insider. The attempt to present me as an outsider dissipated as

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<sup>5</sup> On arrival on the ward, nurses hoped that I was agency staff who had been brought in to give some relief. The ward manager explained to the staff that I wasn't and no such person would be arriving to cover on that day.

soon as the ward manager left. The nurses were much happier to treat me as an insider. Later fieldwork seemed to confirm this. The staff would often drop their formal position on a ward where they are almost continuously on display to the patients. As part of my invitation to the backstage, there seemed to be an understanding amongst most of the staff that there were official ways and then actual ways in which things are done. The ward manager was only privy to official procedures. Perhaps given her position or newness in the role, she was positioned as outsider. I was being welcomed into the insider position. This was one of the very few areas of the hospital in which I had no previous links and therefore it would have been entirely without confusion for me to be positioned as outsider yet a tacit level of trust had been assumed that allowed for access to the inside.

These examples show that any concerted attempt on my part to negotiate a different persona was often unsuccessful; perhaps even misplaced. It takes more than a smarter sweater and good time management to change pre-conceived, perhaps deeply entrenched beliefs and relationships to the department, wider hospital, me or to research generally. When I attempted to position myself as an outsider, those who considered me an insider would find this awkward or even humorous. Others would simply not accept this position and continue to present to me as a fellow back stage member. Likewise, many of those who felt they need to perform within the front stage would consider me an outsider and would make every attempt to maintain this position. This requires a lot of work, especially in a high-pressured environment and there were occasional 'slips' in this performance. I suspect that my invitation to view the back stage was more to do with the difficulty of sustaining such an impression for a prolonged period rather than due to my own 're-impression management'.

Relationships are bound up in performance through interaction (Goffman 1959). By attempting 're-impression' management, I was merely providing another performance to be interacted with. Attempts at manipulating notions of insider or outsider to influence what data might be yielded were equally as futile. Multiple discourses are in play in these settings leading to the position of insider or outsider not being fixed, but a fluid set of arrangements which constantly shift. I came to realise that this should not be a point of anxiety. We construct our realities in this way in every day interaction (Hammersley and Atkinson 2007). We take up multiple positions with multiple agendas (Latimer 2013b; Mol 2002) and we have blurred, constantly re-shaping interpretations of others. Research does not provide us with a window to look through, more a lens, a method of constructing a reality through our own interpretations and interactions (Coffey 1999; Atkinson et al. 2003). The difference when conducting an ethnographic enquiry is that by being reflexive, it allows for

recognition of the potential influence this may have on how as well as what data is generated and interpreted. The importance of this should never be overlooked.

### ***Choice of location***

This research project was multi-sited in the sense that observations took place in two hospitals (University Hospital and Rehabilitation Hospital) but also in that within each hospital, especially the rehabilitation hospital, research would take place in a variety of spaces and departments (reflecting the multifaceted nature of ABI rehabilitation.) The rehabilitation hospital was chosen as it contained a variety of different parts of the rehabilitation process worthy of investigation and even patients who might not be admitted, could still have several interactions with the site (most notably through CBIT.) It was the main rehabilitation centre that an individual might be referred to on discharge from the University Hospital if they were to meet the criteria (an area that will receive considerable attention in later chapters). The University Hospital was selected as it is the main and most likely destination for someone who receives an ABI and is often the first point of contact with the medical setting for many patients.

It was particularly important to investigate both sites in order to attempt to map the trajectory that the ABI patient might possibly face when involved in the rehabilitation process. It was also important as data could be collected from different patients who were at differing parts of the process. I could observe when the ABI was very recent, observe patients when involvement with rehabilitation was only just being established and much later, possibly when much of any official interaction with the setting has ended. However, this was certainly not the only pathway that an individual might face. To describe the process in a lineal, processional way also does not do justice to the reality of ABI recovery. As suggested in the introductory chapter, many individuals move back and forth between the various medical settings or may enter and exit repeatedly at different times and in different circumstances. For example, an individual may be on a ward named A1, the acute ward at the University Hospital. They may then make such rapid progress that they bypass the recovery ward (D7) and be discharged home. D7 is the usual ward in which patients suitable for the rehabilitation hospital are picked up.<sup>6</sup> The patients who were discharged from A1 may then be discharged only to return to the community brain injury team (CBIT) at a later date. Those that left the University

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<sup>6</sup> A member of staff, involved in referrals to the rehabilitation hospital, told me during an multi-disciplinary team meeting that she was “concerned for the fate of those on the ward A1 as they get overlooked,” by the way that current system is organised (field notes.)

Hospital with no ABI identified may not return for many years. Some may have no interaction with the healthcare setting at all yet through a discussion of their difficulties, often with a family member or possibly a GP, an ABI may be speculated resulting in a referral to a brain injury specialist.<sup>7</sup>

During data collection, there were substantial differences in the infrastructure between the locations which had a direct impact on my understanding and position within the setting. In the small rehabilitation hospital, I became quite well known. I got to know certain patients and professionals and they would usually remember me as I walked in. At the University hospital, there is such a 'temporary' culture that I was very rarely challenged (only once in fact.) I was often left alone on the ward, able to come and go as I pleased. My gatekeeper at the University Hospital (Sandy) even told me that she could not introduce me to all of the staff, as she did not know them herself. On another occasion at the University Hospital, I was asked by a member of staff if I knew the whereabouts of a file, believing me to be a fellow member of staff. This is further evidence that I could move in and out of the space with little cause for concern.

### ***Data collection methods***

#### ***Ethnography***

The main process for generating data was through observational methods which lasted 10 months. Observations lasted anywhere between two hours to a whole day for two to three days per week. There is a considerable and rich history of conducting ethnographic work in medical settings (Allen 2010, Atkinson 1995; Bosk 1979; Latimer 2000; Mol 2002; Silverman 1987; Strong 1979; Thomas 2015). Conducting an ethnography allowed me the best possible opportunity to investigate the everyday interactions on the ward as they are performed rather than through a secondary account. My overarching ambition was to investigate what underpins certain practices being carried out. I wanted to know how behaviours become configured as accounts to legitimise or configure someone as 'patient'. Whilst talk is a vital component of this, it is certainly not the only factor and observations allowed me to analyse the space between the actors in terms of how it is used to do much of this configuring work, often without any talk. I would observe how the same space, often

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<sup>7</sup> Some patients were referred to the brain injury team despite no narrative that could establish that they had a brain injury. They had presented themselves to settings such as their GP or a friend and the difficulties described are then configured as consistent with ABI though there was never an accident or event which could explain this.

the ward, came to be taken on as a site of performance by different actors, namely patients, professionals and family members.

I was interested in the mundane, the micro and the everyday. Major events, such as the day there was a full ward evacuation, were obviously interesting and important but it was the actions that normally go unnoticed which interested me. It is in these small pockets of interaction, these everyday encounters where performances are enacted (Goffman 1959). These are the components in which individuals construct their narrative and understanding of acquired brain injury.

### **To participate or to not participate?**

It is difficult to define when observation should be regarded as participatory or not. Indeed it can be regarded as futile to even use these terms other than to describe well established, understood methods as to some extent, participation is almost always unavoidable (Hammersley and Atkinson 2007). However, very shortly after my arrival in the setting I felt that the rhythms and rituals quickly began to flow in the same manner as if I was not present. There were often many different faces on the ward at differing times. Over time, I was considered as much a part of the ward as the nurses, patients and family members and it would be rare for heads to turn on my arrival. However, I made great efforts not to influence the field as much as possible, particularly in the initial stages of fieldwork. This would involve taking up positions in the corner of rooms or not contributing during formal meetings despite having opportunities to do so. I would often concern myself as to what I might do if I witnessed bad or unsafe practice. Thankfully, dangerous practice never became an issue whilst I reconciled myself in the sense that bad practice is all too often in the eye of the beholder. Rather than challenge the perpetrator, which could be both hugely unproductive and confrontational, trying to understand the action in terms of the wider interpretations of their ontology might be more beneficial and in keeping with the purpose of my presence anyway.

It soon became apparent that maintaining a completely disengaged position would be challenging and I came to realise that a certain level of engagement was to actually be embraced. Whilst keeping a disinterested position, becoming involved allowed a different, enhanced experience that only aided the fieldwork as I shall explain shortly.

The first few periods of data collection involved observing CBIT groups. One of the reasons this space was chosen was because the group was made up of individuals who were almost guaranteed to be in

the space for a set period of time for a defined number of sessions. This made gaining consent to research much simpler than the more fluid make-up of other spaces as participants could be given information regarding my research, take an appropriate amount of time to consider it, ask questions and then decide whether to take part, all relatively quickly. All participants gave their consent.

I might be asked questions and certain participants would want to tell me 'their story', something they would not have done had I not have been present. After several sessions, I felt I became less of an attraction. I would sit around the table as one of the group, as this was actually more inconspicuous than sitting at the back, and the session would go ahead as usual. Staff might often discuss an issue and, knowing my previous position at HeadStart, ask me if the point they were making sounded familiar or whether the particular topic discussed was showing up in my research. The CBIT sessions would often involve the group being asked questions. When one of the participants had a string of correct answers, the others would gently mock them and tell me to write it down as this was "*good stuff*" (*field notes*). I would sometimes be asked the answers in the quizzes and I found myself drawing on previous experience and methods training, not to mention common sense, to negotiate these various occasions. I became as much a resource to the group as staff and fellow patients had become. Whilst my presence influenced the artefacts in play, I became confident that fundamental performances remained consistent. I was merely an additional tool used in order to express them.

On the ward, during an Occupational therapy (OT) games session, it became much more fruitful if I was to take part in the activity. This meant collecting sponge balls whilst the group played a version of wheelchair tennis. We also played Boccia, a sport I was known for, so it became expected for me to help out and explain the rules. Whilst initially just a courtesy exercise, I found that by taking part, it allowed a better understanding of the session. I could physically feel some of the difficulties in trying to organise sessions with broken or incomplete equipment. I could acknowledge what it was like to play with reduced amounts of room with individuals with 'high support needs'.

On one occasion, I attended an admissions meeting, a meeting designed to give feedback to the staff in the rehabilitation hospital about the patients discussed in the University Hospital the day before. It quickly transpired that I was the only person to have attended both meetings. Therefore, I was asked to give information and, finding myself in a difficult position to decline, became an intricate part of discussions. I went to great efforts to play down my role due to being anxious not to give incorrect medical information or to give information which was meant only for research purposes. I

gave summative descriptions, only confirming descriptions and explanations if staff had already expressed them but needed clarification. My contribution was taken as it was meant to, additional but not vital; yet again it allowed me important insights. By participating, by actually 'performing healthcare professional', it showed me, to an extent, how staff may select information. Whilst my motivations may have been different, I felt that there were many similarities with the manner I gave the information and those who would normally be expected to do it. Previous experiences of the patient, expectations in terms of both medical prognosis and performance of patient as well as predictions of audience reaction, all played a part in the choices I made in what to report. Without overplaying the encounter, it gave me the opportunity firsthand both to converse in 'medical talk' (Atkinson 1995) but also to understand how some information is privileged whilst other information is relegated.

### **The logistics of collecting data**

As well as CBIT groups, observations also took place on the rehabilitation wards and at occupational therapy, physiotherapy and speech and language therapy sessions. In addition to this, I would sit in on multi-disciplinary team meetings, admissions meetings as well as department meetings for OT, physio and CBIT. At the University Hospital, I would observe everyday practices on the ward, including ward rounds as well as meetings which would take place which determined the potential trajectories of patients currently under the stewardship of the neuro-consultants.

Despite an interest in the topic and an overarching desire to understand it, the research questions at the beginning of this investigation were somewhat unrefined. I was keen to draw on the benefits of ethnographic research which allow the researcher the scope to follow leads and investigate different areas as and when they are deemed interesting. Thick description (Geertz 2000) began with taking notes as broadly as possibly. I would consider layout of the room, temperature, lighting, seating positions, posture, speech, tone of voice, who was standing, who was sitting, different resources employed and when.

The data taken down whilst on the ward was typed up as soon after the event as possible. When I was typing up the notes, I was also analysing the data with further detail being added on occasion. As fieldwork continued, different tropes emerged so efforts were made to explore these particular

areas further.<sup>8</sup> In the final few weeks of observations, time was mainly spent cross checking themes which had emerged. When there did not seem to be any significantly new tropes coming from the observations, I felt data saturation had been reached and I began to withdraw.

I was fortunate because the hospital setting has a culture of note taking. In physio sessions, it would not be uncommon to find physiotherapists or their assistants (technicians) jotting down reminders in notebooks or on scraps of paper. On the ward there were charts and folders which would be constantly attended to by professionals (and occasionally family members.) In the meetings, almost everyone who attended would have some sort of large file in front of them. Therefore, it was very easy to take notes as events and interactions took place. I was able to write conversations verbatim. During some meetings, this might mean that I would have to mentally remove myself from the conversation for several moments so I could concentrate on writing up what I had just seen or heard. However, meetings were often compartmentalised. Patients were discussed one by one, usually in the order that they came on a list that was distributed at the start of the meeting, meaning that if I missed discussion of one patient whilst I was making notes, I could quickly decipher which patient was now being covered. The ward was slightly more difficult. There was no easy space to take notes, only the nursing station which was positioned in the corner, not giving a good view of the ward overall. It was better to conduct observations making quick notes and then remove myself to sit in the social room adjacent to the ward to add detail whilst it was still fresh in my mind. As I gained confidence, it became easier to sit in a more exposed position on the ward, borrowing a chair and taking notes as I wished.

It is disingenuous to claim that the field can ever be entered free from pre-conceived assumptions or expectations. The field is constructed through interpretations and understandings of the researcher and this is exactly what gives these methods such crucial validity. As I had previously worked in the field of ABI, albeit for the third sector, I had experience of medical practices and settings. Before research was undertaken, it became clear that there were specific issues worthy of investigation. I was aware of this and no matter what experience an individual has to the area of study, even if it is felt to be none, this relationship should be recognised. This relationship in itself informs the researcher in entering the field. That is not to say that they will not be open minded and explorative,

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<sup>8</sup> For example, technology and the relationship it has with illness was a concept which the data sprang up and I considered further both through further observations and informal discussions. Conversely, it might also lead to dead ends where areas I felt were growing in significance, such as the sense of space and place, seemed to not bear the significance I had placed on it previously.

just that the assumptions and prior experiences will influence the interpretation of what data is generated (Silverman 1993). The notion of the researcher having no prior experience or knowledge of the site under investigation is almost as unrealistic as it is unnecessary to dwell on. This should not be a point of anxiety. Interaction and knowledge is always shaped and understood through the individual's prior assumptions, experiences and expectations (Atkinson et al. 2003). The starting point of the researcher should not be deemed problematic provided it is recognised.

The nature of ABI rehabilitation meant that a sizeable minority of patients were in hospital at the beginning of data collection and were still there at the point of withdrawal. Others would come and go (perhaps through CBIT) but would be present at different intervals. This was also the case for many of the staff. When it was time to leave the sites, I had some concerns that I would be disappointing or upsetting individuals, particularly patients, who I had come to know quite well. However, my anxieties were unfounded. Many patients are used to the temporary nature of staff and did not seem at all concerned when I announced to them I was due to withdraw from the field.

I was keen not to allow the constraints of NHS ethical approval hinder and relegate the benefits which inductive research offers more than they had to. Therefore, whilst being cautious and courteous to my obligations, I looked for opportunities to investigate issues further as and when they became available. I was invited to attend the MDT meetings by the ward sister after a chance encounter when I explained my interests in an informal chat. I did not know about these meetings until I was invited to attend and it proved invaluable to the research. Similarly, only after discussions with patients regarding their everyday activities did I learn about different groups which they attended. In these instances, I would ask the patient and relevant member of staff if I could sit in on the session and this was never an issue. It also became clear through discussion with patients and staff that ward life differed depending on the time of day. Therefore, I attempted to observe different parts of the day where possible. By taking these opportunities, it allowed me to understand and track the patient throughout the setting (Marcus 1995). I was able to follow a patient, or a small number of patients, for a certain amount of time in order to fully capture the rhythms, flows and patterns of ward life. If I remained only on the ward, with the patients coming and going, it would produce a more static, less developed understanding, one likely to be unrecognisable to the actors involved.

## Interviews

Participant observation was complemented by semi-structured ethnographic interviews (Spradley 1979). In total I conducted 14 interviews with 16 participants (two patients were interviewed alongside their carer who happened to be their husband on both occasions.) Each participant was interviewed once. This included three interviews with health care professionals, eight with individuals with acquired brain injury and three interviews with different carers on their own. These sets of individuals were sampled as I felt that not only did the sample demographic best represent those from the field of study but, in some instances, different interviewees would experience the same event or interaction as each other and it would be interesting to understand how understandings and experiences of the same event varied. Interviews were no longer than an hour. This was initially due to the issue of fatigue amongst those with ABI although it also helped to encourage staff to take part as it would not encroach too much into their busy schedule.<sup>9</sup> Whilst all staff interviews took place in the workplace, all participants were offered the chance to choose where they wished the interview to take place. Therefore, I met one carer at home, whilst her husband was attending day centre, and I met the other two carers in cafes. Four patients were interviewed at home, one in a cafe and three more in hospital. Only one was a current inpatient but it was easier for the other two to meet me in hospital as it coincided with a CBIT group they were attending. For one of the interviewees, the group he was due to attend had been cancelled yet he still fulfilled his obligation and undertook a two-hour trip to make our appointment. He explained he had nothing else to do that day.

The use of semi-structured interviews was particularly useful. It is fairly common for patients with ABI to be described as going 'off topic'. This was an important observation in itself; evidence and experience of the complexity that some have maintaining conversations and interacting with others. There were also times when the conversation would otherwise descend into chaos so an element of structure in terms of having some set questions was essential. A lack of conventional flow in conversation was something many patients were aware of and some even asked to be told if it were occurring. In reality, the interviews were mostly conducted in the manner that they might with anyone. The guide would occasionally be followed closely, more often with carers who found it difficult to talk about themselves, but more often it would only be fleetingly observed or abandoned

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<sup>9</sup> This was also written into the NHS ethics application as part of a way of ensuring comfort and safety for patients. Interestingly, when describing the interview process with patients, the professional present suggested to the group that they could talk longer if they wished.

altogether when a topic brought up by the interviewee became particularly relevant or interesting (Atkinson and Silverman 1997).

I found the combination of having a carer present with the patient particularly interesting. The patient was given the option to have another person present. This was not always possible (as one was an inpatient and another did not feel he had anyone) whilst on other occasions patients did not want anyone present as it gave them the chance to tell 'their story'. However, it was helpful because it presented an opportunity for discussion and even sometimes conflict when the patient and their loved one disagreed with each other. This would most likely be a disagreement in regards to the recollection of the same event or the extent of the difficulties the patient was experiencing (see Janet in chapter seven). Again, this allowed me to observe the interviews as part of data collection. Discrepancies in accounts, disagreements in how they construct their world based on the same incident all form part of the wider interpretation of ABI.

Interviews would be audio recorded using a Dictaphone and then transcribed later using a software package named Dragon Dictate. This was particularly useful as accounts were annotated verbatim. Whilst it was not my intention to undertake any sort of conversation analysis, by having the pauses and repetitions, it meant that tone and intonation could be taken into account informing the data further. At a more functional level, by allowing the Dictaphone to collect the data, I was able to concentrate on the conversation so it felt as natural as possible; in turn assisting the interviewee to feel more relaxed.

I conducted interviews towards the second half of the fieldwork process. This was partly due to the need to build rapport with participants. It was also because the questions asked were informed by the data that had already been generated by the observations. Interview data would then give leads that informed future observations (Walford 2009). Patient interviewees were initially recruited largely through CBIT. Whilst it is recognised that this may potentially give a misrepresentation of patients as this pathway is not available to all, it did mean that the majority of the patient participants had experienced a significant number of services and were therefore able to discuss a range of issues. I also hoped to interview two inpatients and whilst I was successful in interviewing one, the other patient was in a group the day I was scheduled to interview him and when I returned he had been discharged. Whilst I did consider finding a suitable replacement, I felt that the data gathered from informal discussions with him on the ward, many of which were as nearly as long as some of the interviews, would be sufficient.

Two healthcare professionals were approached directly and they were both very enthusiastic to participate. One of the professionals was a speech and language therapist who attended and contributed to decisions during the MDT meeting. She divided her role between the hospital and CBIT meaning she was able to comment on and compare the two. The other staff member was an OT technician who openly admitted having very little to do with goals set for patients and was much more involved in the 'doing' part of rehabilitation. They were chosen because over the preceding months, they had played an instrumental part in many of the observations that had taken place and I felt that it would be very useful to document their account drawing on what had been observed and interpreted. They were also selected to gain a range of differing positions in the hospital to reflect the range of knowledge they may have of the wider issues so that it might reflect their understanding and experiences 'on the ground'. I had hoped to interview more staff members but this became difficult due to time constraints on both sides. Again though, I often had the opportunity to have informal conversations with professionals, especially when shadowing certain departments and many insights were gained this way. I was also able to ask for clarification on certain points, either verbally or by email and this was useful too. Another professional involved contacted me directly having seen an advertisement for my research. Initially I placed her as a carer though only once the interview with her started did I reposition this assumption. I shall discuss this in more depth shortly.

All carers got in contact through adverts that went out via HeadStart, either in their newsletter or by mail shots. I had also attempted to recruit from the wards but this was unsuccessful. Firstly, this was because visiting times were quite limited. Carers were very busy during this time and it was difficult to spend time discussing research to any depth. In addition to this, for most carers, time with their loved one in hospital was a very emotive time and many felt unable to take on anything extra at this stage. Recruiting from one source, in this case a charity, needs to be undertaken with caution. It could be assumed that doing so might mean that the carers recruited had already felt motivated in looking for and finding assistance and therefore had a particular, distinct perspective from those who had not. However, this was not always the case. Whilst the names of the carers had made the HeadStart database this did not mean they were active in accessing support. They may have been referred without any recollection of this themselves. Indeed, one of the carers felt she was gaining no support at all whilst another felt that any support she got was minimal.

As highlighted, interviews are in themselves accounts and occasions, worthy of observing and investigating as they are unique settings for performance. The interviews provide an occasion for the interviewee to express themselves (Atkinson and Delamont 2006). This involves more than just the content of what they say but how they say it. What they do not say, tone, behaviour and their willingness to be interviewed in the first place, can all be data worthy of analysis. Like observations, the space is as interesting as what occupies it. When a person is required to give an account, especially in a formal setting such as an interview, it gives them time and space to stop, take stock and consider what they think happens and what they want to disclose (Atkinson, Coffey and Delamont 2003). It gives them a chance to perform and represent themselves in a way in which they wish to be perceived. Observations can then play a part in verifying this or at least understanding it from another perspective (Atkinson and Delamont 2006). It must be remembered that observations are also only representations. However, this is what we do in everyday life and it seems to not interfere too much here. We seek clarification, we get alternative views and we build our understanding based on prior assumptions and experiences. When all of these act in accordance with what we assumed, we can presume that our assessment, at least to us, is accurate.

Aside from the more subtle and complex interpretations that can be understood from interviews, I also had to be wary of the not so subtle messages and agendas being forced into play. As previously mentioned, one interviewee was reconsidered from carer to that of professional. She was a supported housing manager and it quickly became clear that her main intention during the interview was to advertise the home. Her speech was full of words like “*audit*” and “*client group*”. She was very keen to explain that this was the clients’ home and families could come and go as they pleased. She was more defensive when questions were asked, in all innocence, about issues such as autonomy. This interview became a vital account in its own right but not for the reasons I had initially envisaged. It became very useful in observing the perceived packaging of ‘care’ into a commodification; something that could be advertised and sold. I interpreted the request to be interviewed as an opportunity to sell her product. By giving this particular performance, the manager was also showing how removed she was from the experiences patients described in their interviews. Without stretching the point too far, her interpretation of good care was more bound up in passing certain official standards (she gave me their latest inspection report to take a look at).

Other interviewees also used the interview in other ways, introducing agendas I had not expected. The other two professionals used the interview to show some (controlled) frustration at some of the practices and changes they saw around them. I found their frankness on certain issues to be

enlightening. It seemed that all three carers who were interviewed alone used the interview, to a greater or lesser extent, both to express their frustration and concerns but also to ask for advice. This leant on all of my experience and training to know how to remain as a detached researcher whilst also being sensitive to an obvious appeal for help. I felt I was able to provide information, mainly through signposting to services, without blurring my position. I felt I had an ethical obligation to do so. Again though, through conducting interviews, I could also make observations and it seemed with both professionals and carers, there was a lack of avenues to discuss such issues.

In all interviews, I was mindful of those who had offered themselves for an interview as well as those who agreed to be interviewed. Often an individual would volunteer themselves expressing that they “*have plenty to say*” (*field notes*). More often than not, that might be in relation to a particular grievance with a service or procedure. This has the potential to give an unrepresentative set of accounts. To counter this, I also approached others who had not necessarily been so forthright in coming forward. I had no reason to assume there was any particular grievance they wished to get across.

Interviews proved invaluable in providing further understanding of particular events which I may have already observed, occasionally leading me to reconsider my initial interpretation. For example, Janet, a patient with CBIT, was often perceived to be a lively, extroverted and humorous member in group sessions. She would explain that she didn’t do her homework (the work they had been set in the previous session) and couldn’t understand what everyone was talking about. This was perceived in a rather light-hearted way and she was often told by the group leader to sit and watch during an activity as a way of joining in, rather than attempt the activity herself, if she found it too difficult. When interviewed, she made it apparent that her lack of understanding and subsequent non-involvement was a major source of concern and anxiety. She wept as she explained to me how the groups made her feel less able than others. Having interpreted my observations differently, two very different pictures of Janet would emerge. By triangulating methods, I introduced more rigour and cross checking into my interpretations. In this instance, it was able to show a complex interpretation of the situation; a misreading or poor ‘fit’ between the service and the individual.

### ***Analysis***

Data analysis took place as a form of situational analysis (Clarke 2003). In order to answer the research questions, it was important to use an approach which allowed for analysis of a variety of

materials to take place. This included utterances, silences, mannerisms, and seating arrangements as much as it did official documents, formal interviews or thick descriptions of specific events (Geertz 1973). It also includes analysis of the ways in which these different materials might relate and what this might accomplish (Latimer 2004; Latour 1991). One of the strengths of this method of analysis is it allows for the different materials, despite differences in the manner in the way they were collected, to work together to form an account of the setting. As an inductive piece of research, it was vital that the methods allowed for exploration and interpretation in order for themes to emerge which this mode of analysis accomplished.

Analysis developed over time. In the first instances, I made no assumptions of priorities of importance, considering everything as data. This was necessary to determine areas of further consideration and focus whilst being mindful not to close down possible tropes too early. A constant comparative technique involved reading, re-reading and categorising data into themes as they became more significant. This was initially conducted by hand which I felt allowed for a fuller immersion into the data as it required multiple readings and considerations. This data was then transferred onto a computer, where further sorting and reanalysing would take place. If enough data began to emerge which suggested a new trope, a new theme which deserved its own category, data would be re-analysed taking this into account. This would also be considered in future analysis as a form of cross-referencing. Accounts given through interviews could be valued alongside how the 'reporting' seems to play out in the field (Atkinson and Delamont 2006). This in turn allows the interview to be analysed as to the 'moves' (Latimer 2000) being undertaken by the interviewee in the manner in which the account was given. By understanding data situated in the wider context it leads to a greater understanding of the multiple discourses in play at any one time.

Over the period of data collection, analysis meant that data collection could become more refined. As data emerged that could be used as evidence to verify existing claims, it would be noted. Periodically, the entire data set would be reread and reinterpreted. This was a particularly useful exercise during the period of interviews as it both informed and was informed by the interview process. On completion of data collection, tropes were reanalysed again in order to understand the narrative. It was important that this was not a forced exercise, making links and comparisons where none could be made. I made every effort to allow the data to speak for itself; for themes to emerge and complement each other.

### ***Limitations***

The two main concerns to be levied at ethnographic work are that there are issues regarding generalisability and the over-reliance on the subjective nature of the researcher in question (Hammersley and Atkinson 2007). I acknowledge these arguments but only to a point. In the first instance, it is fair to say that it would be difficult to generalise all findings and arguments in this thesis in order to describe ABI rehabilitation across all of the UK. However, this was not my intention. By its very nature, ABI rehabilitation is complex, with multiple systems used to organise practices and procedures. It would be both futile and disingenuous to try and make generalisable statements from one study undertaken in this manner. However, it would be fair to say that several arguments and overarching points that have emerged from this study would be found to hold elsewhere, particularly when settings are similar to the field sites I worked within.

As regards the issue of interpretation, I argue that all research is to some extent an issue of interpretation. Factors such as what to study, who to study and length of study, all inform the research before it even takes place. Ethnography aims to hold up a mirror to life which is, in itself a construction, made up of interpretations (Atkinson and Delamont 2006). Rather than attempting to standardise and measure the everyday, ethnographic work generates data in a similar way to which the everyday is carried out, thus presenting a highly valid interpretation.

### ***Conclusion***

The purpose of this chapter was to provide an in-depth account of the methods used in conducting this study. It explained the positioning of the researcher and some of the theoretical interpretations as to how data might be interpreted. Attention was particularly paid to the work that is undertaken before fieldwork is carried out, namely gaining both NHS ethical approval and access to the setting, with a discussion in regards to the important part this plays in the potential shaping of data collection. Factors such as researcher influence and choice of location were also considered in how they may also play a role. Having laid the foundations for this study, the following five chapters will now explore and consider the data which was generated.

## **Chapter Four: When is a patient a patient? When is a professional, professional?**

### ***Introduction***

As summarised in the introductory chapter, the number of difficulties that could be experienced by the ABI patient is extensive and complex but also often highly individualised. Many different outcomes can be brought into focus as soon as the patient is deemed stable enough to begin rehabilitation, whilst others might appear over the course of the patients' time in hospital. Very often, many difficulties do not become noticeable until many months later, mostly when the individual has left hospital and is attempting to maintain some semblance of the life they had before their injury (with varying levels of success). Even then, what may appear as an outcome of brain injury for one may not be regarded as such by another. The professional may see something they regard as an outcome of ABI whilst the patient and family have interpreted it differently.

This chapter begins to explore how the concept of 'configuring' ABI is accomplished in more detail by the healthcare professionals involved. The main point of focus is the multi-disciplinary team (MDT) meeting, the meeting where the various departments come together to discuss patients. I consider how the meeting is organised and analyse the perceived role of the meeting before analysing what the deeper, underlying accomplishments of the meeting might be and how this feeds into the patient experience of rehabilitation. In particular, I pay attention to the space in-between talk, where the various actors make their 'moves' (Latimer 2004). I look at what information is privileged, what is relegated and how these decisions play a vital part in figuring the patient. I also consider power dynamics and the performances involved in employing strategies to interact with them by other staff members. I conclude by considering the significance of this space for the functioning of the hospital and the reproduction of organisational practices and values. These meetings have been chosen as the starting point for the empirical data as they provide an excellent, contained, example for providing an overview as to how this work is carried out. Data from field notes and interview transcripts form a considerable part of the empirical chapters. All names of participants and places have been anonymised.

### ***The MDT meeting***

The multi-disciplinary team meeting takes place in the main committee room of the rehabilitation hospital on a weekly basis. Whilst several other meetings take place regarding individual patients with smaller numbers of professionals involved, this is the main meeting where every department

attempts to be represented and every patient on the neuro wards are considered, no matter how briefly. It begins at 09:30 and can easily be still going 90 minutes-2 hours later. As a result of this, some professionals only attend for part of the meeting but in the main, the professionals stay throughout. Members of staff act as key workers for individual patients so occasionally a professional may say what they have to say for a particular patient they are responsible for before leaving.

On arrival at my first meeting, I was struck by the grandness of the room used although I couldn't help but notice that, similarly to the rest of the hospital, it had seen better days. The room itself had a large oak table as its centrepiece. The walls are adorned with wooden panelling whilst going up one side is a large fireplace, with a historical painting above it. At the back of the room is a single paneled glass front with a glass fire door which was often difficult to open and even more difficult to close. Around the table are leather backed chairs. When the meeting was busy, there were never enough chairs so those that arrived late would often have to leave immediately to find one from elsewhere. It would often be a point of humour as to what type of chair returned.

As mentioned, every department would normally be represented in some way or another, normally by the head of each department. They would feed into the meeting with any information from their staff and, in turn, relay that information back to their staff at a separate departmental meeting afterwards. Sometimes, a more junior member of staff would have been asked to attend in place of their senior and it is sometimes quite obvious that some junior members relish this opportunity and thoroughly enjoy it. This is in contrast to some of the more experienced members of staff who often appear as if they would like the meeting to progress more quickly.

There are two neuro-consultants, both female, who are responsible for patients on the neuro-rehabilitation wards. The different departments represented at the meetings include the consultants, either one or both, who always chair the meeting if they are present along with doctors, registrars, ward sisters, occupational therapy (OT), physio therapy, speech and language therapy (SLT), community brain injury team (CBIT), HeadStart, a dietician and administrative staff who are often responsible for organising follow up meetings, goal setting and discharge. Some members of staff may have two roles in the hospital. For example, the speech and language therapist for CBIT is also contracted to spend half her hours as an SLT on the ward. Occasionally, two or more members of the same department might attend, especially if they are each a key worker for different individuals and they have something significant to report.

Once the room is fully occupied, there is not a lot of physical room for manoeuvre. The first time I attended, I was very aware of this, especially when chairs became a precious commodity. I went into the room with Tamara, the outreach worker from HeadStart who I had, by chance, met in the car park. I positioned myself at the far end of the table away from the consultant who was already there. This was possibly in an attempt to be as inconspicuous as possible, although it was undermined somewhat by not realising that Tamara was making space for me to sit next to her so I kept being moved along across several chairs which members of the meeting found particularly funny. I came to find this underlying familiarity towards fellow staff members, the reluctance to take oneself too seriously all of the time, to be a common trait amongst professionals.

By the side of the wall are two large filing cabinets on wheels, opened to reveal that they contained patient files though these are not often referred to explicitly during the meetings. Over the course of observations, I discover that these are permanently homed on the ward and it is the responsibility of the first person to arrive at the MDT meeting to go and get them. On one occasion, it was left to one of the consultants to go and collect the cabinets, something she was most put out about.

In the centre of the table is a large pile of notes provide by Gwen, one of the admin staff. These are used to guide the meeting. There are two neuro wards at the hospital, wards 7 and 8, and each week, individuals on one ward are discussed in detail with those on the other ward only being discussed if there is something that it is felt cannot wait. The following week, this is reversed. It is a matter of debate what counts as 'unable to wait,' depending on the priority of the individual staff member and on several occasions, patients from both wards would end up being discussed for equal lengths of time. (Often, the meeting begins with some confusion as to which ward is the priority that week anyway). In the notes provided there tends to be the following information:

*Name of patient*

*Hospital number*

*Health board area*

*Initials of consultant*

*Date of admission*

*Date of Injury/diagnosis (this differs from admission because after injury they are likely to go to another hospital such as University Hospital first. Not everyone has a date of injury/diagnosis given.)*

*Indicator of rehab (R) nurse (N) or 'trachy' (#)<sup>10</sup>*

*Goal planning meeting date (Goal)*

*Other (blank throughout)*

*Key worker (Not everyone has one)*

*Social worker (Fewer than half has one)*

*Status/ Action (This consists of a brief medical history, current interventions and proposed next course of action)*

*Planned discharge date*

The official purpose of the meeting is to provide an official point where all departments come together and share information and updates about the patient from the point of view of what they in particular specialise in and are working towards with the patient. This information is then collated, considered and a plan for the future is then discussed. In reality, much of the talk is also focused towards more logistical and organisational matters. This is usually in regards to organising life after discharge. Practically all patients will have a planned discharge date, no matter how recently they have been admitted. Being a 'key worker' (the main contact person for that particular patient) can mean a large proportion of the staff members time is spent trying to find the right person/organisation to fund a vital piece of equipment or bed in the community or liaising with family members. Often, this can become very time-consuming and complicated. The meeting also acts as a point to discuss and give advice as to the best course of action in these circumstances as well. This advice, such as how to get a certain service, can often be as a result of prior experiences or personal relationships rather than any official protocol. For example, on one occasion, it became apparent that the 're-ablement team' (not present at the meetings) would not become involved with a patient if the community brain injury team were already being accessed as the 're-ablement team' claimed this would be duplication. CBIT argued that their service was different and others tended to agree with this, believing the real reason for withholding their service was more to do with saving money and reducing waiting list sizes. Therefore, key workers learned that if they applied for the services in the 'correct order', they would be able to get both services for the patient but if they got the wrong order, only one could be involved. The MDT meeting was an ideal place for finding this out.

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<sup>10</sup> This is short for Tracheotomy.

### ***The patient is configured***

The MDT meeting, however, does a lot more than provide information on medical and logistical issues. To suggest that the meeting only consists of information sharing and negotiations of the next course of action is a far too simplistic description. In actuality, the MDT meeting is a vital space for the individual to be configured, categorised, negotiated, moved and re-categorised between the labels of 'patient' and 'person' (Latimer 1997). This is highly influential in shaping the course of action that the patient can expect in their overall rehabilitation experience. As described in chapter two, at its most influential, the configurations play a significant part in determining legitimacy and the options available to the patient, including their disposal from the medical setting. When the individual is in hospital they are a 'patient' yet when it is time to leave, they become more aligned to the category of 'person' (Latimer 1997, 1999, 2000). The sooner an individual is re-configured as 'person', the sooner they are ready for discharge. The very way that the meeting is organised and structured allows for this to take place. Every detail, from the layout of the room to the priority given to the speaker all plays a part in this configuring work.

The layout of the room ensures that the consultants always sit at the head of the table, nearest the door facing into the room. Everyone else who enters often has a favoured area of the table in which they sit, this is even commented on occasionally, but it is not quite as fixed. No one but the consultant, if the consultant is present, will sit at the head of the table. A member of staff, who is nearest to the filing cabinet, will act as an assistant in handing across the files to the consultant when needed but the consultant will rarely get up to find the file themselves. The ergonomics of the room means that it is clear to anyone entering, exactly who is leading the meeting and conversation.

The patients are discussed in the order that they appear on the list. However, it is the consultant who tends to dictate the pace of this conversation. They will extend the conversation if necessary or shut it down equally as quickly. For example, during one conversation of a patient with high support needs, discussion extended into a larger debate on the seemingly unclear criteria and how there were inconsistencies as to who might qualify for health or social care. This determines who might pay for future care; whether it is the health board, social services or the individual themselves. After discussing appropriate housing for a patient decided to be under the criteria of social care, Joanna (Consultant) brought talk to a close by saying "*we don't get involved in that as it will run and run.*" Housing is notoriously difficult to organise for patients and one of the main causes of delay in terms of being discharged from the hospital. It is often an area of great frustration for staff acting as key

workers. On this occasion, with no tangible outcome looking likely, the consultant removed the staff from responsibility and opted to move on.

Sometimes a more experienced member of staff, often the physio, will make attempts to hurry along the conversation by announcing the name of the next patient on the list whilst talk of the previous patient is still ongoing, if they felt that they had debated the previous patient for too long. However when this happens, the consultant will normally retake control of the conversation by intimating that they too are ready to move on or ignore the interruption as they see fit. When an individual is discussed, it begins with the consultant announcing their name, followed by a question or statement. More than just providing surface information, this statement gives the rest of the staff an indication of the configuration, 'patient' or 'person', which the consultant is assuming or, at the very least, yearning for. Consider the following field notes from a meeting:

*The next patient discussed was David who was due to come onto the ward today. He was known to several members of staff from being on a ward at University Hospital. Initially he was described as "emotionally labile" and "prone to become distressed". However, as these notes were being taken down, Joanna (Consultant) highlighted that it is highly plausible that he is possibly manipulating staff, especially regarding his tracheotomy. She goes on to say "There is no sense to it. It's a controlling thing."*

In this case, a patient (David) who had yet to be admitted onto the ward was already being configured where his position of 'patient' is being undermined and questioned. He is described as having tendencies to not perform 'patient' appropriately with the ward sister present jokingly adding, "well there will be no pandering on ward 8 then." By dismissing some of his emotional and behavioural issues as something which he chooses to adopt, displaying symptoms which the professionals do not expect, the patient was already being positioned to potentially be configured as 'person', the category needed for discharge (or 'disposal'). Despite the configuration of 'person' being the dominant discourse here, this is not a straightforward dichotomy. It can be fluid and negotiated (Nochi 1998). For example, after David was suggested to be controlling by the consultant, Sandra (physio) highlights that "this is understandable and he is holding onto the one thing left he can control." Sandra was offering an alternative interpretation to the narrative that had been given to ensure that a category of 'patient' was not abandoned too quickly.

Most individuals are figured as patients, especially on initial arrival or when there is a change in circumstances and these individuals are considered with sympathy and a duty of care. There might still be some additional background information given which gives an underlying prediction as to how the healthcare professionals believes the stay may unfold or to justify the reason that the patient has been categorised as such. The following extract is an example of this. It is taken during a discussion of a new patient in her early twenties named Violet, illustrating how the relationship between the parents and senior professionals have helped to configure the individual as 'patient' - even to the point that this relationship overrules another professional opinion:

*Joanna (Consultant): Violet is ticking along isn't she? The parents are very sensible.*

*Katie (OT): They want a self-propelling wheelchair but I'm concerned that she (Violet) is impulsive.*

*Joanna explains that she feels this is a risk worth taking as Violet is in the middle of the ward so people are around most of the time to observe her.*

*Laura (Psychologist) is putting in a "traffic light" system so Violet knows what speed is suitable in what place when she is in the chair.*

*As a concession to the OT, Joanna informs all of the staff that they can tell Violet that the chair can be taken back if necessary. However, at the same time, Joanna reminds the group that "we want her as independent as possible."*

*Katie explains that the concern the OT's have is that she will lunge into her chair from her bed.*

*Joanna: Has she done that?*

*Katie: No.*

*It is decided that a wheelchair would be issued with certain constraints put in place. (These constraints are not made specific).*

*Katie agrees with this and tries to emphasise that she is "all for anything that leads to a successful outcome," but she had been professionally obliged, even pressured by her department, to report these concerns.*

Here, despite the concerns of the occupational therapist regarding the safety of using a self-propelled wheelchair, the consultant has used other evidence to configure Violet as 'patient', such

as using the statement that the parents are “*sensible*”.<sup>11</sup> Joanna allowed this configuration to overrule the counter argument. In order to back up her position she played a trump card, a reminder that it is the work of the professionals to make people better. As a junior professional, it is very difficult to argue with this position when it is expressed by the consultant. Violet, as such, is deemed worthy of the configuration of ‘patient’. This leads to the OT having to emphasise that she understood and even agreed with this, in case her previous protestations had been misrepresented to suggest that the OT felt Violet was unworthy of such a category.

Once the position of the consultant is made apparent, accounts are invited from the various departments. This is not necessarily in any organised fashion; some departments may have no contact with the patient but will listen in anyway. The key worker for the patient may have significantly more to say and may even temporarily lead the conversation. This information can reinforce or contradict the position set out by the consultant. The following is an example of reinforcement when there is a movement from ‘patient’ to ‘person’:

*First on the list was Leslie and his discharge date was discussed. “He wants to go in May. He told me,” Many around the table (ward sisters, OT, physio and administrative staff) smirked or sighed at this. Angela (Consultant) says, “well he is very bad cognitively because he did worse than Geraint Jones in certain tests.” It was agreed that this indicated poor cognitive skills.*

*It was suggested that the family think he is better in certain company than when in a hospital, clinical setting. This is responded with “They just want him cured,” and it was agreed from representatives from all departments that they were a very difficult family to work with.*

Despite cognitive tests being used to show that the patient (Leslie) cannot be trusted, what seems to be equally, if not more, important is that he had not done enough patient work to be held on medical grounds. Leslie was giving instructions to staff as to when he thinks he should be discharged, rather than the other way round. Comments surrounding his family followed this narrative with their

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<sup>11</sup> Sensible is a word often used by professionals to represent all manner of things. More often than not, sensible tends to suggest that the parents perform their role well such as following advice, attending meetings etc. (they are response-able) and blend the correct level of concern and interest with an agreement with the advice of professionals.

explanation for his poor cognitive test being interpreted by professionals as further evidence of a non-trustworthy performance.<sup>12</sup> There was no attempt made by any other professionals to defend this categorisation and when I returned after a two-week absence, the patient had been discharged.

Non-medical factors can play a significant part in configuring the patient. This can be a particularly powerful strategy to use. For example:

*Angela tells the group how, "The family are financially crippled by having to travel down to see him. There is no reason why he needs to be here and we shouldn't be keeping people here if there is no good therapeutic reason to do so especially if the family want him closer to home."*

By "therapeutic reason", it can be assumed that Angela is referring to physical benefits of the individual having immediate access to services such as physiotherapy or occupational therapy. These are then downgraded in favour of the wishes of the family which are brought into focus as they are aligned with the wishes of the consultant. Therefore, the consultant can be seen to be backing their concerns. This is a very powerful emotional tool which one could struggle to argue against. The subjective interpretation of other staff as to the possible gains from staying in hospital are now not just being judged against whether they produce results, but also whether they are a risk worth taking in the knowledge that the family are struggling with this arrangement. If the patient was to stay in hospital, it would only exacerbate this hardship so discharge is now positioned as even more beneficial. Similarly, the husband of a lady named Betty had concerns that there is too much delay in her discharge. This was again seen as a fair comment and one that should be brought into focus. Rather than be defensive of his complaint, it was used as a driving force for speeding up discharge.

When the information reinforces the configuration of either 'patient' or 'person', the conversation often shifts quickly to the next individual on the list. However, if there is some discrepancy or contradiction, the consultant might then re-configure the information given to them in order to maintain the category that they have originally suggested. For example:

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<sup>12</sup> It is quite common for an individual with ABI to perform tasks better and score higher in cognitive tests when in a familiar environment. However, in this instance, the configuration of person had been made and therefore, their comments were interpreted within this context.

*Angela: "So what does she need to go home?" Sandra (physio) and Mark (OT) suggest they would like a little more time to assess movement. Angela: "Is it functional walking that will actually help her?" Sandra (physio) explains further between the three of them (inaudible for the rest of the meeting participants). Angela: "So she'll be here in three weeks then." Angela announces to the rest of the group who have begun to talk amongst themselves that discharge will be put back from 30.04.13 to 20.05.13.*

The discharge date was put back but the position of moving to 'person' was maintained with a definite discharge date kept in mind for the rest of the group. Even then, Angela wanted further evidence that this delay was worthwhile. The fact that Sandra had to make an appeal, doing this quietly to avoid embarrassment, shows how aware she was that moving a configuration is very difficult to do and this needs to be negotiated carefully.

Sometimes, the case to configure the individual as 'patient' can seem quite compelling but the consultant, with sufficient support, can continue with their chosen categorisation of 'person' by allowing certain information to be privileged whilst relegating others. The following field notes were taken in one meeting:

*Head nurse: I'm worried about the health board not letting her go home. I'm worried about her very high interventions record.*

*Angela (first Consultant): Well it's something the husband has always fixed on and that's never changed.*

*Head nurse: Well we didn't have a "best interest meeting" at the start and we should have.*

*Head nurse discussed concerns about the 24-hour nature of care and the patient being incontinent when the children get home from school. The mother's bed would be in the living room.*

*Joanna (second Consultant): Don't worry about that.*

*Head Nurse: I'm not worried.*

*Joanna: You are worried.*

*Angela: Husband is not stupid. He knows what the situation is.*

A "best interest meeting" is a chance to arrive at decisions where it is agreed by all parties, usually healthcare professionals and families, as to what would be in the best interests of a patient who lacks capacity in the long term. Despite the nurse feeling that this meeting should have taken place,

the consultants repositioned her concerns to that of trivia and her evidence was disregarded. Again, the family's attitudes are brought into focus in order to add weight to the configuration, leading to the patient's disposal from the setting.

On rare occasions, the case put to the consultant can be so compelling that they find it untenable to continue to figure the individual as they expected. On these unusual occasions, the consultant uses it to highlight the importance of these meetings; evidence showing that they are flexible, open and reasonable. On other occasions, they just have to concede. An example of this is when the group were discussing the discharge of a patient named Mandy:

*Angela (Consultant): Mandy had no insight at all but it does seem a little better this week although I'm not sure she had a better day yesterday.*

*Mark (OT): She had a flash of insight and then she forgot it 10 minutes later.*

*Angela: She is being discharged home to mum.*

*Mark: Mum has early stage dementia.*

*Avril (Dr): Maybe we should start listening to her (Mandy).*

*Angela: It's early stage dementia though.*

*Ellen (Speech and language therapist) reaffirms that insight is terrible.*

*Angela: We're getting a lot of the "I was like this before; I'll be fine when I get home."*

*After further discussion it was felt, "This is going to be a nightmare of a discharge."*

This patient, who is deemed to have no insight (awareness of their own difficulties and limitations deemed the most significant barrier to recovery), is being discharged home to a mother with dementia. Angela initially tries to downplay the significance of this but when the poor insight is brought up a second time, the argument is unsustainable and she is forced to reconsider. However, even at this stage, she is only going to concede that this case is particularly difficult, possibly in order to save face (Goffman 1955), in light of what appears to have been a mis-configuration. By describing discharge as "*a nightmare*", she is also deflecting attention away from the process whilst predicting an unsatisfactory outcome, from a medical perspective, as a result of this change in configuration.

In extreme cases, the individual can be seen as a lost cause with regard to them having any chance of being seen as anything other than a person who should not be in the hospital. This differs from an individual who has been re-categorised to 'person' after it was felt 'wellness' had been achieved. In

this instance, the survivor is deemed problematic as well as undeserving. This can often be when difficulties such as challenging behaviour, a difficult family or when continued issues (e.g. poor motivation) lead to the individual not adequately performing their role of 'patient'. This can also happen if staff feel that the individual has not responded to treatment, has made requests for treatment which are deemed unnecessary or they feel they were misallocated the patient in the first place. In those instances, the staff might take it in turns to provide evidence as to why that person is unsuitable. The more experienced staff seems to have the tacit knowledge to know when this will be deemed acceptable:

*When asked about Nicki, an OT describes that she seems a bit perkier. However, it is then mentioned that she creates loops where she asks fellow patients and professionals to do something for her. If they are unable or unwilling she makes them feel as though it's their fault. Joanna (Consultant) felt this was unacceptable.*

A discussion follows where it is felt by all that Nikki's initial admittance to the hospital was inappropriate. A private hospital specialising in mental health issues is felt as the best option for future discharge because she would be too much strain for the parents to deal with at home. It is felt that this will potentially cause an issue for Nikki who does not want to leave this hospital:

*Joanna: She is not going to like being told she is going to leave hospital but we're not putting up with it. She's not going to live in hospital and at the moment she is living in hospital.*

*Her personality disorder is quite severe...We won't talk about her feet. Ignore her feet. If you pay attention to it then it reinforces the "I'm disabled, I'm a bad person, label."*

*Head nurse: Can she walk again?*

*Joanna: Yes.*

*Sandra (Physio): We fell out last week because she's not wearing her orthopaedic shoes. She has got some shortening though.*

*Joanna: She wants to be disabled and see herself as a bad person. We have said to her, if you had a spinal injury or were paraplegic, you'd be out by now. Cognitively she is normal. Every time we focus on and explain to her about leaving there is some 'fall' or 'incident'. We haven't anything for a week or so now so she might be getting the idea that we won't believe her when she makes up stories...So we are making slow progress.*

Nikki has well established psychological issues which are openly vocalised by professionals. However, in this instance, the mental illness is used as evidence against her by being relegated to symptoms that should not be considered relevant for her rehabilitation (and even that they are holding her back). Nikki does not match up to the expectations of patients on this particular ward. She is 'living' in hospital yet living is what people do; recover is what patients do. Staff feel that she has been misallocated. Nikki is difficult to work with and staff felt the best course of action, accordingly, is to 'dispose' of her as quickly as possible.

In another instance, there is a patient named Lucy who is gradually moved from patient to person as the meetings progress. Initially, the consultant makes statements such as *"I'm concerned that with her we are making one step forward and five steps back."* However, relatively rapidly, over the course of a few weeks, this rather conservative style of assessment becomes less prominent with the entire diagnosis called into question:

*Angela: Don't forget this is a girl who spent the last five years of her life without leaving the house.*

*There was then more discussion as to the definition of narcolepsy. This is a term which is used by several professionals around the table each time this patient is discussed and each time, the neuro-consultant advises caution when using the term.*

*Angela: I would be very dubious about putting another medical label on it.*

Others also then offer anecdotal evidence and opinion:

*Mark (OT): She got up and walked around the ward and asked the nurse not to tell anyone that she had been up and walking.*

*Rhiannon (Ward Sister): Mum and Gran took her out and when she got back, Mum said that she had stood for a short while and she said, "No I didn't."*

Initially, some attempts are made by other staff to keep the category of 'patient' alive. In the instance above, the psychologist suggests:

*Caroline (Psychologist): She got told off for going over to a patient that had been crying out. So there is some confusion as to whether she is concerned that she was told off for walking around unaided...It's very interesting because we have been doing a lot of work around mind*

*and body which has been very interesting in her case as she sees them as very separate.  
Maybe as we begin to link the two it will help her.*

However, eventually this battle is lost and as the week's progress, more and more stories unfold and when her name comes up, members of staff take it in turns to share their story:

*Physio are asked how things are going with Lucy.*

*Physio: Always so tired.*

*Mark (OT): She needs to get up.*

*Angela: She can do it at the weekend which is maybe when she doesn't have to be performing.*

Eventually it comes to a head as this larger extract shows:

*Angela: Lucy. I don't know what we are doing with her. She seems to have returned to her bed to the point where she won't take her T shirt off and she is asking nurses to cut it off. She's getting friction burns by staying in bed.*

*She is lying prone and seems unable to lie on her side.*

*Victoria (Psychologist): She is still having suicidal thoughts. She has seen Caroline (another psychologist - not present) who is requesting that she doesn't have hot food so it doesn't land on her face. (She is not sitting up to eat.) It is also requested that she has a plastic mirror so she can see her food. (Plastic so that she does not have a means of attempting suicide.) It seems that this was generally viewed with scepticism.*

*The response to these requests was that a discharge plan should be recommended.*

*Angela: Just get on with it (discharge). She has clearly gone backwards as she is back on a large amount of drugs again. And in light of recent events, the mum and gran are not doing best for her. I mean who lets their daughter stay in bed for no reason?*

*Mark: But they think there is a reason: the Schuman's disease (said sarcastically).*

*Angela: Yes. This is a limiting illness which most people just get on with it.*

*(Mark agrees).*

*Angela: I think she needs psychological help as does her mum and gran I think. She now wants cold food which in this place I imagine would pretty much consist of sandwiches or salad.*

*There was concern expressed by Mark that by making these changes the staff are pandering to Lucy by treating her as if she cannot sit up.*

*Angela: Well she won't waste away. (Laura is deemed overweight) (People smirk to each other). She has plenty of supplies shall we say. (People laugh). Maybe a few days on salad is no bad thing.*

The healthcare professionals discussed how Lucy has not suitably taken up the responsibility to perform 'patient'. Throughout the narrative, words are used to express this directly. She is accused of performing being ill (malingering) and the notion that she is less ill on weekends is used as evidence to prove this. By using terms such as "*pandering*", even the conduct of care is seen as a negative action which should be discouraged. Indeed, Lucy and her family are not felt to be 'response-able' (Latimer 1999). As described in chapter two, by not being response-able, I mean they are not deemed to be 'doing' the social appropriately. They are not fitting in and getting along with the 'moral forms' (Garfinkel 1967; Latimer 1999) of the setting which involve deferring trust and expertise to the professionals. Not only is this disruptive to the medical ordering of configuring Lucy as 'patient' but it is also disruptive to the social ordering of the setting. Over time, this poor performance by Lucy has worsened in the eyes of the professionals, exacerbated by a family felt also to be not performing their role adequately. Lucy, as such, has become a scapegoat, a benchmark of 'bad patient' against which other patients are judged.

At various points, it is felt that it is important to realign the overall position to that of caring. Again, this is often led by the consultant who will make a statement which will provide some defence for the individual who, by now, is a lost cause. In Lucy's case, for instance, Angela says, "*I feel sorry for her actually*". This is immediately supported by the ward sister, Rhiannon, who confirms this is a "*terrible situation*".

Occasionally, this repair work (Goffman 1959) is performed by another member of staff. This could be embarrassing for the consultant as it can act as an indicator that the narrative lost sight of the caring principles they are all supposed to embody. In such cases, the consultant might act quickly to reclaim their position and agree, much as how Rhiannon did above.

This work may also be necessary when, on some occasions, the consultant makes a comment, and it is not reciprocated by other staff. If this happens, they might back track in a manner that does not undermine their position. The term "*bless him*" is very useful at this point as it softens the last

statement they made or changes its meaning from one which can be viewed with a hint of sarcasm to one which is a factual statement. For example:

*Angela: The husband was also flapping about whether she will be discharged on the discharge date regardless of whether everything is in place...He is a bit stressed, bless him.*

By saying “*bless him*” after making a statement, it does not necessarily mean that the consultant changed her view. However, by using this discursive resource, it shows an acceptance on the part of the consultant that they will get nowhere in pursuing her original position. This is then performed in such a way that does not overtly embarrass or undermine their position.

### ***Discussion***

Having discussed how the MDT meetings are used to reinforce configuration of the individual, I now consider the importance of this site in understanding the wider cultural practices involved in organising ABI within biomedical discourse as well as considering the additional value of the meetings from a sociological perspective.

By taking the disease as the point of focus, rather than assuming a more holistic approach, biomedical discourse begins to compartmentalise outcomes of ABI in order to understand them. Success normally follows a trajectory (Hannigan and Allen 2013) by moving from illness to wellness, measured through technologies such as improved scores in validated tests and completion of specific goals. Overlaying this are managerial principles, also moving away from care at the bedside towards measurable outcomes such as throughput of patients and availability of beds (Allen 2015). In ABI, here is a group of individuals where this discourse does not fit particularly well or, in some cases, at all. The meeting plays a formal part of the process of re-figuring the individual as best as possible in order for them to fit into the medical discourse. The perceived movement of illness to wellness has to be negotiated with targets and scores used to provide a framework to show this movement is taking place. These meetings attempt to achieve this with the various actors involved coming together to ensure those regarded as ‘patient’ have recognisable, achievable outcomes.

Organisation and logistical considerations are one reason why this work is important. Sociologically, it is also important in order to replicate relationships between the professional and patient alongside recognised grounds (Latimer 1997). As discussed, those where the outcomes are unclear become

problematic and such patients need to be 'solved' (Berg 1992). A biomedical framework can be ill fitting and, against such a powerful discourse, it is the patient that needs to be 'disposed' of. This meeting is a vital component in achieving this work. Through the accomplishments of these practices, the professionals are understood to be performing 'good medicine' (Berg 1992). Good medicine, however, does not necessarily mean a 'good outcome' for the patient. As shown with Lucy, the meeting played an important role in de-legitimising her as 'patient', thus rendering her unsuitable to remain in the setting (Latimer 2000).

The consultants in particular are caught in a juxtaposition between the individual needs and wishes of the patient and their family against the overarching policies and targets that are set for their everyday practices and relations. Therefore, a different type of ethical arrangement is needed in order to configure and to allow the flow of patients to take place (Chambliss 1996). If this was not established, the hospital would be unable to function. In increasingly pressurised situations, with resources scarce and demand high, decisions have to be made as to when a patient leaves the hospital, when certain services are withdrawn or whether some services will be available at all. As discussed, configuring the patient plays a vital part in this. The meeting, therefore, not only allows a suitable environment for this configuring work to be done but allows for a deemed vindication of decisions to be accomplished. To use Latimer's (1999) interpretation of disposal, the accountability is allowed to shift from the professional to an 'other'. In order to reconcile this, a different set of ethical rules and expectations are required to what might be considered in wider society. Unlike most other settings, the concept of life and death, a fundamental yet largely hidden component of human existence in the UK, is dealt with on a daily basis by healthcare professionals. It is necessary that in order for staff to operate, a particular moral conduct and practice of organising is developed (Chambliss 1996; Garfinkel 1967). This not only allows the healthcare professional to function but allows for the necessary organisation of the hospital. Illness, death and dying become part of routine, of the everyday. To allow this social world to position death as mundane means to disassociate ones ethical foundations between work and the outside.

There are times when life-changing decisions need to be made. The hospital is required to have the necessary organisational capacity to ensure that this can be achieved. As a result, the organisation is deferred to as the overall decision-maker in order to take responsibility away from the professional. This is an important tool when it comes to disposal of the patient. To withdraw a service from a patient requires ethical decisions to be made and often these may be against the wishes of the patient or family members. Having a system where organisation, responsibility and accountability

can be deferred away from the individual to the process, allows the decision-making and the overall process to continue. The MDT meeting forms a key component of this. Ethical considerations that might be seen as important outside hospital can be brought in and out of focus as needed. It can potentially free professionals of any guilt as they can feel secure that they had the opportunity to give their opinion and information correctly. In such accounts, any decision was made with all of the available information present and even if individual staff members disagree with the decision, they know that the processes of the hospital organisation play a key role in taking the final decision out of their hands.

Many of the examples in this chapter show how the meetings reinforce power relationships within the hospital. Latimer (1997) discusses how the configuring work re-enforces hierarchies between professional and patient. This is evident here by the work undertaken by the professionals in determining the trajectory of patients, perhaps particularly stark when the decisions made mean 'disposal' from the setting. In addition to this, however, is the power relationship between professionals, making explicit the intrinsic hierarchies within the hospital set up. The fact that meetings take place in the grandest room of the hospital and even seating positions ensure that configurations of patients, at least within the MDT meeting, are given from a position of authority, namely the leading consultant. In one instance, a junior doctor arrived and there were no seats available except for the seat next to the consultant. It was usually occupied by the other consultant who, unbeknownst to the junior doctor, was missing that day. Rather than take up this seat, the junior doctor thought it would be better to find another from outside the room until she was persuaded to take this vacant seat. She was then gently mocked for not wanting to do so. This tiny action shows the deference that the junior staff initially has to the consultant's position within the hospital and the tacit knowledge they have of the hierarchical system.

What is also on show in this chapter is the privileging of biomedicine as a configuring tool. This will be discussed in more depth in the following chapter but is worthy of brief consideration here. In configuring Lucy, there are active attempts to bring a medical diagnosis into focus by those who wanted to maintain a configuration of patient (such as the psychologist). The use of the term narcolepsy is actively discouraged by the consultant who is aware of the semiotic value that such terms give to legitimising the patient. As evident from other literature (Jeffery 1979, Becker 1993), by removing medical labels, this can be a significant 'move' for subsequent disposal. As disposal with Lucy is potentially difficult as, according to the definition of Berg (1992), she is difficult to 'solve'

given there is no discernible pathology, the consultant wants to remove as many other (symbolic) obstacles as possible.

The meeting also plays another vital role which cannot be underplayed. To use Goffman's dramaturgical analogy, the MDT meeting also provides the back stage, a safe environment to enact performances (Goffman 1959). This is also very important for the organisation and repetition of hospital practices. The hospital can be a highly pressurised environment. The staff are potentially dealing with death and dying, highly stressful situations and complaints from families and patients who, by the very nature of the injuries, could be at best ungrateful and at worst threatening and abusive towards staff. It is perhaps unsurprising, then, that there is a high ratio of staff absenteeism.<sup>13</sup> As discussed in depth in later chapters, additional pressure also comes from the expectations of other professionals, family members and patients in applying a medical discourse to a group of individuals where this discourse might not apply well. Therefore, the MDT meeting becomes an important space to act as a regular release valve. It allows staff to come together and discuss their interpretations of certain patient actions, bound up within frustrations around protocols, organisational practices and a lack of resources.

This practice also allows staff to show each other that they are all in it together. This strengthens the feeling of togetherness. Sometimes, this togetherness is directed against other professionals outside the hospital who are deemed to be only looking after their own interests, family members who are seen to be difficult, or patients who are not performing adequately. Again, it is particularly important that the consultants play their part here. Showing that consultants are not immune to the stresses and difficulties of hospital life, by knowingly giving access to a back stage performance, suggests to the staff that they are more aligned with them than decision-makers external to the hospital set up.<sup>14</sup>

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<sup>13</sup> Towards the end of my field work, beds were being shut whilst there were so many members of staff absent on sick leave; 50% at one time.

<sup>14</sup> I spoke to a member of staff about this and she said that whilst she too observed how this backstage is carried out, personally she prefers to keep her backstage work for when she gets home. Therefore, in some instances, even those who know and understand the rules of the backstage choose not to take part.

The rules and structures of the meeting allow this 'performance' to take place because members of staff have the tacit knowledge to know these rules; they know what can be said and what cannot and they know the level of frustration is monitored and somewhat controlled by the consultant. There is an unspoken, underlying assumption that all staff cares greatly for the patients' welfare and they would not be working in this area if they didn't. Therefore, with that implicit assumption left unsaid, frustrations can be aired. If that assumption is missing, perhaps their attitudes and understandings could be misinterpreted.

### ***Conclusion***

This chapter has taken a small but vital site within hospital practice, the MDT meeting, and used it to map out how an individual with an ABI might be configured in various ways. It shows that even before the point of passing into the hospital setting, the individual is already being configured to aid being understood through an organisational discourse to ensure discharge as a viable option later. I have shown how individuals are discussed as part of the figuring and re-figuring process and how this is negotiated in the meeting. I have also considered how individuals who are perceived to be a poor fit might be re-configured to that of 'person', rather than 'patient', in order to dispose of them (Latimer 1997). I then examined the purpose of these practices, particularly considering how this works within the overall management and organisation of the hospital. From understanding why individuals may be configured in a particular way, the following chapter explores how this is accomplished in other forms considering the process and implications of medicalising and, as importantly, de-medicalising the patient.

## Chapter Five: Medicalisation/De-Medicalisation of patients

### *Introduction*

Having established how a patient might be 'configured' in order to ensure they are 'solvable', this chapter considers how medicalisation is accomplished as a process for achieving this in more detail after ABI. Using the concept of medicalisation as explored in chapter two, I discuss how medicalisation is important for the professional in configuring the patient and for the patient in performing patienthood 'successfully'. Drawing upon field notes and interview transcripts, I consider how medicalisation is bound up in the social, brought in and out of focus and used in conjunction with other categories in order to 'read the patient', marking them as appropriate or not. I explain how medicalising and de-medicalising the patient can be problematic for the individual's identity, causing a site of conflict between professionals, patients and family. Finally, using a case study of two ABI patients, I consider how the principles of medicalisation can play a key role in configuring the individual, influencing the trajectory of the patient narrative both in configuring the patient and affecting the options made available to them in the rehabilitation process.

In what follows, I show how the identity of the patient plays a crucial part in assisting the professional to configure them. In particular, the manner in which the identity is displayed within the setting is crucial. As the individual must perform 'patient' in order to be configured accordingly, the interplay between 'performance of patient' and the resulting categorisation of them as legitimate or illegitimate, good or bad patient, suitable for rehabilitation, unsuitable for rehabilitation is critical.

Our understanding of medicalisation is vital when you consider that the main avenue in the UK for assistance of the sick is the NHS, a public resource considered stretched to the point of breaking, particularly in mainstream media accounts. Discourse from NHS literature suggests that the individual is expected to only look for assistance when all other avenues have failed. Even then, they must be legitimated. This process of medicalisation, whilst contested, is very important in allowing the individual to 'pass' into the medical domain. Individuals and communities are encouraged through societal norms to behave in a way that keeps the likelihood of any interaction with sickness, and therefore health services, to be kept to a minimum. Many of the controls which the State enforces keep the population away from accessing this service. The GP is an obvious example of this, acting as a gatekeeper for the individual to access further intervention with the health care system.

In short, it becomes an individual responsibility to look after oneself in order to perform 'good citizen.'

Changes in technological and organisational practices has meant a closer examination of illness to the point where there are increasingly porous boundaries between what is considered in and out of the realms of biomedical intervention. The highly complex, nuanced and varied outcomes of diagnoses such as acquired brain injury (ABI) mean that there can be some considerable negotiation in understanding outcomes and what counts as medical problems (which need to be acted on) or not (Bowker and Star 2000). Diagnosis and symptoms become individualised with issues being medicalised in certain circumstances and not others. Often, various resources, such as scans, family members, space and other materials will be used or discarded in order to justify such decisions.

Importantly, in medicalising an issue, a medical account is given of a particular phenomenon. Specifically, this is achieved by incorporating different technologies and actors which are drawn upon to make the 'illness' visible (Foucault 2000). This, in turn, isolates the issue. For example, the use of an MRI scan allows the brain to be considered as separate to the individual, an 'object' to be worked on and fixed. It can show areas of the brain that have been damaged. The area highlighted as damaged might be thought to control behaviour or emotion. Understanding the scan, and therefore the brain, in this way then transforms behaviours in the patient into problems; illnesses that can be addressed. This allows the intervention of specialised professionals such as neurosurgeons, consultants and physiotherapists to each perform their specialised role. This exposure to the medical gaze (Foucault 1973) creates information which can then be configured and interpreted, reducing the illness into a series of symptoms which can be considered as measurable scores and results. This evidence is crucial for the professional in the configuration of 'patient' as it both legitimises the illness as a collection of measurable symptoms and provides a marker in which wellness can be judged. These markers could come in a variety of presentations including a score, a threshold of pain or a shadow. The incorporation of the professional actor here is crucial as they have learned the expertise to 'read' these results in order to make judgements as to what course of action to take next. Biomedical charts, scans and reports give the suggestion that this is accomplished using an objective, scientific rationale, free from subjective analysis and interpretation. As already established in chapter two, however, the notion of total objectivity here is questionable and this will be explored further below.

### ***Medicalisation brought in and out of focus in order to (de)legitimise 'patient'***

The initial configuring of 'patient' is evident as early as the initial admission meetings on the neuro acute ward of University Hospital when a professional is providing details to their colleagues. Again, the meeting is usually led by the consultant who sits at a desk at the front of the room with more junior staff forming a semi-circle around her. This sets up the 'stage' from which the consultant can speak. From here, she is able to access a computer which displays images of brain scans. The conversation is largely in the form of a question and answer session with the consultant asking questions for the various members of staff who occupy the ward more regularly to either answer or find the answer. This time limited space exposes the factors which the professional feels are vital in configuring the individual. It is here that different issues are medicalised (or not) by bringing them in and out of focus. Most often, there is always a blurring of medical and social factors but subtle adjustments in emphasis allows the professional to make clear where they feel the individual is currently positioned, much in the same way as this is done during the MDT meeting in the last chapter. Frequently, the initial introduction is the name of the patient followed by the cause of injury. A simple few words can then begin to place the patient within a certain moral configuration. Almost immediately afterwards, technology is deferred to in order to configure the medical response. The following field notes were taken during an admission meeting:

*Malcolm Dublin (Patient)*

*Ward Manager (WM): Fell over after leaving the pub having had one too many.*

*Consultant: As you do.*

*Reported by the nurse as doing well. He has good insight.*

*The scan is put up on the screen but not really referred to.*

*An immediate discharge plan is considered which involves a referral to the charity HeadStart.*

*Darren Evans (Patient)*

*WM: Darren injured after climbing a 7 ft. gate for some reason.*

*Consultant: This looks like a very dodgy brain.*

*The consultant feels this doesn't marry up to the information being presented and indeed it transpires they are looking at a scan of a different Darren Evans.*

*Howard Timms (Patient)*

*Ward Manager (WM): Lives alone. History of falls. A bit doddery.*

*Consultant looks at his scan: Ahh bless him. Is he on Warfarin?*

*WM: I don't know sorry. I don't have his notes.*

*Consultant directs staff to find out: Why did he fall and was he on Warfarin?*

In the first example, the words *“as you do”* are used ironically by the consultant to align herself with the culture of the patient whilst, at the same time, recognising it as an avoidable injury. This in itself would not warrant the individual to be deemed illegitimate but the narrative given by the staff from their notes, even at this early stage, was sufficient to re-configure this patient as a non-medical ‘person’ rather than a medical ‘patient’. The scan was not used to medicalise the patient so discharge became an available option.

In the second instance, again we can see some form of moral judgment in the Ward Manager’s phrase *“for some reason”*, which emphasises the needlessness of the injury but also suggests resignation that this is typical of so many injuries she sees. Displaying the wrong scan means that the configuration of the patient ends here, although it was interesting to see that the consultant used the word *“dodgy”* to describe the brain scan. Firstly, this shows that she has the expertise to see how the scan does not meet her expectations from the story she has just heard, causing her to doubt what the scan is saying. Secondly, this description moves the brain out of the scan. It is no longer a series of pictures, shadows and numbers but an artefact in its own right with the capacity to have values attributed to it. The informal use of the word *“dodgy”* moves us away from the professional discourse to one of personal interpretation and subjectivity. It is also in keeping with the ‘unprofessionalism’ of putting up the wrong scan!

Lastly, we see that the third patient, Mr Timms, is configured as elderly. He is described *“as a bit doddery”*. This is a word most commonly used when referring to elderly patients rather than other patients who have mobility issues and can potentially configure Howard as a social problem rather than a neuro patient, less deserving of a place on the neuro ward (Latimer 2000, Hillman 2014). *“Bless him”* excuses Howard of any blame and holds the potential for him to be legitimated as someone in need of help (just not here). The anticoagulant Warfarin is immediately brought into focus as an explanation for the falls in a way that shifts Mr Timms away from ABI and into a different medical category. This helps dispose of the neurological units’ responsibility for the patient (Latimer 1997) and so when it was unclear whether it was a factor to be considered, not only was it retained as a possible avenue to explore, but it became central to the future of this patient.

In these examples, we can see that the social, moral and medical are drawn upon as grounds in various ways. The manner in which the injury was sustained is particularly interesting. There is no evidence to suggest that this will influence the care that the patient is likely to receive for better or worse. In fact, a clear definition of how the injury was received is often welcomed. It allows the patient to pass the first test as to being medicalised and configured as 'patient'. At this moment, a clear understanding of the injury at least means that the professionals have a place to start. The moral judgement comes soon after. The comments, such as ironically saying "*as you do*" and "*for some reason*" shows the staff are making each other aware of the clear delineation they see between preventable and non-preventable injuries. However, in context, the comments do more than that. The fact that professionals recognise the avoidability by which some injuries occurred before immediately moving onto how they will treat the patient shows that they are performing the role of 'good' professionals. Their interpretation of an injury as 'avoidable' bends the sick role rules in the configuration of patient, but their willingness to carry on regardless shows they 'care'. In bringing it into focus, it also reinforces the team ethic of the group. They are all aware of the frustrations of this work, but being in it together can make it more palatable. However, it may inform staff thinking as to how successful the stay in hospital might be but only alongside the scans, notes, medication and other actors which all play a fundamental part. This also makes 'disposal', moving the moral responsibility away from the staff (Latimer 1997) a more viable option later.

### ***The importance of visibility in medicalisation (For Professionals)***

I have considered how medicalisation is brought in and out of focus by the professionals, alongside social and moral considerations in order to frame, position and legitimise the individual. I now pay particular attention to how technologies, such as scans, are employed and how they might be used in order to accomplish the medicalisation and legitimisation of the patient (Pickersgill 2013).

The medicalisation process and therefore legitimisation can usually only happen if it is accepted that the symptoms are visible. Sometimes the professional has to work harder than other times in order to do this. For example during the ward round meeting at the University Hospital, scans would be available for most patients. The relationship between the professional and the technology is an interesting one. It takes a high level of skill and expertise to be able to 'read the scan'. On my first visit to the meeting, I have a chat with Tamara, the outreach worker from HeadStart. She regularly attends this meeting:

*Tamara tells me that she finds this meeting the best part of her job as she really enjoys seeing the scans. In particular, she explains that having been in post 28 months, she loves that she can see the scan "...and go oooh as I can see that something is wrong as I have learned to read the scan." She is proud that she has the tacit knowledge to interpret the scan in the same way that the other professionals have learned to do it.*

Tamara feels that the scans are important, even if they do not add much to the conversation. It is a sign of expertise to be able to read them. She has learned to read the scans by attending the meetings and observing how others do it. When a scan is interpreted as particularly bad, comments will be made such as *"even I can see that"* by professionals who do not feel they have the expertise to *"read the scan"*. The results of the scan are also seen as markers of legitimisation, a role designated only to the experts so being able to use the tools of legitimation elevates ones prestige (even if it is only self-prestige) as they have an important level of expertise. If they have this level of expertise, they have what is required to medicalise the patient.

However, even those that are expected to 'read' the scan can have trouble. For example in a discussion between the two consultants, in front of the other staff:

*The scan is referred to and there are multiple interpretations to what a dark patch might be. It is thought that it might be excess glue or evidence of the coil.*

*Angela: It's not normal. You don't normally have a big blob.*

*It is decided that it might be due to high blood pressure.*

*Angela: Poor man.*

The scan informs the professionals that something is wrong but a variety of causes are ruled in and out: glue, an inserted coil or poor blood flow. This patient was initially socially positioned by the staff, described by the consultant as *"the Frenchman who's a bit odd"*. He is a suicide risk and, using the scans, he is deemed unsuitable to be transferred to the rehabilitation hospital due to ill health. It is then decided by the consultant that social work needs to be involved... *"because it won't be good if he goes and kills himself after weeks in hospital"* (once discharged). The scan is used as evidence that this patient is too ill to move to the rehabilitation hospital but, possibly due to the uncertainty surrounding the interpretation of the scan, discharge elsewhere is not ruled out. Here, they have effectively 'disposed' of the patient this way (Latimer 1997) with the staff not wanting to be held responsible for his actions.

The scan is usually shown on a plasma screen during a meeting whilst ongoing discussion is taking place regarding the patient. It might only be made explicit within the conversation if it reinforces the other evidence. For example, during a discussion of a young man who had just been admitted to the ward, the scan was referred to in order to assemble the clinical picture of a patient, should one be needed:

*Consultant: Mark Roberts.*

*Ward Sister: Poor man bless him...He was assaulted for his weeks takings whilst getting out of his van...It's going to be on Crime watch.*

*The scans were addressed for the 1st time.*

*It was felt that there might be a small aneurysm.*

*Ward Sister: He is doing quite well.*

*He scores 80/100 in the screening test four days post injury. In this case, this is deemed a success.*

*It is felt doubtful that he would require any in-patient help.*

On this occasion, when the patient was described to the team, it was felt that his assault was awful. This is emphasised by the use of the term “*bless him*”. The scan possibly showed nothing at all but, to legitimise the patient, he was afforded a small aneurysm. Here, the technology was interpreted to medicalise the patient although it had to work hard to do so. As this did not delay discharge or significantly change the diagnosis, it was acceptable and un-harmful to do so.

Sometimes, the scan does not match up to the evidence. In these instances, such as if the patient did not display problems that might be typical of damage to a particular part of the brain, the scan is ignored, relegated or disregarded as evidence. For example:

*Consultant (Angela) scrolls through the scan. We get to a particular slide and everyone simultaneously lets out a: “whoa!”*

*Angela: This is impressive. It is a massive bleed. The brain stem is not happy. We should be able to see the dark bit here but that is brain (pointing to a part of the scan with the arrow of the mouse) that has come down from above.*

*She describes it as an “unhappy brain”.*

*Angela: How's she doing now?*

*Nurse: She is much brighter this week. She listens to commands. She is still obviously sleepy.*

*Angela: (Pauses) There is no indication of infarct so she may be ok. How old is she?*

*Nurse: 54.*

*The team move on to discuss the next patient without further comment.*

This scan is initially identified as potentially an indicator of a very ill patient. Everyone seems to be able to see this. The consultant adds her expertise by explaining in further detail about what the different shadows may indicate. When the nurse explains that there is no evidence of this with the patient, the consultant adds a small disclaimer, *“there is no indication of infarct so she may be OK”* before looking to leave the conversation with this patient as soon as possible. The scan was not helpful here in medicalising the patient.

The examples above show how professionals position and configure individuals through a medical lens in order to legitimise them, drawing upon the social in order to accomplish this as much as the available scans. They perform vital functions of the sick role such as making the patient blameless for their injury and displaying professional expertise. It also allows the patient to be ‘solvable’. I now go on to consider how medicalisation might play a role in the patient performance.

### ***The importance of visibility in medicalisation (for patients)***

Despite many patients reporting that an ABI is better described or understood through experiences rather than a medical discourse (as described in later chapters), ABI and ‘doing patient’ cannot function in isolation. As described in detail in chapter two, ‘doing patient’ involves a complex coming together of micro-interactions, perceptions and activities within a given context, which are understood within society as being representative of the performance of ‘patient’. External signs and factors play a key role in the legitimation of being a person with an ABI. Assumptions about illness and patienthood play a part here. Part of this is the semiotic function of cultural artefacts in health and illness; in particular the significant absence of them after ABI is many cases. ABI is often considered as a hidden disability so medicalisation plays a key role in making the illness visible.

The notion of visibility is vital for both professional and patient, though the understanding of visibility and what this means, differs considerably. From a patient perspective, there can be a very powerful relationship between medicalisation and ABI. It is argued that the significance of medicalisation has been exaggerated (Strong 1979), particularly from the perspective that it has only

a one-way dimension. To a large extent, the individual has to accept or reject the label that comes with medicalisation in order for that medicalised configuration to hold. An issue, such as impulsive behaviour, can be accepted or rejected as a medical problem depending on the individuals' own relationship with it. If they decide that it is not a medical problem, this can considerably restrict the options available for them both within the medical setting and in accessing services in the wider community.

For some individuals with ABI, to have symptoms and experiences framed in medical terms was considered a positive experience. Some people, at all different stages of their rehabilitation, complained that the nature of hidden disabilities would mean that they did not have the necessary resources to make their illness visible. Family and friends would tell them that they look well and after the initial joy of their survival, and comparatively rapid improvements in the first few months, the length of time that it took for further improvements start to become a drain. Often, the prolonged difficulties are less tangible and visible with improvements more difficult to recognise. This leads to friends, colleagues and family to begin to ignore the injury, giving it less legitimation for issues that they might have previously. The ABI survivor may often be blamed for events that take place which they feel might be a direct or indirect result of their injury. For example, Glenys, now back at work, was struggling with anxiety. She reported that a colleague responded to this by saying *"for God's sake Glenys, it's been a year. Get over it"* (field notes). In another example, in an interview with Liz (a patient now at home having been admitted to University Hospital, the rehabilitation hospital and CBIT) she explains a conversation that she had with the leader of the Community Brain Injury Team (CBIT) about her husband:

*Liz: She (leader of CBIT) hit it right on the nail when I said about my husband and he said it was like "well come on it's over now let's get on with it" and it's...I do feel that with him, that it's done now let's put that aside where's my tea? Why have you done this? Why have you done that? ...No it's not over with.*

Liz feels that she has very little to visibly remind her husband that she has an ABI. As a result, she believes that he often feels that it is no longer legitimate to consider her as a 'patient'. To be able to draw on medical evidence is a shelter to the individual (Latimer 1999, 2000). Often, attending Community Brain Injury groups would provide respite from the outside world who *"don't understand"*. As the following extract, taken from a discussion at a Community Brain Injury Team meeting about fatigue shows, the individuals feel they need to set apart their difficulties:

*Paula: Tell you what I hate. When you say to someone I'm tired and they say so am I.*

*Karen: They don't understand. I sometimes have to go up the stairs on my hands and knees.*

These individuals feel all too often that their difficulties are 'trivialised' (Jeffery 1979), forgotten or compared to everyday experiences by the lay public. To be able to point to medically defined evidence as a cause for their difficulty sets them apart and legitimates withdrawal from society for reasons beyond their control. In the same discussion above, Jason comments that:

*Jason: I don't mind going (sic) here as we are all in the same place.*

By place, it can be assumed that Jason is referring to several things. He is referring to the situation of the illness career in which they all find themselves but he is also referring to place in terms of legitimation. That is, they are all in the same place of being in a fragile state when it comes to being seen as 'legitimate patient'. He can relate to others here; but more than that, he recognises that this medical space legitimates his complaints. By being allowed in this space, he is 'passing' as a legitimate ABI patient. The Community Brain Injury Team meeting is a place where the outcomes of the injury are not openly questioned; people understand each other and there is no struggle for legitimation, at least in the front stage (Goffman 1959).

An individual who 'looks well' but is not working can have a stigmatising effect. The patient might be aware of the emasculating, dehumanising effect of both being unable to work and being regarded as non-working (Engström and Söderberg 2011). Expectations of what disability is 'meant to look like' can play a key role here. Many of the patients described how they turned towards culturally defined stereotypes, using props (Goffman 1963) in order to accomplish disability when it was felt necessary. For example, Liz would describe how she would take her stick out, not because she needed it but because of what is represented:

*Liz: I do take a stick out with me and then you are visible with a stick. Like when I was wearing a patch. It instantly said there's something wrong.*

Unlike the common perception of wanting to hide the stigma to be the same as everyone else, Liz may want to be accepted but feels it important that others were aware that she is not the same. She has to go out of her way to achieve this. This differs to a mother of a young man with an ABI who,

during an interview, commented on how difficult it was for him to come to terms with the notion of disability. For her, she felt that the cultural artefacts were, in themselves, full of symbolism which inhibited rehabilitation: *“This was just something that he had to overcome but of course everything you have to put in place to keep them safe carries banners that say I am disabled”*.

Often, especially in the early stages after an ABI, the individual will find it very difficult to come to terms with their various difficulties. These can be for a variety of reasons (cognitively, psychologically or logistically) but the outcome is often the same, they find it difficult to engage with the rehabilitation process. In order to assist the individual to make sense of themselves (vital for positioning the patient as ‘solvable’), the first move that professionals commonly make is to medicalise the patient’s difficulties and encourage them to do likewise. This begins in the acute ward but is pressed in earnest during rehabilitation. To have these difficulties legitimised in medical terms allows the patient to give up some of the responsibility that they may feel for not being able to perform their identity in a manner previously expected of them. It offers a completely different construction of self; the individual is not selfish or lazy, they have frontal lobe damage. For some individuals, this movement to a medical definition of brain injury actually carries with it a large element of relief. This is because until they were medically diagnosed they had no idea why they were getting angry, were unable to hold down work or a steady relationship. The medicalisation of these social conditions provides a platform, a tangible thing that the individual and, often more importantly, the family can understand and proportion blame to. This ‘move’ (Latimer 1999), in turn, makes it easier to medicalise a set of behaviours in order to tackle them rather than view them as inherent and bound up in an individual’s identity, even if this sometimes simplifies the situation beyond recognition. Another part of this legitimisation process is that it allows, even requires, therapeutic intervention (Scott 2006). The access to this domain can come as a surprise to individuals involved who, firstly, would never have attributed feelings or issues such as low self-confidence and lack of initiation to the medical and, secondly, would not have known how to access services that might assist them. These may be services which would have likely remained invisible without the label of brain injury opening such avenues to them.

There can be problems if the individual does not become exposed to the medicalisation experience. In an example of the importance attached to having access, a brain injury survivor called Daniel spoke of having huge amounts of anxiety. Daniel lives in a socio-economically deprived area. It has a high rate of drug and alcohol abuse and, whilst he prides himself for staying clear of such habits, his relationships and experiences of those that do intimately shape his understanding of his ABI and

accompanying medical intervention. He considers drug and alcohol abuse as a failure on the part of the individual and this is where the blame for the problem should lie. These people are 'bad' not 'sick'. His ABI came as the result of the legal term 'reckless driving'. In the crash, he killed another driver which led to him spending three years in prison at a time that he might otherwise be receiving rehabilitation. He had no exposure to rehabilitation during his time in prison. As a result, this has led to a rather different relationship with his ABI and rehabilitation than that experienced by others with the same diagnosis. Daniel initially felt no sense of entitlement towards receiving help. He has no feelings of disappointment in a system that denied him access to healthcare. This is partly because he is unable to separate his punishment for the crime from the denial of the right to healthcare.

However, it also seems that Daniel was initially unable to comprehend the possible potential that receiving medical assistance might give him. He saw his difficulties as separate from the medical, as something which must be dealt with on his own, much as he understands the alcohol and drug addiction he sees on an everyday basis. His ABI had been 18 years previously and it was only when a friend suggested that he visit the GP did he begin to reconsider his anxiety in this medical context. By medicalising the anxiety, the GP reframed Daniel's understanding of it. It now felt tangible, something that could be acted upon. Previously, he had taken over the counter anxiety medication which concerned him further as he felt this was a slippery slope to the drug abuse he sees around him. When he was invited to attend anxiety groups run by the Community Brain Injury Team (CBIT), the only reference points he had to draw on were the Alcoholics Anonymous and Narcotics Anonymous meetings that his friends attended as well as some of the groups he attended in prison. For him this was still tied up with 'badness' rather than 'sickness' and it took some time for him to re-configure his issues as medical.<sup>15</sup> Once he considered his issues as medical, Daniel reported that even if he was unsure that the groups were doing him any good, the feeling that he was doing something positive about his issues was a major source of comfort. The movement of a social problem to a physical one was vital for Daniel. He described himself as an "*ex-body builder*" and this may partially explain why he understands his body in the way he does; a series of individual parts each requiring specific goals to improve. He could now see his anxiety not only as something medical but an actual 'thing' which could be isolated, worked on and fixed.

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<sup>15</sup> Laura, the OT running the session, mentioned to me that Daniel was the biggest surprise for her by the fact that he turned up every week. She had thought that the way he viewed his injury would be a barrier to his progress.

Here, I have described how medicalisation, contrary to common assumptions, can sometimes be reframed to assist the patient in performing 'patient'. I now consider how interpreting issues through this lens can be a site of conflict.

### ***Medicalisation as an area of confusion and conflict***

Inevitably, professionals do not normally come into contact with patients until after they have received an ABI. As a result, the professional attempts to build up a picture of what the individual may have been like before their injury by 'reading' the patient and by asking family members for information as well as through discussion with fellow professionals. This is important for configuring the patient and deciding whether they are allowed to 'pass' or not. Evidence that can be used to build this narrative might include the manner in which the injury was received, the behaviour of the family and the current behaviour of the patient. This will then be mapped onto other indicators such as scan results, responses to treatment and adherence to established, measurable targets.

The initial 'reading' of the patient by the professional can take place almost immediately; perhaps as early as when the patient enters the intensive care unit (ICU). Information gathered from the family can also often be gathered very early on when the family may not be in the best position to give an account. This account may be distorted, sometimes exaggerated or even fabricated. The family may report the individual in a very positive light when they may not do so in other instances. This is entirely understandable, a natural reaction one might assume if an individual is presented with a loved one who has a significant chance of dying or becoming permanently disabled. Just as powerful a motivation, the family might, even at this early stage and despite the obvious need on the part of the patient for medical intervention, automatically take on the role of ensuring the individual is configured as deserving and blameless for their injury (Parsons 1951, Jeffery 1979). They are ensuring that their loved one 'passes' as patient, especially when the individual is unable to do so themselves (Garfinkel 1967). The consultant is aware of this work and it was reported by several professionals that the views of the family are only partially used to build the narrative and is never taken at face value. Nevertheless, the patient is configured and understood against this construction of what it was assumed they might previously have been like.

The configuration of the patient will often evolve significantly during the individual's hospital stay, particularly during the relatively early stages of rehabilitation. For example, a patient named Lynda, on the neuro ward, had a shunt fitted. This is a relatively common operation after an ABI. Although it

varies, a shunt allows fluid, most likely to be in the brain, to move to another part of the body. This relieves pressure on the brain and, in Lynda's case, almost immediately, her personality changed. She became a lot more outspoken and verbally aggressive to staff. However, as this was framed in medicalised terms; a visible sign towards recovery, it is tolerated, even celebrated as the following extract shows:

*A story was told of how Lynda's brother came in. He was hitting her with a rolled up paper. She did nothing for ages before grabbing it off him and then she "bopped him on the head". (People laugh).*

*Angela (Consultant): So she can use her upper limbs in a directive fashion...Aggression possibly becoming a problem? PTA? (Post traumatic amnesia)*

*Ward Sister: Not sure. It's not been tested.*

*Nurse: She (Lynda) told Rhiannon (Ward Sister) that she was not the sharpest bulb in the pack.*

*Angela: Lovely!*

*Nurse: Which I think is pre-morbid. You don't look at people in a certain way without having years of practice.*

Whilst the staff seemed to enjoy Lynda's minor misdemeanours, they always framed it, albeit sometimes with a knowing sense of irony, within medical terms. Hitting her brother means that Lynda is physically recovering and her aggression could be a result of posttraumatic amnesia (PTA). However, we once again see the blurring of the medical and the social. As a result of medical intervention, Lynda's pre-morbid personality may be showing through. By seeing Lynda's issues as medical, they can be isolated, worked on and fixed but some of these outcomes (that could just as easily be framed as medical e.g. inappropriate comments or anger issues) are framed in the discourse of the social. By doing this, if such conduct was to become problematic later on, it could be viewed as both a victory for the medical, which fixed her so that these behaviours became visible, but also a social issue which has no place in the medical domain, therefore rendering her as inappropriate.

To medicalise her behaviour is also to legitimise it. By legitimising it, Lynda is understood differently. Her bad behaviour is almost celebrated. As the weeks pass, there are signs that this begins to change, particularly when Lynda refuses to consider her potential transfer to the rehabilitation hospital and is also rude to the consultants. She is now beginning to not fulfil her obligations of

'patient' (Parsons 1951) as she is not deferring to the expertise of professionals, nor is she making every effort to recover. Her rudeness was also problematic as it affected her performance of patient. However, discharge was imminent at the time I left the field and, whilst her behaviour was no longer as celebrated as it once was, it was felt that staff could tolerate it in the short term.

The ABI, bound up in the medical requirement to intervene, opens up the potential for behaviours to be medicalised and deemed worthy of intervention. In many circumstances, an individual without a diagnosed ABI has learned to cope with the condition with relative ease. They may feel a certain pressure to change their behaviour, or at least adapt, in order to fit in with social conventions but it is not scrutinised to such a degree since the cause of the behaviour has not been identified and medicalised. Sometimes there is confusion within the narrative as to how to configure the patient. The confusion is not so much in how the narrative is configured but regarding the tools used to configure it, such as the particular behaviours of the patient to be considered. Certain behaviours, such as anger or 'inappropriate comments', may not correspond with what the professional believes to be typical of the configuration that they have made of that particular patient, especially in regards to their identity.

Initially, especially on the neuro ward, the professionals attempt to configure the issues in medical terms. However, this can sometimes be unacceptable to family and patients who reject this position, favouring a more social basis by claiming that this behaviour is typical of the patient. This stance by the family is itself then re-configured as part of a medicalised narrative by the professionals. The refusal of the biomedical narrative by the family can be considered by the professionals as a form of denial on the part of the family. The family have either consciously or subconsciously refused to consider any suggestion that there are further deficits as part of their own coping mechanism. In an interview, the speech and language therapist (SLT) explained that all the energy and concentration by the family is put onto wanting the patient to survive and rejoicing that they have done so. This anxiety, relief and joy thus overwhelm any recognition of ongoing issues. As such, the notion that the family may be telling what they interpret to be the truth is rarely considered. The family may not realise the negative long-term impact of refusing to hold the patient in a biomedical understanding because once they are re-configured as a social problem, the patient is ready for disposal. They may feel it is in their interests to reject the medicalisation of their loved one in order to create what they see as a more accurate 'reading' of the patient. However, it is the professional's reading of the patient which will ultimately allow the patient to 'pass' and once the patient has been disposed of, it is very difficult to re-engage with the medical domain in the long term, something which may be

important but at this stage is not recognised. In the extract above, Lynda was configured biomedically but, in the meeting, social issues such as pre-morbid identity were also being considered.

Since the family can play a vital role in the configuration of 'patient', the relationship between family and professionals are often the main sites of conflict when it comes to competing discourses in understanding the patient. To emphasise this, I return to an extract from an MDT meeting used in the last chapter. It is an example where conflict with family has been ongoing and has ultimately worked against the patient. The patient was physically very able but it was felt that he had not made the cognitive gains expected in his time at the rehabilitation hospital:

*It was suggested amongst the staff that the family think he is better in certain company than when in a clinical setting. This is responded with "They just want him cured", and it was agreed that they were a very difficult family to work with.*

It is very common for an individual with ABI to be able to perform certain tasks, such as making a cup of tea, when in their own environment and in an atmosphere which they find more comfortable. Making a cup of tea is one of the more common 'tests' after ABI due to its multiple components making it a potentially challenging task. Having liaised with the patient (if deemed possible) and perhaps the family, certain goals would be set and, using a goal attainment scale (GAS), these would be measured. In the case of making a cup of tea, the task may start with the goal being to pour water into a mug and adding a tea bag. This would then be worked up into a task which in all but setting resembles making a cup of tea, possibly with adaptive technology to assist. In such instances a task as commonplace as making a cup of tea has been re-configured to become a measurable task. The family, in this instance, responded to the activity not as a series of quantifiable tasks but as a social activity, bringing in outside assumptions, such as familiarity of a home environment, to re-understand the scores and measurement based interpretation. Rather than considering the response of the family as a good sign of recovery and progress, their statement was used against them. Because the family disagreed with the medicalisation of the patient and the corresponding progress scores, their actions were labelled as deviant.

If the patient is outspoken, aggressive or 'non-compliant' (a term used by professionals to indicate a whole manner of things) then these are initially put down to being medical problems. Issues such as confusion are associated with the brain injury and the individual. However, family members will

often complain of a lack of forthcoming information given to them and the patient about the patient's diagnosis and, perhaps more importantly, what to expect and how to deal with potential difficulties<sup>16</sup>. This 'limbo' that family members describe only adds to the sense of unknowing, confusion and anxiety. Family members will also discuss how they knew very little about brain injury in the early stages and how they have to pick up what they can, sometimes using a combination of finding a particularly helpful member of staff and by seeking out literature (often from websites). For example, in an interview with a wife of a patient who had since been discharged, it was discussed that she used the internet to find information. This was prompted by some literature she received from a third party to take part in medical research. She explained to me:

*I knew he had had a subdural haematoma but I didn't know how bad that was and guessing from the research literature that it was quite severe...It helped I think when I look back at what I was told on S4 neuro, I think possibly because it was all so... Because I've got no knowledge at all and it's such a different language, I didn't really understand how serious or whatever it was...*

This extract shows that family and patients can be very confused, especially at this early stage, due to a whole variety of things (and not just for cognitive reasons). In the case above, the wife had no idea about the severity of the injury until she was invited to take part in the research which explained that she had been chosen because a relative had a severe brain injury. The term "severe" is used to categorise injuries resulting in a loss of consciousness between 6 and 48 hours alongside posttraumatic amnesia which lasts between 24 hours and 7 days. This is not a clear indicator of the long-term effects of the injury but without this information, the word severe has even more powerful and worrying implications.

The family will often try and makes sense of the situation using a whole range of resources such as websites, knowledge of ABI from television and from friends who have had what they consider to be related experiences. This can build up a confused picture of both the injury and the likely pathway. The patient, already struggling to retain information, becomes more confused which leads to greater levels of anxiety. Rather than consider the lack of understanding as potential grounds for the increase in anger and frustration, the behaviour is re-configured as either an outcome of the injury or possibly signs of a family which are not 'response-able' (Latimer 1999). The responses and

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<sup>16</sup> This is discussed in more depth in chapter seven.

performances of patients and families are key to being 'response able'. In conjunction with other artefacts, if the family are deemed unable or unwilling to behave in the expected fashion, especially if they do not defer knowledge and expertise to the professional, this undermines the individual's position in the configuration of 'patient'.

***Case study: When medicalisation is 'successful' - Robert***

So far, the emphasis has mainly been on the notion of medicalisation as a process for configuring a patient in order to determine whether they are legitimate or not. Perhaps more importantly, the significance of medicalisation means that if legitimacy is not given or is taken away from the individual at a later date, this de-medicalisation can be disastrous for the individual in regards to their gaining access to legitimation in the medical domain. I now consider this further with a case study of two individuals in the rehabilitation hospital - Robert and Lucy - one of whom benefitted from having their outcomes medicalised whilst the other, by being de-medicalised, found themselves isolated and eventually discharged from the setting.

Robert is a patient in his late 30's. He was already a long-standing patient at the start of the study although it was felt that he would be discharged as soon as suitable supported housing had been finalised. At the first MDT meeting I attended, he was described to me by Joanna (Consultant):

*"...as a heavy drinker who has since stopped who lived a highly chaotic lifestyle resulting in a serious assault by his flat mate".*

This narrative presented a very clear picture to the professionals. They were able to understand the circumstances that led to the ABI. Despite his lifestyle being described as *"highly chaotic"*, it at least meant that Robert could be easily read and his assault allowed others to easily configure him as a victim, holding open the position of a deserving patient (Latimer 1997). He had also been treated as someone who was HIV positive, although later tests revealed that this was not the case. It was thought to be his father who had misinformed the professionals of this.

Robert could be medicalised for three very clear reasons. Firstly, his physical difficulties were visible, both on the body and on the scans. During a physiotherapy session, Robert was performing a series of exercises in order for the professionals to gauge his mobility. Whenever Robert was asked to complete a task, he would do so despite it appearing that he was nervous or not keen. His first task

was to stand up from the bed without using his arms. He achieved this but without appearing confident. He was then asked to remain standing but to shut his eyes. He does this easily so is asked to continue for another minute but with his feet closer together. Again, this is achieved but Robert seemed to need to concentrate very hard. When he completed the task, he was congratulated but seemed emotionless. Later, he was given a score of 18 and informed by the physio that...“*whilst good, it needs to be in the 40’s before he would be ‘allowed’ to go (discharge) without sticks*”. When being told this, Robert again seems emotionless; the numbers seemed to mean nothing to him but form an important role for the staff to understand and configure Robert. The scores mean that for the physiotherapist, they can be seen to be isolating specific difficulties, removing them from both Robert and other difficulties he may have, into their area of expertise. They can then work on this particular issue, lack of mobility, with an improvement in score meaning a perceived improvement in Robert. The exercises do not look like walking with sticks. To the layperson, standing with your eyes shut for a minute does not represent walking at all. However, Robert is improving in these exercises and this is important. Whilst Robert may not see this, the fact that the score is gradually increasing, albeit not yet to the desired level, the greater legitimisation Robert and the staff have for pursuing this medical course of action.

The second reason medicalisation was successful is that overall Robert was seen to make significant, “*miraculous*” progress, over and above the expectations of the staff. The symptoms that were bound up in the medical were interpreted as responding to medical intervention. Joanna (Consultant) explained: “*He’s a miracle boy. When I saw him on ICT I thought he would never get off*” (*field notes*). Rather than question their own initial expectations, Robert was seen by the professionals as the best example of the system working.

Thirdly, Robert was openly compliant with what was asked of him, deferring authority to health care professionals (Pilnick and Dingwall 2011). It was easy for professionals to see that he was attending sessions and performing his role. This was backed up to a considerable extent by his father who told him to “*keep his head down and do as the nurses say*” (*field notes*). In doing so, both Robert and his father were ‘response-able’. His father had provided the staff with significantly incorrect information in suggesting that his son was HIV positive. This resulted in considerably more manual work for the staff with regards to the precautions taken when working with Robert but this is not considered problematic; the father remains an ally. This combination of everyone involved buying into the overall medicalised definition of Robert, allowed everyone to follow the same biomedical narrative that would eventually contribute to his achieving ‘wellness’ and discharge.

There were several incidences where Robert complained of symptoms which did not fit this model. When this happened, the incidences were responded to in several ways. Firstly, if an issue became apparent and it did not fit the overall medical model, it might be downgraded or disregarded altogether. For example, Robert was irritated by a rash which was considered trivial and largely ignored. During the MDT meeting, Joanna told the group just to “*keep an eye on it*”. A couple of weeks later, Robert was presented to the group as ‘well’. This was confirmed by the nurse but she added that he had a very nasty in-growing toenail and was “*riddled with athlete’s foot*”. Rather than consider these as worthy of addressing, conversation turned to generic talk about how one “*gets rid of athlete’s foot these days*”. This was from the head nurse and the use of the term “*these days*” suggested that this is was something that was very rare, something she had either not dealt with for a long time or was considered an issue outside the medical domain, not for her to be expected to act upon. This question was largely taken as one that could be ignored and the group defaulted to reminding each other what a “*miracle case*” Robert is. Nurses reported that Robert would often become “*fixated*” with his toe; this behaviour being common after ABI, but it was the toe, not the fixations, that were brought into focus and the issue was relegated as a result. If left unchecked, “*fixating*” on issues can have significant implications for the quality of life for the individual.

Secondly, when Robert showed other behavioural issues, these were reinterpreted as part of his personality and were treated as such. For example, it became clear that he had paranoia as well as a particularly strong desire for some independence and he was concerned that he would be followed when he was at his supported housing. This was brought up in the MDT meeting:

*Angela (Ward sister): He asked if when he was out he would need to be followed. I said not followed. Supervised or accompanied, but not followed.*

*Mark (Occupational Therapist): The doves in the sky will watch you Robert.*

*Head Nurse: Ah bless. (Everyone laughs)*

This extract shows that his concerns were reinterpreted as a simple misunderstanding or bad choice of words on his part. His previous narrative, described as “*chaotic*”, involved alcohol and drug abuse. It was not deemed appropriate to frame his understanding of the world with the same terms of reference as others. By talking about birds watching him, Mark was trivialising this paranoia. It was seen as another part of Robert’s identity, existing prior to his injury and therefore not worthy of bringing into focus. It might also be that paranoia was deemed outside the remit of direct

intervention that the rehabilitation hospital could provide. It was considered to be an issue that he would just have to cope with as they could only do so much.

Similarly, during a games session with the Occupational Therapists (OTs), Robert was unable to take turns, another common problem following ABI. A games session is organised by the Occupational Therapy team and runs once or twice per week, depending on staffing, in the social room which links up wards 7 and 8. There are different sessions which might focus on physical or more cognitive activities. Sessions are often devised in the morning before they are due to take place and might often change in both content and style depending on which patients are available to take part. Whilst written onto individual timetables, there is an implicit sense that the games sessions are less vital for the medical progression of the patient. Therefore, certain patients may be unavailable due to 'medical appointments' or because they are asleep and it is felt best not to disturb them. Participation is not compulsory although attempts may be made to persuade some patients more than others, especially those who it is felt would not participate unless prompted or those who are gaining a reputation for withdrawing. It is also quite often a session that is put onto a patient's timetable if it is felt that they have a bare timetable that week or if most other interventions are being withdrawn so it is included in order to give the patient something to do. Often, there are cycles where certain patients are always assumed to show enthusiasm to attend, or are invited based on prior enthusiasm. As a result, despite the sessions being available for all, it is the same familiar faces at each session. Robert is one of those faces. There are no formal assessments or measures during these sessions, but the patient is always being observed and the sessions might be used as evidence when trying to ascertain goals for a patient at a later date.

This session was organised with a loose objective of helping to improve memory. In the session were Robert, Paul, Winnie and Britney. The patients were sat in a semi-circle around a circular wooden table in order to play a card game. The session was being run by a male OT (Mark) and an OT technician (Anita). The premise of the game was to pick a decade, 60's, 70's, 80's or 90's and then list as many things from a certain topic from that decade e.g. music hits or football players. The patients had to take it in turns to think of something from the category and if it was on the list, then they gained a point. Like the tools used in most of the sessions, this was a game which could be bought in any toyshop. It was not devised with any ABI specific benefits in mind. Often, some of the categories might be considered too obscure and the answers were then abandoned in favour of ones that OTs felt were more suitable. Some of the patients needed significantly longer to contribute either due to cognitive or communication difficulties. The other patients might lose

concentration during this time and begin to talk amongst themselves, play a different game or shout out their answers. Much of the session was an attempt on the part of the OTs to maintain a balance between completing the game, keeping it relevant, fun and challenging for everyone whilst ensuring everyone got a chance to participate. The medical relevance of the session was largely ignored.

*The men start shouting out answers.*

*Robert shouts out an answer when Anita (OT technician) is trying to encourage Britney (a patient with high support needs).*

*Anita (to Robert): You concentrate on shuffling.*

*Paul (another patient): Yeah Robert. You concentrate on shuffling.*

*Robert laughs and Paul smacks his own wrist in front of Robert.*

The inability to successfully interact with others can have significant consequences, especially in the future supported housing he is moving to. However, as Robert is considered 'well' it was not addressed. The interaction was potentially reconsidered as gendered, typical masculine behaviour of competitiveness. Robert and Paul were fulfilling their role as 'naughty boys' with Anita playing the role of 'teacher'. It takes a certain level of insight to recognise this opportunity for role-play and another incident suggested that this was not something Robert was particularly consistent. In the same session, Robert is trying to explain a game he was taught and was unable to recall the name of the OT who taught him:

*Mark teases him about this saying "He was only your OT for 7 months". Robert didn't seem amused.*

Teasing and black comedy is a tool used regularly during interactions in the hospital. This also means, however, that issues such as memory loss remain overlooked. Rather than encourage Robert to use strategies that might help him to remember the name of the OT, gendered responses are again used in the form of teasing Robert more akin to members on the same sports team or work colleagues rather than that which might be expected in a patient/ professional relationship.

Finally, when Robert presents other ailments and brings into focus problems which do not suit the narrative of him improving, they are renegotiated so that they do fit the wellness narrative. Robert regularly complains of having a problem with his eyes as well as pain in his shoulders. Again, he often becomes 'fixated' with these difficulties. The professionals reconsider these as a sign of

successful rehabilitation. During an MDT meeting, the focus of talk regarding Robert is about his potential supported housing. When this is concluded, a nurse asks if there is anything medically to talk about. Angela (Consultant) reports that:

*Angela: Nothing else except for an in-growing toenail medically wrong with him. As his awareness increases, he says things like my eyesight is not good but it's never been good but he notices it now.*

The toenail is mentioned but is not considered medical. His insight is improving. Therefore, the other issues of his eyes and painful shoulder, which have been long standing problems, are only coming into focus now as Robert is recognising them as a problem as his brain is able to recognise it. These difficulties are considered as issues that do not belong in the rehabilitation hospital because they cannot be cured here, would not delay discharge and therefore are not worthy of attention.

When Robert did not leave the hospital until many months after the expected date, due to a dispute within social services regarding responsibility for payment, not only was he blameless but he was considered a victim as this extract from an MDT meeting shows:

*Everyone agrees that this is very unfair on Robert as he has already visited the supported housing he was due to go to several times in order to get used to the place. Also, it was felt there would be nowhere else for him to go anyway.*

### **Case study: The danger of de-medicalisation – Lucy**

I now turn attention to the circumstances which results in an individual finding that they have not had their issues understood as medical and, in some instances, the issues that were once considered medical have been re-configured as social. This patient, in short, has been de-medicalised. Certain potential medical labels were offered during discussions around her and were either ignored, rejected or used against her. This can have catastrophic consequences for the individual in terms of gaining access and being legitimised in the health care setting. In order to show this, I return to Lucy who was discussed in the last chapter.

Lucy is a woman in her early 20's. She spent most of her time in bed, either asleep or watching her television. From her initial description to the group, there were negative connotations connected to

her. In Becker's words (1993), she was already being configured as a 'crock' with the consultant claiming to the inter-disciplinary team that she "*only eats McDonalds, has pain that cannot be taken away and manipulates her Mum who, in turn, never gave her the chance to grow up*" (field notes). It is clear that Lucy is being configured morally with information such as exclusive eating of junk food being used to position her as someone who makes individual choices to be unhealthy thus inadequately fulfilling the sick role. As the weeks progress, it becomes clear that Lucy is experiencing chronic pain and she had remained in bed for a number of years prior to admission to hospital. There is no talk of a medical diagnosis. She is not afforded time to discuss the approach to her care or how this pain can be both classified and relieved.

As discussed in the last chapter, during meetings, medical terminology is brought into play but with caution and only then so it can be rejected. It is noted that these terms are mainly from the family, Mum and Nan, who are not considered a reliable resource. Therefore the use of the word narcolepsy, the medical term for the "*energy saps*" that Lucy experiences is discarded. When the medical term narcolepsy is used in an MDT meeting, Angela (Consultant) tells the group: "*I would be very dubious about putting another medical label on it*". She refuses to allow Lucy's experiences to enter the medical domain. At times these "*saps*" as the chosen expression puts it, can have significant consequences as the following extract from the same meeting shows:

*The physio explains that Lucy had an energy sap and fell off the loo.*

*Angela: I'm a bit concerned about how she is taking one step forward and five back.*

*Sarah (Physio): I'm sure everyone knows about the energy sap in the pool (Hydrotherapy) which resulted in a full evacuation<sup>17</sup> which wasn't particularly useful. She won't be going back in the pool.*

Rather than consider the medical causes of this fall, the incident (and therefore Lucy) were considered unhelpful for the organisation of the hospital. As a result, she would be denied the treatment even though only the week before it was said:

*Dr: Hydrotherapy seems to have worked wonders for Lucy.*

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<sup>17</sup> Describing being pulled out of the pool as a "full evacuation" suggests that this was a considerable undertaking, inconveniencing many people. In fact, only one patient is normally in the pool at any one time so it would only have been Lucy who was evacuated. The use of the term "full evacuation" continues to position Lucy as an inconvenience.

*Physio: Yes. She really enjoys hydro but is not keen on attempting the gym. (People laugh).  
We obviously need to do both so she can function out of the water as well as in!*

Whilst ultimately, the professionals made a small gesture of fun towards Lucy and her lack of interest in physical activity (Lucy is defined as obese), initially the pool was regarded as the potential answer to her engaging in the rehabilitation process.

One of the main problems for Lucy was that her condition was not medicalised in the first place. As a result, any problems that do present themselves are relegated to the social which is deemed out of the remit of the medical professionals. As this extract shows:

*Angela (Consultant): Joanna was going to discuss her with the cardiologist but there was absolutely nothing wrong in the test...I think there is a lot going on with Lucy. These things are long-standing only she has now become an adult.*

The lack of anything visible, tangible or measurable is a major disruption to be able to medicalise the issues and configure Lucy as 'patient'. The discussion with the cardiologist was a request from the family. They were attempting to use the technology to force the medicalisation of Lucy but it was felt that they lacked the sufficient authority and expertise to make this call. The professionals reclaim this ground by emphasising that *"there was absolutely nothing wrong in the test"* showing how they hold the expertise to make this judgement. Psychological issues are relegated to *"a lot going on with Lucy"*. These are seen as more trivial and not something worthy of attention here. Indeed, they can not only be downgraded but actively used against the patient. Angela suggests that Lucy *"needs psychological help as does her mum and gran"*. This suggests that these issues are not able to be isolated and fixed but, rather, a social problem exacerbated by the very people that the staff would normally look to in order to form an allegiance in configuring the patient. The family are seen as part of the problem rather than the solution, themselves becoming pseudo-medicalised leading to someone suggesting, on one occasion, that the best operation that Lucy could have would be *"a Mum and Nan ectomy!"* In another instance, Mark uses the term *"Shumen's disease"* in a sarcastic manner in relation to the reason that the family are using to justify Lucy staying in bed. The medical professionals disagree with this diagnosis. Again, the family, unlike with Robert, have not played their part by deferring expertise to the professionals; they have not been 'response-able.' They have tried to enforce their own medicalisation into focus, labelling her conditions as narcolepsy

and Shuman's disease. By denying these terms and by relegating other issues to 'social' problems, Lucy has been de-medicalised. This denies her legitimacy in the setting.

Eventually, Lucy is admitted back to University Hospital where she is put on the neuro-acute ward. This is felt to be highly inappropriate for her care needs but justified by suggesting that from there she will then be moved to somewhere more appropriate. She never returns to the rehabilitation hospital. Her personality, behavioural and psychological issues again mean that she is not able to perform the role of patient in the manner that is expected by health care professionals. She is seen as a problem; a person (not a patient) in a hospital, which ultimately leads to her disposal.

### ***Discussion***

This chapter has highlighted several key points that consider the concept of medicalisation in terms of legitimacy, organisational capacity and re-enactment of accepted practices. Medicalisation of ABI symptoms can be brought in and out of focus within the overall narrative of configuring the patient (Latimer 1997, 1999). This assists the work of the professional greatly, giving them and biomedicine more widely, grounds for legitimisation. However, as discussed in chapter two, whilst the impact of this on the patient in terms of access and legitimation has been widely acknowledged, what has been shown here is the manner in which it can also be advantageous to the patient. What is also highlighted is the potential lack of alternative options for the individual when illness prevents the performance of patient.

As shown, there is interplay between medical and social discourse to form 'accounts' (Garfinkel 1967) in order to assist with configuring the patient. In the case of the scans, they were used to legitimise as and when other moral configurations might correspond with the medical interpretations. Likewise, the technology was ignored when there was no need, or desire, to do this work. Medical discourse was as much part of 'the social' as any other artefacts and was interacted with accordingly. In addition to this medicalisation work, we also see the manner in which it can bring power relationships into play, another important facet in the organising of the setting. The capacity to medicalise, alongside grounds of expertise such as reading the scan, distinguish staff between those able (and allowed) to do it and those that cannot. As this ability represents the function of having the necessary artefacts in play to begin to configure 'patient', being able to read the scan is recognised as part of having a particular hierarchical status within the setting. These

hierarchies are not predetermined but are constantly constructed and negotiated in the everyday practices of the clinic (Latimer 2000).

Importantly, medicalising outcomes of ABI means that that these outcomes can be organised along medical grounds. This means that they can begin to be positioned as a 'solvable' problem (Berg 1992). In accomplishing this work, good medicine can be achieved as the individual enters the setting 'ill' and leaves 'well'. This reinforces the discourse in which biomedicine was best placed to assist the individual here. When the 'individual' cannot be organised so that they are 'solved', the social can come into play by re-positioning the individual to that of 'person' (Latimer 2000). By de-medicalising the patient, they are 'disposed' of, stripping them of their legitimacy, thus ensuring that the professional is not held accountable for that individual (Latimer 1997).

It is important to recognise that medicalisation is also an important device for the patients. The patient may benefit from this work as they are able to perform 'patient' using distinguishable rhetoric. By recognising biomedicine as the dominant discourse, patients appreciate the power it has for legitimisation. Through medical labels, they are not only legitimated within the medical domain, but in society more generally. Using the sick role as a backdrop, the obligations ensure that the patient has responsibilities to seek assistance to recover as well as to make progress. Indeed, it gives an acceptable set of tools for the patient to 'perform patient' (Goffman 1959; Garfinkel 1967). Their illness has been 'arranged' so they can perform the sick role along recognisable grounds. The patients are fulfilling their obligations accordingly. Interestingly, this chapter has also highlighted performances which perhaps reflect the wider societal interpretation to perform illness along these recognised, familiar 'routes'. As discussed in chapter two, Goffman (1963) uses the term "*passing*" to refer to a successful concealment of potentially stigmatising qualities (in this case, disability). Ironically, as we can see from the work of Liz, for example, some do exactly the opposite and use props in order to "*pass*" as disabled. This is all, of course, bound up in the idea of legitimacy. Even those who have been legitimated have felt the need to continually perform in order to keep this identity in play and, so, secure their place in the medical domain.

From an organisational perspective, using medical diagnosis to determine legitimacy means that the organisation of the medical space can be done on medical grounds. Priority can then be given to those determined to be in need and with those denied access felt to have been done so on legitimate grounds (Latimer 2000, Hillman 2007). Patients are organised along 'medical' lines, giving them 'routes' for disposal. However, this chapter has shown how this system can act against the

patient. With medicalisation itself being a social process, some patients accept labelling but others do not. This system of organising is only satisfactory when it is understood and adhered to by all of the multiple actors involved. When the illness being considered, in this case ABI, means that the 'fit' is less established, it puts the patient in a potentially vulnerable position. In addition, when illness also limits the 'performance of patient,' possibly even acting against the recognised performance, this chapter has shown how ill equipped the organisation of the healthcare setting is at providing alternative options for this patient. Medicalising is potentially useful for ensuring the patient 'fits' into the healthcare system but plays no role in assisting the healthcare system to 'fit' the patient. In fact, by attempting and failing fit, the only available option might ultimately be 'de-medicalisation' and 'disposal' from the setting altogether, with moral accountability put on the patient without the medical support or societal legitimation in place to help.

### ***Conclusion***

Following the previous chapter which considered the importance of configuring the ABI patient to ensure 'fit' in the healthcare setting, this chapter has taken a specific component of this, medicalisation, and shown how this can be both advantageous and problematic for the patient. An increased moral agenda reinforced by popular discourse has encouraged individual self-responsibility. With the increasing importance on the individual to 'pass' into the medical setting, this chapter has shown how ABI due to its complex, multifaceted components, make this a complicated process (Mol 2002). Through medicalising symptoms and outcomes, 'moves' can be made to ensure that the doing of 'patient' is able to 'fit' into the discourse. It positions the patient to be able to move through the process in a trajectory which starts with a recognised 'illness' and ends with a recognised 'wellness'. In order to achieve this, it can mean that a great deal of flexibility and reinterpretation is needed to ensure the patient is recognised as such. As shown with Lucy, whilst flexible, if the patient is unable to be made to 'fit', they can be de-medicalised, positioned to have no mandate to remain as 'patient'. With the discourse favouring individual responsibility, it is the patient who is looked to have failed to have maintained their part of the (social) contract in terms of performing 'patient'. They are not deemed to have been 'response-able'. Medicalisation and de-medicalisation are very powerful tools in achieving this configuring work. The need to be seen as legitimate in order to 'pass' into the category of ABI patient and has never been so important in terms of receiving help medically, financially and emotionally. If they have been 'de-medicalised', they have effectively been denied this legitimation. It is too simplistic, however, to suggest that performance and configuration of the patient is exclusively the role of professionals and decision

makers. The performance of patient transcends this, interacting with technologies, rituals and rhythms that make up the medical setting in order to ensure 'fit'. The next chapter will explore this further, particularly looking at the organisational principles of the healthcare setting and the corresponding disciplining and surveillance work that it carries out.

## **Chapter Six: Organisation of the Rehabilitation Ward**

### ***Introduction***

The last two chapters have primarily focussed on how the individual with an ABI becomes configured as a 'patient'. Specifically, it has considered the 'moves' made by the professionals in this complex negotiation. As shown when considering the ergonomics of the MDT meeting room or the interpretation of scans, these complex negotiations do not take place in isolation and interactions with the space and technologies play a vital part (Mol 2002). This chapter moves away from the more formal opportunities, such as meetings, used to configure the patient and will instead consider the role of the everyday when the vast majority of identity-work is accomplished by the actors involved. In particular, I begin to consider how patients and other actors, such as family members, understand themselves within this discourse.

### ***How the space 'works'***

In order to understand the significance of the interactions and movements that take place between actors when configuring 'patient' in ABI, it is imperative that the spaces in which it takes place are considered. The ward is not a space without meaning, symbolism or power. It is itself a core component in the discourse of creating and sustaining identities. It is interpreted and configured by the actors involved in order to make sense of themselves, often using the 'other' and the space as a reference point. Additionally, the organisation of the ward plays a significant role in understanding interactions between the various actors who inhabit the space. Using theories from Latimer (1997, 2001) and Foucault (1978), the ward acts as a form of discipline and surveillance, an organiser that encourages actions to be performed in a particular way. The way that the space is utilised and interpreted reinforces the cultural practices and expectations of those involved. Drawing extensively from field notes, this chapter considers this in detail, beginning by considering how the ward is set out ergonomically. The everyday practices that make up life on the ward are then mapped onto this. In particular, I analyse how daily life is carried out in response to the organisation which takes place.

It is generally acknowledged in medical literature that after acquired brain injury, the vast majority of visible, measurable improvements take place in the first two years post-trauma. After this time, gains may still take place but are often more subtle. Many of the long-term consequences of ABI, however, means that ongoing, often lifelong support may be required to prevent the individual further deteriorating in either physical health or quality of life. Duration of stay in a hospital such as

the rehabilitation hospital also varies depending on a variety of factors such as the particular difficulties being experienced by the patients, what the ward can offer which other services (or home) cannot or whether there is indeed a suitable home with support in place. Although the usual length of stay would most likely be a matter of weeks or months, as described in chapter one, a stay on the rehabilitation ward can be a matter of days, weeks, months or even years.<sup>18</sup>

The neuro-rehabilitation wards at the rehabilitation hospital are described as traditional nightingale wards, meaning the beds are in rows facing into the room with a central passageway down the centre. This design is not so common in newer hospitals which tend to have phased this out though there seems to be mixed opinion amongst the staff here as to whether this is a good thing. Whilst it allows interaction between patients and prevents the isolation that comes with single rooms, it does not offer the pseudo-experience of being in a personal space, of being more 'at home' which many specialists in the rehabilitation hospital are keen to create in order to aid rehabilitation. The main part of the building is historically listed which means, whilst quite impressive on the outside as an old manor house, is not always considered fit for purpose once inside. For example, many offices are upstairs, with a grand staircase leading up to them. There is no lift so any meetings with people with mobility issues have to be moved downstairs. Whilst there has been some expansion, this has been limited given the size of the surrounding areas as well as the desire to keep much of the grounds intact to be enjoyed by patients and visitors. Therefore, unlike many other hospitals, the rehabilitation hospital is quite small, is not particularly busy both in terms of volume of occupants or sense of emergency and therefore has a general feel much more sedate than that associated with other hospitals.

As discussed in the introductory chapter, there has been little investment in the rehabilitation hospital due to expectations of it being imminently closed. Only tasks which are necessary to literally keep the hospital open have been tackled. The result of this lack of investment has meant that the hospital wards and surrounding areas might appear dated, even shabby, at times. There were continual small projects, such as the putting up of art on the corridor walls or the relaying of the pavements outside, but never any major refurbishment. The impact of this on the patients and staff

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<sup>18</sup> Staff are aware of the pressure to hit particular NHS targets to discharge patients but they told me that they feel these targets are inappropriate for people with ABI, impossible to manage and are largely ignored on the ground. A group of occupational therapists were talking about a target called DTOC (Delayed Transfer of Care) and joked that when dealing with ABI they should have DTOC and DTOC+ as delays can be so significant and long.

is unclear though generally speaking it appears to be the staff that vocalise their concerns more than the patients. That said, it was reported during an MDT meeting that a family came to view the hospital and decided against it due to its condition. This led Mark (OT) to comment *“Well it’s the people and not the place which matters.”* This typified the attitude of the staff; the doing of *“first class medicine in a third world environment!”* (Latimer 2000 pg.11). Indeed, overall, it did appear that the lack of investment would often galvanise the staff and patients frequently commented that the hospital had a special, community feel to it.

Entry to the hospital is normally through a grand doorway though there is an adjacent fire escape, often open, which is just as often used by regulars. The original door has been replaced by rather modest automatic ones. Once inside, there is a waiting area and reception, stationed by porters who are sometimes required to perform other duties, such as organising the post or taking patients to different parts of the hospital, meaning a visitor to the desk can often wait for some time before being seen. This is also the place where staff can collect keys for various offices as well as their post. At times, it can become the main point for staff to stop and have a chat. Once past reception, it opens out to an area with five potential corridors and rooms leading off it. (It is also the room which holds the volunteer tuck shop so can also become quite popular at times.) The corridor leading to the neuro-rehabilitation wards is fairly long and leads past departments such as speech and language therapy, dentistry and physiotherapy before arriving at two doors for the two neuro wards (wards 7 and 8).

The neuro-rehabilitation wards themselves are locked by a secure key pad. In order to gain access, you have to either know the number or press the buzzer for admittance. On the door are instructive signs and posters. The first informs us that entry is only permitted at certain times of the day and meal times in particular are not to be disturbed. The other is an NHS poster showing a selection of individuals of different ages, all with various visible ailments. We are told that only one of these patients needs to go to A&E and we are encouraged to guess which one. Underneath the image is a breakdown of where the different individuals should be looking to access the NHS with one illness not being granted any access at all. (It is the man holding his chest having a heart attack which requires emergency attention). On entry, there is a short, narrow corridor with various small rooms off to either side such as toilets, shower room and a laundry room. At the end of the corridor are two rooms facing each other. On the one side is the staff room. The door is on a sliding runner and is usually open unless the staff are having a meeting. This office is not particularly large and it would be difficult to fit any more than three or four comfortably though during meetings such as handovers, it

would not be uncommon to have seven or eight in the room. In the office, there are two computers, numerous files of different sizes and countless pieces of paper, some official, some seemingly less so, attached to cork notice boards or taped to the wall. These attachments vary from lists of phone numbers, a new protocol, reminders to staff to take keys with them or a sign-up sheet for a member of staff's birthday night out. On the wall outside is a whiteboard which shows a breakdown of the beds currently occupied. Within the outline of each bed are the initials of the patient currently occupying the bed space. Opposite the office is what is known by staff as 'the side ward'. It is a private room which is relatively unique for the rehabilitation hospital. In fact, this is the only private room on this ward. Private is not a particularly good word however as, like the office, this room also has a door on a sliding runner which is nearly always open. Whichever patient is in this room will be constantly in the eye line of staff and anyone who moves along the corridor can also glance in with ease.

The corridor opens out onto the ward. The ward is in two sections, male and female. The male section comes first and this is approximately twice the size of the female section (possibly reflecting the standard demographic of ABI patients). The ward has high ceilings and the paintwork is white or vanilla. There are numerous chips in the paint where, over the years, wheelchairs and beds have scraped against the walls whilst moving in and out of the ward. The floor is cold and hard, giving the room quite a functional feel. The female section is divided by a partition wall with a doorway in it. Except size, the male and female sections are otherwise very similar. Once through this ward, we come to a room known as the social room. This is a multipurpose room which, amongst other things, acts as a meeting room for patients, a place for staff to hold meetings and the room for the OT social groups (as described in the last chapter). It has a television and sofas for patients and visitors to use, attempting a homely feel whilst simultaneously being used to store wheelchairs and other equipment. In addition, it also links wards 7 and 8. As a result of this variety of uses, the social room can have many different people walking through as they move from ward to ward, collect equipment or arrive for meetings.

Back on the ward, immediately to the left after the staff room is a nurse's station, though this seems to be rarely used. There are four beds on each side of the room with a central walkway down the middle. There are large pillars also down the middle meaning that anyone who uses this walkway has to negotiate them which often can mean a build-up where the corridor meets the ward when medication trolleys, cleaning buckets, wheelchairs and volunteers with sweet trolleys all meet at the same time. Each bed space contains a bed, a small cupboard and a table on wheels so that it can be

positioned over the bed. Over time, this inventory might be added to as individuals look to personalise their space, albeit modestly. Perhaps a chair or an extra table may make their way over to a patient's bed space where it becomes commonly accepted by everyone that this particular individual always has two tables. There is very little in the way of personal belongings and it is encouraged that this stays this way in the shape of yet another poster depicting an exaggerated, bulging suitcase being dragged along asking if this is really necessary. Some amounts of personalising of space do take place but this is largely kept to a minimum. In some cases, it does not take place at all, perhaps somewhat surprising given the vast lengths of time that an individual may spend on the ward. There might be several photos of family members and friends. Depending on the individual, this can have a therapeutic motivation with names of the individuals being placed underneath on sticky notes allowing the patient (and anyone else who cares to look) to know who is who. On rare occasions, personalised bedding might be used, even the occasional teddy bear. Some patients will have some form of electronic equipment such as a television or laptop although, again, this is not always the case. There is no facility for hiring a bedside television unlike in some other hospitals, although the television in the social room (the result of a charity initiative) is available for all.

The space around the bedside can be 'made private' by drawing the curtain around the space but it is normally only the staff that does this.<sup>19</sup> Above the bed is a whiteboard where information can be added and taken away. The information tends to contain the patients name, their consultant and information regarding dietary requirements. At the end of each bed is a file containing medical information pertinent to the patient. This is considered the property of the staff rather than the patients and quite often staff will arrive at the bedside, consult the file and leave with little interaction with the patient themselves. The beds are usually dressed in the standard hospital thin sheet and blanket with white synthetic pillow. The bed itself is used for a whole variety of purposes. It is the main resting place for patients but is also the base where all personal activities will take place. Some patients might read, one female patient spent her time card making and many watch television (often watching a different channel to the patient in the next bed which can make it quite loud and confusing to concentrate on the ward.) Much of this will take place whilst the patient is lying on the bed. Even fully clothed, able patients will normally sit on their beds rather than use chairs available on the ward or in the adjoining social area.

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<sup>19</sup> The patients use other strategies to close themselves off from public space, such as using technologies such as headphones. This is explored in detail in chapter eight.

The space immediately begins to position the patient in particular ways. What is allowed to be present, what is restricted and the performances within this space by those who regularly inhabit it all play an important role. What we might traditionally use to display identity, for instance, can be stripped away, possibly leading to a curtailment of self (Goffman 1961). Clothing, personal belongings and even interests are largely kept in the background. Whilst this might be necessary for the efficiency and organisation of the ward, it results in an initial standardisation of the patient (Goffman 1959, 1963). Little can be taken visually from the patient who is wearing the same nightgown, in the same sheets and watching television in the same way as the patient next to them. There might be some clues as to a narrative of the patient bound up in any pictures or small artefacts that might be present. These may even take on additional meaning as they so clearly stand in isolation to the more generic artefacts around them but they are insufficient to provide a whole picture of the individual. The overwhelming message is that this patient has the face identity of 'patient' (Goffman 1959).

In addition, the information on the whiteboard privileges certain information whilst relegating others. It tells the staff (and anyone else who wishes to read it) the individual's name but after this all information is directional, describing what has been selected for this patient in regards to eating and mobility. There is no room here for social information such as interests or preferences. Again, the intention may be to increase the efficiency of the ward but it does more than this. It displaces the individuality of the patient, removing information pertaining to the 'social', unnecessary when configuring the patient along biomedical grounds. It gives a fragmented representation of the patient (Allen 2014; Mol 2002) by reducing them to a series of inputs and outputs, measures and scores which either informs practice in working with the particular patient or highlights the current baseline which can be worked on and fixed.

The ward occupies a rather unique position in the organisation of the rehabilitation of the patient. At its most basic, it could be described as a holding area, a space taken up by individuals whilst they are waiting for something to happen; a glorified waiting room. This something could be visiting hours, lunch, or groups and classes such as gym work with physiotherapists or crafts with the occupational therapy department. Activities, however, make up only a small component of the day. There is far less 'doing' than waiting as classes may appear once or less on a daily timetable. The vast majority of the time is spent waiting. This means a large amount of time is spent doing very little at all. For some, this is because they need to rest after a certain class, fatigue being exacerbated by the brain

injury, whilst for others it is because there is quite literally nothing to do other than wait. Learning to cope with this is something which patients must learn to do in order to perform 'patient' sufficiently.

The ward is not meant to be comfortable, much like other waiting rooms (Hillman 2007). Unlike other waiting rooms, however, it is a place where clinically defined medicine takes place through authorised practices. For the duration of the patients stay in hospital, it is also their home. The space has these multiple roles. The setting is organised as a negotiation of these functions so that it is the most efficient way of holding the maximum number of people whilst still being able to perform medical tasks. Those responsible for throughput of beds do not necessarily want it to become a place which is desirable to be in for a prolonged period of time. However, due to the exceptionally long stays in hospital after ABI, the patient must adjust accordingly. Learning to cope in this way takes great socialisation. The routines, expectations and environment become the everyday. These become the 'norm' and how the various actors engage with, and respond, to this new norm is significant. In the performance of patient, those that are able to be seen to adapt to this every day, those that are 'response-able', are more successful than those who, for a variety of reasons, are interpreted as looking to configure their own discourse and, in turn, 'not adapt'.

What is also important here is the performance of being 'seen to try'. It is perfectly acceptable, almost expected, that the patient complains of being bored or de-motivated. However, the patient must learn early that they must cope in a way that is not interpreted as 'disruptive' to the waiting room or to 'doing medicine'. By 'disruptive', I also refer to the prevention of performance of patient by either that patient or by others. The patient has to find their state undesirable and seek competent technical expertise, taking advice in order to get better (Jeffery 1979). If the patient objects strongly to their situation, disrupting the 'doing of medicine' by either complaining excessively or becoming de-motivated, they are not fulfilling their role sufficiently. For example, Robert found a patient next to him to be disruptive. The patient, Stewart, was unable to adapt to being on the ward and would shout at every member of staff who came past, claiming he needed something. Robert would complain of Stewart's bad language even though the bad language of other patients, due to the context in which they were used, entertained him. Stewart would be equally as 'disruptive' to staff. His shouting would be perceived as both disorderly and deviant and, on one occasion, the nurse explained to Stewart: "*I'm not having this*", encouraging other staff to also ignore him. He found it difficult to adapt to ward life, quite possibly due to the nature of his ABI, and his behaviour was incompatible with expectations. In contrast to this was Paul. Paul went home for a weekend visit and it was reported in the MDT meeting that when he returned he reported to

staff that he had not wanted to. This amount of defiance was interpreted as perfectly acceptable. This is because despite such a claim, Paul could be trusted to perform 'patient' as this extract from an MDT meeting shows:

*Paul told staff that it was good of him to come back. This prompted a discussion where it was commented by a doctor that whilst he doesn't like being here "he is fairly good."*

*Mark (Physio): He does what we say basically.*

On the ward, Paul spent much of his time pacing up and down the centre of the room. He may, when asked, complain about the quality of the food or the lack of things to do, but he understands the importance of not making a fuss, not being disruptive and performing 'patient' properly. This means finding that blend of not being happy to be on the ward whilst, at the same time, being willing to operate and perform within its routines.

The break in routine becomes very important for many patients (discussed in depth in chapter eight). In one MDT meeting, for instance, it became evident that the importance of sessions as a break in routine was also known to the professionals. Winnie (a long-term patient) had been "medically fit for discharge" for many weeks, yet the long-term nature of the building work to make adaptations to her home meant that she was on the ward much longer. When asked about her, the physio says:

*Cheryl (Physio): Physio has been scaled right down to two per week which is only because she's here.*

*Angela (Consultant): Which is fair enough, as she hasn't got any reason to be here.*

It was felt that there was no more that could really be achieved from a professional perspective and that Winnie had made all the physical gains that they felt she would make. Therefore, contact and sessions with specialised professionals were scaled back to the absolute minimum. However, it was not discontinued altogether. Part of the reason for this was to ensure that the improvements that had been made were not lost but more importantly, the significance of the sessions as providing a break in routine was deemed important for Winnie in terms of organising her time on the ward. Whilst she did make trips into town with her brother, this was only when he was able to visit and without any alternative social groups in place on the ward, the only way in which Winnie could have a break would be to attend sessions. Importantly here, specialised intervention becomes an

organising tool and is as much about being seen to be doing something 'medical' as it is about actual rehabilitation.

For the patients, the ward is the space where the everyday is carried out. Only everyday life here is both inverted and subverted. Not only does the private become public but the everyday is carried out in a way which differs to how it might outside of the hospital. There are rules, some explicit some implicit, which individuals need to attune themselves to relatively quickly if they are to be successful within this space. Being able to wait is just one example of this. Lunch, washing, sleeping and friendship making are other examples of these practices. A variety of factors ensures that daily life is, as one patient described it, *"like normal life but at the same time isn't."*

***"How ward daily life is like normal life but at the same time isn't"***

The routine of rising in the morning would traditionally take place in private. On the ward, whilst several patients may get themselves up, behind their curtain, this will still be more public than at home. For example, individuals have to walk through the ward to the communal toilets, situated in other rooms. Many are unable to get up without assistance. This could be due to physical difficulties or they may lack the necessary initiation or organisational skills to carry out this process. Most patients will fall somewhere between the two categories where parts of the routine could be accomplished by the individual as long as they are assisted, often known as 'prompting'. The patient would have to wait their turn for this help but once this began, the health care assistant (HCA) or nurse would assist the patient throughout the process. The amount of assistance given is personalised to the individual. For example, Geraint, a patient in his 50's, was able to brush his own teeth but required physical assistance to put the toothpaste onto the toothbrush and needed reminding in what order to carry out the task. He would hold the toothbrush with one hand whilst a HCA would squeeze toothpaste onto it. Geraint, sitting in his wheelchair, would be encouraged to lean over the sink to brush his teeth. Whilst he was doing this, the HCA would be preparing the next part of the routine of finding a dry towel. A relatively simple task such as brushing teeth becomes compartmentalised. It is broken down into small chunks, some of which are for the patient to accomplish and others are for the professional to do. The extent to which the labour is divided is generally at the discretion of the professional and whilst it is felt desirable by the professionals at an organisational level that the task is completed by the patient as much as possible, occasionally the professional who is actually carrying out the task will do slightly more, particularly if they feel they

are running short of time. This might be resisted by the patient who wishes to remain as independent as possible or embraced as they prefer to have the task completed for them.

The breaking down of tasks is just one example of where daily life is *“like normal life but at the same time isn’t.”* The very fact that an additional person is involved in the completion of these tasks is, in itself, disruptive. It means that what might be considered a highly individualised process becomes negotiated with an ‘other’. In reality, for those that require assistance, this is more than just negotiated and often the process is given over to the ‘other’ who will take control and direct proceedings. This reinforces the power relations between the patient and the professional. The following is an example of this, describing a patient being ‘prompted’ to eat his lunch:

*Feeding this gentleman was accomplished by a gloved health care assistant (HCA) who stood to the right of the patient. He (the patient) was a large man sitting in a chair and with the HCA standing so she was approximately the right height to conveniently assist. She puts the food, in this case the mincemeat with mash and puréed veg, onto the fork, taking components of the dish together. She waits until he has stopped chewing and either this, or a gentle nod on his part, prompts her to raise the fork to him. He spent much of the meal looking away from her, up the ward towards everyone else. As he turns his head back to her, he opens his mouth. The fork is then put in his mouth, released and he turns away from her, looking back up the ward. There is no conversation between the two for long periods. After approximately 5-10 minutes, the HCA raises the fork to the patient (I discover his name is John) and he says “no”. She replies “too fast, sorry”. He turns back to look up the ward. She seems to start to daydream herself, staring into the middle of the room.*

The task begins when the professional allows it to. John is unable to start without her assistance. The tasks take place at a negotiated pace with the division of labour often in the hands of the practitioner. Whilst John had some input, the HCA would determine when he was to next have some food. John would indicate when he would like some food by opening his mouth or nodding and this would be understood and used as the sign to give him more. However, if the HCA wanted to slow the pace down (e.g. if she felt he was at risk of choking) she would do so. Similarly, if she wanted to speed up the task, she might hold the fork of food in front of John’s mouth, indicating she is ready.

Choice is given to the patient when it is felt possible but this is often a limited choice. Time spent in bed is a good example of this. The patient may remain in bed for a certain length of time but after a

while, at the discretion of a senior nurse, that individual is woken up and told that it is time to get up. The patient may not always like this or be in agreement but it is done so under the assumption that it is important and necessary for the patient's wellbeing. When I first went to visit Robert, he was in bed with his head under the covers. This was the way that he had slept since arriving on the neuro ward after he was assaulted. At this point, it was often a lengthy negotiation between staff and Robert every morning where he would want to stay in bed but others wanted him up. On this occasion, the head nurse woke him up, telling him that he had a visitor (me) and he would have to get up to speak to me. This did not go down too well with Robert! The staff has the control, on the whole, as to who stays in bed and who gets up. However, once the patient is up, and perhaps sitting in their wheelchair watching their bedside television, they often go back to sleep.

One of the key features of brain injury recovery is getting enough rest yet it is widely accepted by staff and patients that the manner in which sleeping is organised on the ward means that getting enough quality sleep can be difficult. This, alongside the large amounts of 'nothing time', means that it is common practice for patients to snooze during the day. As sleep is regulated, the performance of the patient in relation to this can be a form of disciplining. In the instance of Lucy, being in bed for much of the day was an example of her not performing patient. This is interesting as the stereotypical view of hospital might be to expect to find the patient in bed. As already discussed, prior to being admitted to hospital, the staff learned that Lucy previously spent much of her time in bed at home. Rather than configure this as a sign of illness, the affect of this was to re-configure this as poor parental practice with the consultant saying:

*Angela: I mean, who allows their daughter to remain in bed all day?*

Lucy had spent years on her life in bed prior to admission, a symptom of her problems according to her parents. Alternatively, as she had been de-medicalised, the act of staying in bed, rather than viewed as a symptom, was viewed by professionals as further evidence of deviance or malingering. On other occasions, patients who have been referred to as disruptive, such as Stewart or Geraint seem to sleep for longer periods, only being woken when they are needed for something important. In this instance, it is not disruptive for them to be asleep. It might be that it is more efficient for the organisation of the ward when they are. So the bed and sleeping becomes an activity which the patient can utilise for various reasons (tiredness, boredom, to exclude themselves from the group) but this is done under the gaze of the healthcare professional who, in turn, can use it to their own advantage. However, it must be done appropriately and to the correct extent. This differs from

patient to patient and is largely bound up in what is expected of them as well as their configuration of 'patient' or 'person'.

Washing is another part of everyday life that was in some way inverted and subverted on the ward. An important part of the morning routine, how often it is that we say that we need a wash to 'feel more human'. Washing does so much more than helping us to become clean; we wash to distinguish between night and day, sleep and awake, resting and active. In the hospital this might be done by others. As with the other tasks, this could be for a variety of reasons, such as deemed lack of dexterity or mobility on the part of the patient to wash themselves. Others may lack the planning and organising skills to complete the task. This, as well as memory difficulties, means that the individual may get confused and repeat or confuse a part of the task. For example, a patient named Ellice would put shower gel onto dry hair, thus confusing the expected order of washing herself.

Again, washing is normally a private affair. To have an additional person involved in the process takes a significant shift in attitude towards both the activity and the self. It renders the body a more public space, literally and metaphorically laying the self bare. The individual has to allow the body to become a site of work, a part of the organisation of the hospital. For the staff, whilst the body will be treated with dignity, it will not have the same sacred value as it does to the patient. The washing of the patient, just like helping to feed the patient, can become a task-orientated activity. The staff member may have a preferred routine. The patient may be asked how much they can do for themselves and may be advised to ask for help when they need it. However, against the backdrop of both a concern for the individual's insight (and through this their safety) as well as a tacit awareness of the pressure to be efficient, it is more likely that the staff member will perform certain tasks for the patient when the patient may have played a more considerable part themselves. Once again, the patient may allow the staff member to do this. This can be due to lack of motivation on the part of the patient. Equally, it is down to the performance of patient. The patient must be seen to be giving themselves over to the expertise of the medical domain and if they are seen to resist the efforts of the staff, they may be slowing down the efficiency of the task. Likewise, if they give themselves over too much then they are also not being seen to be helping themselves enough. It is a fine balancing act, often difficult to negotiate. By following the lead of the professional assisting, the patient can feel that they are on the safest ground in terms of performing their role appropriately and being configured as trustworthy.

Going to the toilet is another, perhaps even starker, example of this inversion and subversion. One of the most private and individualised daily activities becomes public. Patients may sometimes have to ask to go to the toilet and they may need assistance either getting to the toilet or when they arrive. This activity, like washing, becomes routinised, task-orientated and moved away from the individual. It is even termed by professionals as 'toileting'; a term I would argue is more in line with the medical than the social. The patient must get used to this positioning of the task to be successful. On one occasion, Geraint said he wanted to go to the toilet. He was quizzed several times on the matter, suggesting that he is not deemed trustworthy. He started to become frustrated and insisted he needed to go. By the end of this exchange, Geraint, the nurse and two HCA's were involved:

*Geraint needs the toilet:*

*Geraint: I need a shit.*

*HCA: What was that?*

*Geraint (louder): I need a shit!*

*HCA: You've just been.*

*Geraint: I need to go again.*

*Emma (Nurse) comes over to Geraint: What is it?*

*HCA: He says he needs a (whispers) shit.*

*Emma: Ok I'll take you. Which one? (Which toilet)*

*Geraint: Any one.*

*Emma then explains to him that if she takes him, he's not to get angry if the choice of toilet is not to his liking.*

*As Geraint begins to transfer, largely independently, from his chair onto a travel hoist, Emma explains to the HCA who is holding his arms that he previously got as far as the drugs room (heading towards a certain toilet) and he "became quite aggressive shouting, I don't want to go in there." This is all discussed between the staff as Geraint waits on the travel hoist next to them, hovering in the air above the wheelchair.*

Eventually Geraint does leave for the toilet and he returns sometime after. The nurse asks from across the ward if he went and the answer from the HCA was a resigned "no".

Here, the act of going to the toilet has been subverted to be completely different to what might usually constitute the task. Geraint needs to negotiate time on the toilet. This is debated and he has to put his case forward. He is disciplined by staff who gives him examples of behaviours which will not be tolerated during the activity which he has to agree to in advance. This is all accomplished amongst the other patients. The task has become so mundane, so task-orientated that it is deemed acceptable to do so.

This is a good example of where the various and differing understandings of the identity of performing 'patient' after brain injury can lie at the heart of the conflict between patient, family and healthcare professionals. In hospital, Geraint wears a pad which his wife is not keen on. When he goes out with her, he sometimes returns wet as she has refused to put a pad on him. During the MDT meeting, this is held up as a ridiculous act on the part of the wife. It is felt that if she is withholding the pad for the purposes of dignity, surely the fact that he then wets himself has rendered her protest redundant. However, this may be missing the point. To Geraint's wife, to wear a pad is to give up. It configures Geraint as significantly 'more disabled' than she is willing to accept. When it is found that Geraint is not wearing a pad, or has been helped by his wife onto the toilet, it causes anxiety and anger amongst the staff. They point to health and safety issues; Geraint has not been assessed for using the toilet and the wife has not undergone the necessary training. They also point to irresponsibility on the part of the wife who is in danger of harming Geraint. Indeed, on occasion the threat of a POVA (protection of vulnerable adult order) against the wife was touted in meetings where she was not present. What could be more harmful for Geraint here is the refusal of Geraint and his wife to perform a version of 'patient' that fits the organisational discourse of the hospital. They are performing disruptive behaviour and are configured as untrustworthy; they are not 'response-able'. Whilst part of the disruption is the tangible work required by the staff to clean up Geraint after he comes back to the ward wet (something they point to as a source of frustration), what is just as disruptive is the fact that Geraint, and particularly his wife, are refusing to allow Geraint to be configured in a particular way. She has refused to follow the narrative of Geraint along biomedical grounds and is reinterpreting his brain injury in the manner she sees fit. This goes against the configuration of Geraint pursued by the staff and goes against the organisation of Geraint on the ward. Whilst this can be tolerated to an extent, if no common ground can be found, this 'lack of fit' will work to position Geraint as eligible for disposal from the setting.

***The patient is disciplined: The everyday organises and disciplines patients***

The everyday on the ward does more than provide structure and organisation; it disciplines. Not only does it discipline patients but all who enter the setting. As mentioned, a pass-code is required to enter the ward, typed into an electronic board next to the doors. This is understood to be to prevent patients who lack insight from leaving the ward (and hospital). It also prevents people from coming in. It acts as a marker in two ways. Firstly, it tells us that the space is separate, different to the rest. Secondly, it also tells us that the space is controlled. Before you have even entered the space you are being told that you need permission to come in. Someone has to give permission and policy dictates that this would be the professional. However, this role has to be taken up by the staff member and this is not always the case. During observations, I might be asked to explain myself by any member of staff, including HCAs who would normally have little other authority regarding the organisation of the ward. On other occasions, I might sit in the staff room unchallenged for the whole morning. Sometimes, I might be let in onto the ward by a passing cleaner. The taking of control was very much dependent on the controllers. However, I was never given the pass-code. It was debated amongst staff and determined as not appropriate to do so. The pass-code is the symbolic gesture of legitimacy and authority. If I was given the code, I would be given control. Not just control of admitting myself but the trust of controlling others. This was not given away lightly.

As discussed, when waiting to be allowed to enter the ward, there would be a series of signs on the door giving instructions as to when admittance would be allowed and when it would not be. There were even posters which reminded us of the importance of being 'good patient' (Dingwall and Murphy 1983), questioning whether our ailments warranted hospital attention. Being permitted to 'pass' into the space, in both senses of the word, are in play here. Without having the pass-code, you are a visitor. That could take many forms (family member, staff from outside, contractor etc.) but you have to be allowed to enter. In our other role as 'person' or citizen, the time waiting is not lost in reminding us of our moral duty to look after ourselves and not use up the resources of the health setting unnecessarily.

On entering the ward itself, there is still further disciplining going on. This is largely dependent on your perceived status on the ward. For example, a patient would have a different relationship with the organising and disciplining principles of the ward than a visitor. Everything that takes place on the ward disciplines from the layout, the time of day, the purpose for the visit or the more explicit rules that must be followed. Being a traditional nightingale ward means that all of the beds can be viewed simultaneously. This resonates with Foucault's (1978) interpretation of Jeremy Bentham's

Panopticon in that the patient could be under the gaze of the professional at any time. The private is stripped away leaving the patient on view, even when asleep.

The side ward is an interesting space because of the way that it is used. Traditionally, families and patients would prefer that the loved one gets their own room. A patient on the sub-acute ward in the University Hospital is judged by the nurses to be misallocated to them. It was felt that the only reason he was there was because the family refused him to move on to a place where he would not have his own room. Due to complications with the patient, it was felt the consultants buckled under this pressure, allowing him to stay. However, the side room on the rehab ward is used differently. It was first used by Stewart and later by Geraint once Stewart had left. These were two patients who were judged by staff to be disruptive. Stewart was thought to sleep all day before being awake and shouting out all night, disrupting others. During the study, Stewart certainly did sleep a great deal. Geraint was thought to be aggressive to other patients (though I never witnessed this) and therefore it was felt that both patients were best suited to the side ward as it meant the other patients would get more peace. It was a utilitarian approach to organising and disciplining on the ward. The gesture, however, was more symbolic than logistical. Whilst it seemed that Geraint slept a lot more in the day when moved to the side room, something his wife was displeased about, he could quite easily go out onto the ward (when awake and in a wheelchair). Similarly, the room was hardly soundproof and if Stewart decided to shout all night, it would make no difference whichever room he was in. The side room is overlooked by the staff room which means surveillance is both more direct and immediate. Rather than seeing this room as a luxury, those who understand the organisational practices of the ward recognise it for its disciplining connotations. Stewart believed he was in the room because his wife was a cleaner and they had agreed that she would clean it in exchange for him having the room. No part of this assumption was true. The important thing here is that the staff are being seen by other patients and their families to be trying. In a reversal of roles of being seen to try to be 'good patient', the staff are doing 'good professional'. They are performing an authoritative role by being seen to take action and visibly discipline the patients who are not conforming. Therefore, the performance is possibly more important than the tangible results in this instance.

Routines also play a key part. I have already discussed the importance of the various classes and activities. However, interaction with these groups plays a key role for the disciplining of the patient as well. The sessions are given to the patient and they are taken away. There is little, if any, interaction with the patient as to how many sessions they will have or at what time of day. They are given these sessions and on the whole, they are expected to attend in order to perform 'good

patient'. When they do not attend, this is reacted to in several ways, usually in keeping with the overall narrative of the patient. For example, in the case of Lucy, non-attendance was viewed as deviance, further evidence that she is inappropriate for the setting. She is deemed to be not 'willing to try'.<sup>20</sup> Others, who are considered 'legitimate', will have justifications for missing sessions given for them, especially if it is legitimated by a professional on their behalf in the first place.<sup>21</sup> During a physiotherapy class, a psychologist arrived to explain that a patient would not be able to make the session as he was fatigued having spent hours working with her. Rather than consider this an issue (e.g. laziness) or poor organisation, sympathy was shown to this patient and the opportunity was taken to reinforce his configuration by agreeing how hard he worked. The sessions, then, both give opportunities for the patient as a break from the norm but also an opportunity to 'perform good patient'. They are being subtly disciplined to take up this opportunity.

When a patient wants to leave the ward, they often have to get permission for this; they have to be physically allowed out. This might just entail standing at the door until they are noticed on the security cameras and the button is pressed in the office for them. This makes a subtle clunking noise whilst the magnetic locking system becomes free, meaning the door will open when pushed. This requires socialisation. Very often, I would be standing at the door, with the button having been pressed, having not trained my ear to know that the door was open. Patients would then show me that the door was open. This is learned behaviour from being disciplined. Patients have learned that there is no need to ask to leave the ward if they are already allowed, standing under the camera is sufficient, and they, unlike me, know how to exit the ward without looking foolish. Some patients would not be allowed to leave the ward unaccompanied. They would have been judged untrustworthy or unsafe to do so. This configures and categorises patients in various ways providing a clear indicator of the level of ability of a particular patient. Independence is one of the key measures that a patient will mention when discussing goals so being able to leave the ward is crucial to achieving this.

The importance of routines certainly does not end with the formal sessions. The everyday activities discussed earlier also play a crucial part. Having to ask to go to the toilet, waiting for a glass of water, brushing your teeth when someone else has time or having your clothes selected for you all act to discipline the individual. These small, every day practices all work to configure the performance of

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<sup>20</sup> The importance of willingness to try will be addressed in some depth in chapter eight.

<sup>21</sup> I call this "moving the goal posts" and this will also be discussed in chapter eight.

patient as much as any scan result or medication regime might do. By performing in accordance with these rituals and rhythms, the patient is committing to a particular presentation of self which is recognisable as 'patient'. It plays a crucial role in allowing for the organising of hospital life, along a biomedical discourse, to be successful. In short, those that learn to do this get on better than those who do not.

### ***How organisational practices can be perceived***

I finish presenting data in this chapter by briefly giving examples as to how these organisational processes may be perceived by patients and family members as contradictory to the privileging of a biomedical discourse. In the following chapters, I develop the analysis in more depth to discuss how patients (and family members) respond to the organisational and disciplining practices that make up ABI on the ward.

It has already been established that for long periods of time, there is little in the way of formal activities for the patients to take part in. Many professionals emphasise the need for rest in the short-term as fatigue is a massive problem after brain injury. The brain takes many months for improvements to take place and often, certain improvements are needed to be made visible before the next stage of rehabilitation can take place. This, however, is often context dependent and very often, rehabilitation is both sped up and slowed down depending on the length of stay of the patient on the ward. Winnie is an example of this where rehabilitation was slowed down to a minimum when it was judged to be some time before she was due to be discharged. The perceived lack of anything going on can also be put down to a general feeling that there are not as many staff to go around as professionals would like. In an interview with an Occupational Therapy (OT) technician, she explained to me that she feels she does not have the time with the patients on a one to one level as she would like due to the increasing scarcity of funding for staff cover. Another reason for the perception that nothing happens is down to expectations which feeds into the experiences of the patient and the family in understanding their part in the system. In an interview with a Speech and Language therapist (SLT), Ellen, she explains:

*I think initially when people arrive they expect, again it goes back to sort of people's expectations of what they will receive here, so initially it's like they haven't got anything on their timetable this week but because, again, it's the logistical problem that we have to do the timetable a week in advance so they arrived on Monday and so (will) not get a timetable*

*till the following Monday. So yes that's a big concern and also I think the ebb and flow of patients, who's in that time means that yes, you may be able to see somebody four times a week one week and only twice a week the next because of annual leave or because there are more patients that have arrived or whatever so yes.*

*Tim: So obviously the therapy of one patient depends on the overall picture.*

*Ellen: Yes. Yes. So it's staffing, it's who's in that week basically in terms of patients as well so yes it can be a bit of a problem. But then I suppose the longer people are here the more they understand that's how we work and that's how things are here.*

The timetables are devised on a Wednesday so if the patient is admitted to the hospital at the start of the week, it could be up to a whole week before any work with a specialist is undertaken. Specialists also do not work evenings or weekends. This takes place against a backdrop where the family have heard from the neuro-acute ward or have read that the first year of rehabilitation is crucial. They may also been told that the rehabilitation hospital is the place where every patient should strive to get to. In the same interview with Ellen she says:

*I do wonder what is said to patients in (University Hospital) about (Rehabilitation Hospital). Is it sort of put on a bit of a pedestal? Don't worry you'll be going to the rehabilitation hospital soon, they'll sort you out there sort of thing is partly... You know, nurses, therapists, consultants in University Hospital) who are sort of feeding into that expectation.*

According to healthcare professionals, this can then lead to unrealistic expectations. Ellen explained how she would often be required to defend the system to concerned family members who expected intensive rehabilitation and had very different ideas of what the organisation of rehabilitation would look like. If you begin the rehabilitation pathway with such differing expectations, it will always be difficult for the two to meet at any point. This can set in motion an inevitable chain of events which leads to failed expectations, disappointment and anxiety on the part of the family which feeds back to the patient, largely due to the coming together of competing discourses.

### **Discussion**

There are two particular overriding tropes which are important in this chapter and which overlap considerably: 1) the notion of power and its relation to authority, and; 2) the performance of patient in relation to this. As described, the ward is organised along systems of hierarchy (Latimer 1997).

This is achieved through formal and informal means. The formal rules may set up the expected power relationship, but it is the informal, continual re-enforcements being enacted throughout the ward that ensure these distinctions remain. For example, the stripping away of identity markers through the reduction of personal belongings leads to a 'curtailment of self' and begins to position the patient in a particular way (Goffman 1963). It reduces the capacity to display identity and autonomy, laying the individual bare, as a medical entity, to be work on and fixed (Foucault 1973). In isolation, this may not be so significant but when the behaviours, such as the breaking down of tasks with the assistance of the professional, are mapped onto this, it becomes a powerful mechanism for creating this separation. This work, with the pace dictated by the professional, and the necessity to make private tasks 'public', all contribute to this relinquishing of power on the part of the patient. Even the ergonomics of the room, such as the selection of beds (Latimer 1997), play their part by having the behaviours of patients organised and prioritised dependent on their capacity to 'perform patient'.

The performance of patient is the second trope which is particularly important here. By using the obligations of the sick role as a loose framework, successful patients understand the necessity to relinquish some of their autonomy in order to be figured as medical patients. In this instance, this is largely what being 'response-able' (Latimer 1999) has come to mean. However, whilst the performance of doing 'good patient' is well established in the literature (Jeffery 1979, Dingwall and Murphy 1984, Berg 1992), what I have shown in this chapter is something in addition to this. It is not just the accomplishment of 'doing patient' in its own right which seems to be important in this setting, but the idea of 'being seen to try' to do so, almost regardless of the success. As an extension of this, taking the concept of being 'response-able', we can see that it is not just being trustworthy to do what is expected that is important, but being trusted to *know that you are expected* to do what is expected. This is a very subtle, but equally very important difference. As long as the patient is seen to be making some attempt, even if it is not always consistent or successful, to perform patient, this is enough when dealing with ABI where a flexibility of patient identity is needed to ensure 'fit'. This will be explored in greater depth in the next two chapters.

### **Conclusion**

This chapter has considered how every day, micro interactions work to position the individual to allow them to perform patient in an expected manner. I have shown how the patient is not defined singularly through a particular decision or event. On the contrary, the label of 'patient' becomes a

fluid process made up from a coming together of various responses and interactions with rituals, routines and technologies (Mol 2002). This includes interaction with the space of the ward as much as it does the actors within it. I have also shown how common performances, such as washing and eating, are re-imagined. Corresponding components become broken down, potentially allowing the routine to become task-orientated, functional practices. This assists with the organisational practices of the ward as much as the biomedical understanding of the body as a site of intervention. Whilst several components that constitute this site may be comparable to other healthcare settings, ABI rehabilitation in particular, due to the nature of potential difficulties experienced, exposes the differences between everyday ward life and life on the outside. I argue that in order for the patient to successfully 'fit', they must learn to interact with these practices. Ironically, the relationship between the difficulties experienced by the individual with ABI and the 'conditions' of the ward, what Latimer calls 'body/world relations', (Latimer 2009) can affect the capacity to do 'good patient'.

The configuration of the patient with an ABI through the lens of professionals has, thus far, been the main focus of enquiry. This has included interactions between professionals as well as an interrogation of organisational practices that constitute the setting. The following chapters consider ABI from the patient perspective. Firstly, I address how the patient begins to interpret and understand themselves alongside their own configuration of ABI before moving on to reflect as to how this perspective interacts with the biomedical discourse and corresponding organisational practices they encounter.

## **Chapter Seven: ABI - What does the patient think?**

### ***Introduction***

I have considered how and why complex configurations and re-configurations take place, drawing on the work of Latimer and others to explore how individuals are understood as 'patient' within the medical setting. In line with this, I have also investigated the concept of medicalisation in constructing acquired brain injury (ABI) in a particular way in order for it to 'fit' into a medical discourse. I now explore interpretations of doing 'patient', ABI and the relationship between the two from the patient perspective. This chapter is split into two halves. In the first half, drawing particularly on semi-structured interviews with patients at different stages of their rehabilitation, I describe how the biomedical discourse can prove to be an incomplete lens through which to view an injury as fluid, individualised and unpredictable as ABI. In doing so, I consider alternative discourses often employed by patients throughout their 'illness career' (Goffman 1963). In particular, the role of experience, crucial in understanding illness and wellness, will be addressed by considering how these concepts can be reinterpreted not as concrete definitives but as fluid and in constant flux. Having established how illness and wellness are concepts which require negotiation, the second half of the chapter examines the fundamental part that the patient plays in this. I conclude by considering how, in some instances, configurations of 'brain injury' and 'patient' can be reconsidered and even reclaimed by the patient, using such terms to forge new identities and ways of experiencing the world rather than the assumed undesirable state which needs to be rectified as soon as possible.

### ***Lack of fit to the biomedical model***

As described in the previous chapters, configuring the patient is a coming together of a collection of complicated and often conflicting artefacts and interactions (Mol 2002) which are used to allow the individual to be 'read'. These can include measures on charts or interpretations of scans as well as discussions with colleagues, family members and assumptions based on similar experiences of previous patients. Through this process, the individual can be organised against culturally and universally accepted narratives, particularly within the healthcare setting itself. This narrative, in turn, attempts to make behaviours understood (even predicted), measurable and definable (Becker 1993). By configuring in this way, it also allows for the presentation of patient to be comparable and judged against the expectations of what it is to do and be 'good patient'. It is the conduct of the patient that can then be measured in terms of whether they are felt to be 'response-able' or not. If

the patient is unhappy with being ill, is motivated to get better and allows medical expertise to assist with this, they are more easily configured and managed. If agreed scores and measures are available to monitor progress, the patient is all the more easily readable. It is also necessary for the organising principles of the hospital which are constructed to reflect the model of trajectory moving from a state of illness to one of wellness. In acquired brain injury, however, this configuration is often difficult to fully achieve. It requires concepts that might be too fluid to be defined with these definitions brought into focus more for some and less so for others. Rarely do ABI patients fulfil these assumptions smoothly. Patients, more than anyone else, can find this biomedical configuration unsuitable for understanding themselves or their experiences following ABI.

Illness is both social and cultural. Whilst we are increasingly encouraged to police our own bodies, one cannot choose to be ill; this has to be legitimated by an 'other' (Foucault 1978). To be accepted, it is significantly advantageous if the illness is made 'visible'. Culturally understood markers are used in order to determine when an illness has occurred such as feelings, medicine, technologies e.g. brain scans, tracheotomies, expertise and defined, medicalised symptoms. Markers that we understand when interpreting concepts such as illness, wellness, patient and professional are not always applicable or reliable when considering effects of ABI. Often patients do not believe they have problems. Symptoms of illness that are attributed to them by professionals or families are sometimes minimised by patients being re-configured to be excluded from the medical.<sup>22</sup> Alternatively, as shown with Robert in chapter five, patients might also complain of problems which biomedical expertise are unable to make visible or solvable (Becker 1993) and, therefore, the patient does not have their complaints legitimised.

The hidden nature of many affects of ABI makes them all the more difficult to comprehend, both by the patient and others. The trajectory from illness to wellness is not a straightforward, lineal process. Often, affects attributable to the ABI do not become apparent until long after any medical intervention (Corrigan et al. 1998), thus, according to a traditional illness model, giving the appearance that the person with an ABI has regressed. In biomedical terms, these feelings of disappointment, even depression, can often be re-configured as a result of 'improved insight', allowing the narrative to be consistent with an illness to wellness model. As shown in the previous chapter, the organisation of ward practices means that regimented procedures unintentionally mask problems as the patient is simply not faced with having to accomplish them. For example, a patient

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<sup>22</sup> A good example of this is when I discuss Margaret on pg.153.

may have not realised that they are unable to wash the dishes in a systematic fashion if they had not been required to do so. This can also result in the assumption by the patient or family that they have regressed and this can have a significant, symbolic impact. The confusion, frustration and anxiety of not being able to comprehend an 'illness' which does not 'behave' as the biomedical model of illness expects, greatly exacerbates the other problems experienced.

In addition to the uneasy relationship between illness and wellness, relationships with time and space are complex and inconsistent. As already established, rehabilitation can take months, years or can be a lifelong process. Chronic illness struggles to align with a biomedical model of illness which is considered to work in precise measures and times. One of the most important cultural markers that differentiate between illness and wellness is the medical site such as hospital. Put simply, it is often assumed that the hospital is where people go when ill and they either get worse and die or, after an acceptable amount of time, they leave when 'better'. This is often not the case for many ABI patients and after many ABIs, patients found they left the hospital without the certainty and understanding that they had reached what they or their family identified as 'wellness'. This would often come as a major disruption to many patients and family members. For example, in an interview with Karen, a social worker in her 40s who received an ABI after an aneurysm, whilst happy to be discharged, still felt very unwell which she felt was particularly worrying:

*I thought that I would die. Even though I was discharged, I still thought I was going to die. As I went to bed at night I was crying, hanging onto my husband because I thought I was going to die because I still had pain which is not normal.*

Karen felt it was abnormal to still feel pain despite being discharged from hospital, a symbolic action that she identified with 'wellness'. The realisation that she still had issues was in many ways as distressing as the difficulties themselves. Interestingly, some healthcare professionals in this study describe being shocked to discover that this socially understood marker of wellness, discharge from the setting, is not reliable here. A rehabilitation coach working in the community with ABI patients explained that she only came to realise how much people were not 'well' when she moved to work in the community from the ward.

The lack of 'fit' between ABI and configuration of patient has the potential to disrupt the very understanding of the concept of 'illness' for the individual. The biomedical model of managing illness and disease is deeply embedded in our everyday practices (Foucault 1978). It is bound up with the

encouragement to consider the body as an 'object', an artefact where components can be isolated, worked on and fixed using precise techniques, measures and expertise. For the professionals, considering the body as an object, however complex, allows them to determine markers which highlight current problems as well as giving potential for realising 'wellness'. It is not just professionals who consider the body in this way; indeed, many of the patients and carers would often also talk about their body and illness from this perspective, at least initially. During interviews, a complaint amongst carers was a perceived lack of forthcoming information from professionals in regards to their loved one, particularly in terms of prognosis and progress. Sophie, a carer for Colin (husband), described this:

*And when Colin left intensive care I was struggling to find out what was going on. And you feel awful asking but at the end of the day, I kind of got to the point where I felt I kind of need to know what's going on and I was conscious that I didn't know... you can't be there when they're doing their round anyway so I struggle to get information. I would try and speak to the nurse on A1 because he'd had by then a tracheotomy as well, he couldn't talk very well. I was trying to sort of, because he was trying to speak so I'd asked the nurse on A1 this (or if) he'd had physio or something and they didn't know so I didn't know what was going on with him.*

Sophie found it very difficult on a practical level to gather information about her husband. She did not know the exact person to speak to or what help he was already being given. Colin was unable to provide this information himself. This information was for more than just logistical purposes. Carers felt it was a fundamental tool for them to be able to configure their loved one in relation to their ABI. Severity of injury, percentage of function left and time needed to get better were all markers being sought out by desperate loved ones in the early stages. As well as carers, patients would also be frustrated with a lack of coherent information. Karen explains:

*I would like to have had somebody who was experienced expertise in the field, because there's not a lot of people out there who've got that, to speak to me and to tell me that these feelings, these pains are normal, you may expect this or this and if you do, this is how you manage it, give us a ring or something.*

Having no definitive answers meant there was confusion and frustration. There was lack of 'fit' between the expected 'science' of medicine and the actuality of this highly unpredictable state. Even

the medical terminology used by professionals could feel misplaced for some ABI patients. Janet, a member of one of the community groups, would often explain that she had a condition rather than an injury or illness. In an interview, she explains: “*you injure your leg. I’m not broken*”. She feels so strongly about this difference that she finds some elements of rehabilitation inaccessible as it constructs a presentation of self in which she does not fit. An event did not happen to break her and there is no marked definition of wellness. A simple use of a word, injury in place of condition, re-configures an entire relationship between an identity, ABI and rehabilitation. On the other hand, a regular member of several community brain injury support groups, Bethan, preferred injury, comparing it to being better than the word damaged. As she interpreted it, “*damage can’t be recovered from. Damage is like damaged goods*”. This simple differentiation plays a significant part in the way in which the patient constructs their injury and, more importantly, by the way they define the potential for wellness. Culturally defined terms can also be important. For example, Andrew, a navy veteran, had considerable reservations with having any part of his ABI labelled or linked to notions of mental illness. He preferred the word damaged as this was in keeping with what he understands. Distinctions between neurological damage and mental health issues were important to him. This shows how the same term can be acceptable for one whilst it is full of negative connotations for another.

When the experiences of many patients failed to live up to the cultural expectations of illness which were found to be unreliable, this might add to the sense of confusion, anxiety and frustration. Patients respond to this in different ways, using different strategies in order to rectify the discrepancy. I now consider this in more detail.

### ***Patients attempt to use the biomedical model***

The expectations of what it is to ‘do patient’ can be confusing during ABI rehabilitation. Many patients and family members report how it could be unclear to know what is best to do; as shown, information given could be sparse and even conflicting. The lack of clarification from a trusted resource, and the corresponding lack of direction in terms of strategy for recovery, could often be more of a concern than the effects of the ABI itself. The common agreement amongst healthcare professionals is that the first two years of recovery are the most vital. This is the period that the majority of recovery will take place with signs of obvious improvements beginning to plateau after this time (Headway UK 2016). Many patients report being aware of this ‘window’ and several grew anxious that they were not maximising this time fully. However, ABI rehabilitation is full of

contradictions. For example, Winnie, a patient in her early 60's in the rehabilitation hospital following a stroke, reported how it was important to exercise but not to over exert for fear of doing more damage. Also, due to issues around potential fatigue, many patients are encouraged to rest before they felt tired, meaning they perceived themselves to be not taking up opportunities when their instinct would be to keep going. Healthcare professionals would comment that it is difficult for patients to recognise the importance of 'doing nothing' and this would often be a source of frustration for both groups.

In addition to the desperation to recover as quickly and fully as possible, it seems the patient (and family members) had a heightened sense of awareness of the social connotations and importance associated with being seen to be 'doing patient' correctly. This is not only a concern with how they are being perceived by professionals but by other patients, friends and family as well. The assumption that 'more is better' meant that by doing nothing or by not giving their all, the patient was at odds with the expected performance required. The nature of medical discourse is so embedded that some patients reported feeling guilty if they felt they were not doing all they could to recover. They also reported a sense of satisfaction when they were taking part in activities designed to aid rehabilitation even if they were unsure what good it did. As Daniel showed in chapter five, it was not the actions in themselves which were necessarily important but the symbolism of what it represented; the importance was in 'being seen to try'.

This all comes together to paint a very confused picture for the patient, struggling to configure their experiences against an ill-fitting medical discourse. For example, in an interview, Karen explained that the "not knowing" was the worst part (interview notes). By this, she meant the not knowing of whether her illness would reoccur, when she would start feeling better and if she was doing the right things to aid recovery. She explained:

*I just wanted to know what happened to me, why did it happen, what caused it, what can I do to aid my recovery and speed up my recovery. Please tell me, anything. I will do anything... You know. What food should I eat? Should I be doing exercise? All these silly questions and nobody to ask at all.*

For Karen, the sense of powerlessness was as significant as the headaches and fatigue she experienced. Karen had configured her illness to be understood on a lineal trajectory and she often struggled to make her illness 'fit' this configuration. For Karen, you are ill, you do (or do not do)

certain things and, as a result, you get better. The sense of unknowing was difficult to come to terms with. Whilst having some reservations about health care professionals, Karen did have a strong faith in a biomedical discourse. She felt that doctors should know what to expect and she found it difficult to imagine an illness where the traditional markers of illness and wellness were missing (or were at least ill defined).

As a result of these missing measures of wellness, Karen would construct her own in order to make sense of herself in relation to her ABI alongside a biomedical interpretation of her illness. Often, these measures would initially appear to be relatively arbitrary with little relation to professional expectations. For example, Karen, interviewed in the summer, explained that she was giving herself till New Year's Day to get better. She decided that however she was feeling and presenting in terms of recovery at that point, this would be the end point in terms of the extent of her recovery and the best she could hope to be. This date was based on nothing other than the need to install a marker with which progress could be measured, defined and judged in order for the ABI to be comprehended. In comparison to others, she was relatively recently post-injury, a matter of months rather than years, yet she felt that she needed to get on with life and without anything tangible coming from the healthcare professionals, she would install her own measures.

At times, personal measures of success can become intertwined with medical interpretations. For example, Sandra, a woman in her 50's who collapsed at home with a brain haemorrhage, put a great deal of emphasis on being able to apply her own makeup. For Sandra, this would be a significant measure of success. When she met a fellow patient in an ABI community support group who was able to do this, she became very upset as she was still unable herself. However, when she later discovered that the type of operation the other patient had received (having a coil rather than a shunt inserted) differed to her, she used this to comprehend the difference in competency. Sandra assumed that her operation was more difficult to recover from (even though there is no medical evidence base for this assumption). This assumption allowed her to continue to see putting on makeup as a goal that was achievable. It meant that she was still able to manage and be in control. In this instance, Sandra had produced a highly personal, social measure of success, but had used a medical configuration, though not one used by professionals themselves, to keep this goal in play.

### ***Different narratives as performance of patient***

In order to make sense of such a potentially huge biographical disruption (Bury 1982; Becker 1999) such as ABI, patients and family members might begin to present a narrative which gives a particular performance of 'patient' (Parker and Wiltshire 2009). Narratives are vital to "give coherence to the distinctive events and long-term course of suffering," (Kleinman 1988 pg.49). Traditional narratives described in medical sociology (e.g. Frank 1995; Nettleton 2013) are typically restitution narratives (typified by the Parsonian sick role), quest narratives (when the sufferer believes there is something to be gained from the experience) and the chaos narrative (where there is no clear beginning, plot or recognisable journey through the experience). Whilst there were certainly aspects of all three of these narratives throughout many of the interviews and observations as part of this fieldwork, it would be too simplistic to suggest that a story was always exclusively one or another. Additionally, other narratives came into focus which may not satisfyingly fit any of the previous narratives. For example, a common narrative amongst patients was a 'success' narrative, similar to a restitution narrative but with some key differences. The patient positions themselves, or they are positioned by others, as someone who beat the odds. They have achieved or even excelled against all expectations. For example, in an interview with Sandra, who was eight months post-injury and had significant emotional issues, she describes her initial prognosis:

*They told my husband that if I did survive I would be very disabled... they were going to do one last test and if I didn't respond I would be 'turned off.'*

Here, Sandra is describing her closeness to death. She felt her life was literally in the hands of others with all medical expectations being contrary to the eventual outcome. She and she alone managed to fight back against both the intensity of the ABI but also this giant medical machine. She even uses the term "they" in order to other herself from the professionals. This emphasises that she did it alone. Not only did she beat the odds but she exceeded all expectations. She has little visible signs of disability which she configures as evidence of not just surviving but as a measure of 'wellness', making a recovery that far outweighed expectation. Professionals viewed this interpretation differently and in community brain injury team meetings they would highlight the lack of visibility as highly problematic for her being able to understand her difficulties.

However, even the success narrative will often have large components of a chaos narrative included. Without the traditional characteristics of illness, such as having defined and agreed problems to be addressed alongside a timescale of improvement which could be deemed reliable, many patients felt

this sense of chaos.<sup>23</sup> Alongside this sense of chaos would often be a sense of 'undeserving'. The undeserving narrative was certainly employed by Sharon, the wife of Geraint as the following extract from field notes shows:

*Sharon explained that Geraint's heart had stopped without warning on holiday in the Canaries. She described it as "your worst nightmare." She said how he was "black belt in karate, the last person you would expect it to happen to."*

Sharon portrays Geraint as a strong, masculine person who went to some length to keep fit. To receive an ABI in the way that he did (hypoxia due to a heart attack) is something which they could not possibly have expected. The narrative emphasised that, in accordance with the sick role, he was deserving of his place in the hospital and for the accompanying sympathy and assistance that comes with it. Similarly, in an interview with Liz (first described in chapter five), she went to some length to emphasise the particularly unfortunate timing of her injury as it coincided with a series of positive, life-changing events. She explained that on the day of her injury:

*We'd been accepted as foster carers. At teatime, we booked our flights to go and see my son in Australia and it was like a trip of a lifetime because we never been that far and we would be going club class because we have a friend who works for British Airways.*

The approval to be a foster carer was the fulfilment of a lifelong ambition, as was the holiday. All this was now on indefinite hold as the confusion of her ABI was ongoing. In both narratives, the ABI is considered to have been undeserved, adding to the sense of blamelessness.

Regardless of the narrative adopted, many patients would often describe an overriding feeling of how lucky they felt. Most often, this would be described as a feeling of good fortune and relief that they had not actually died in the incident that resulted in the injury. The experience of seeing others with more severe, often more tangible difficulties also made them feel lucky, considering how much worse things could have been. However, despite these claims of feeling fortunate, the actions of individuals and the day-to-day practices would not always bear this out. Many would claim to feel

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<sup>23</sup> In keeping within the use of the sick role as a heuristic device, we can also consider that the success narrative emphasises, even exaggerates, the expected accomplishment of some form of betterment whilst the chaos narrative attempts to give excuse and remove blame from failed attempts.

lucky on the one hand whilst describing in some depth how difficult life now was. The performance of 'good patient' might come into play here. Whilst it is necessary to find the state of illness undesirable, it is important to be motivated to recover and the feeling of being lucky to have survived plays a fundamental part in giving a performance of this. For example, Karen explains that:

*I'm very very lucky. I know I'm very lucky. I'm having a psychology assessment at the moment, and having the last one tomorrow but I know deep down, cognitively I'm not too bad.*

However, she then goes on to say:

*I think it's because I felt so unwell for such a long long time it petrifies me that when I'm on my own I'm going to feel pain and feel dizzy and I'm going to panic and I also worry about seizures. I haven't had any touch wood. But there is a risk and that's something which I'm finding really difficult to live with.*

The front stage is the presentation of gratitude, both for surviving and the opportunity to improve further, but the day-to-day reality means this is difficult to keep up. The back stage is momentarily revealed which shows the frustration, anxiety, and tiredness as well as the huge amount of fear that comes with it all.

### ***An alternative discourse is attempted***

The organisation of the ward reinforces the medicalised concepts that help the professionals to make improvements visible. The nurses are given recommendations by the specialists as to how to work with the individual. The expertise of the staff is taken into account when making this decision but scores and measures are privileged. In an interview with the speech and language therapist, she recognised this, explaining that following an informal series of conversations with a patient, she will then carry out a more formal assessment:

*Tim: And so what exactly does the formal assessment achieve which the informal doesn't?*

*Ellen: I suppose it... It confirms your hypothesis and I suppose the more experienced you are as a speech therapist, the more correct your hypothesis. Sometimes you're proved wrong, you know you get more experience of seeing different sorts of communication problems so...*

*and also a formal assessment will give you a baseline so that you know exactly where you are at the beginning so you have something to begin with.*

The expertise of the speech and language therapist is very useful but to be valid, it needs to be turned into a measurable score. This is not to say that experience of the staff is not taken into account. The circumstances of the individual will often be discussed and a clinical picture will be established using a combination of observations and measures. However, the score will be sufficient to hold the patient on certain grounds because this is the trump card. This is 'good medicine'.

As rehabilitation takes place, patients may begin to re-imagine their ABI using a different discourse to the biomedical. ABI becomes configured differently with alternative markers used as ways of comprehension. A new, more social discourse emerges. The medical discourse may still play a role, often an important one, but it is more complementary, used to compare against other assumptions with an acceptance that it is only one lens through which to constitute illness.

For some ABI patients, however, the understanding of ABI through the biomedical was never particularly helpful. Similar to that of other patients with chronic, hidden illnesses (Goode 1997; Rudge and Morse 2001), for many people, the ABI is represented by something significantly more embodied. The consequences of the injury can only be understood as experiential. Many patients would often suggest, *"you cannot know what it is to have an ABI unless you have one"* (field notes). Measures from tests or knowledge of the exact part of the brain injured do not do enough to define or even describe the ABI. As Liz explains:

*I think it's important for knowing that every injury is different with different severities really and maybe yours was a little bit more severe than the other but then like another lady that you've come across, she been at a lot of our meetings, I know she has a lot of difficulties dealing with things but then she tries to say "oh I had a grade this" and there am I thinking what's a grade? Why should people refer to their haemorrhage as a grade because if you've had an injury you've had an injury and it doesn't matter if you've had a mild injury or a...yeah a whopping one you know and like I remember one day she said I died... I died seven times or something and (laughing) I only died three times...because you know well it's not about that it's about what we are now and what we are endeavoring to be and (that we're) recovering not what we had because... it doesn't matter what grade it was. I don't know what grade it was or whatever.*

The reduction of the illness into a medical label, a grade, fundamentally misses the point. Liz feels this is too restrictive, unable to articulate the experience of an ABI as a lived experience. For Liz, the ABI is not what is important; it is relative to the individual and what should be recognised is the attempt being made to do the best they can in relation to their own unique situation. Also, by giving measures, Liz recognises that individuals use these numbers, no matter how arbitrary they appear, to compare to emphasise severity and, in turn, legitimisation. She feels that trying to compare, by its very nature, promotes a hierarchical system of 'deserving' which is misplaced here. She jokes that she is less worthy than another patient as she only "*died*" three times in comparison to a more impressive seven!

Even here though, patients recognise the medical discourse as an extremely powerful tool for communicating illness. Even if defining ABI in this way does not feel suitable to explain the lived experience, many patients would still refer back to this discourse for the purpose of emphasising such attributes as severity, expertise and rates of recovery. Importantly, even Liz tells the story of her illness in terms of length of time in a coma and then in hospital. The medical discourse is the most established way of understanding and communicating illness. Communicating in this way is felt to add credibility and legitimation to the narrative. It is so embedded in every day practices that it is not seen as a complicated step to move between a medical and other discourses. The medical is the way to describe to others whilst other discourses are a more personal way of making sense of it.

During fieldwork and particularly in interviews, many patients would consider their ABI in relation to how it impacts on themselves rather than through a medical definition or score. Theirs was an ABI understood out of personalised experiences. Therefore, each ABI is a different 'thing', made up of different artefacts that constitute it, individualised to each patient. These artefacts are made up of deeper, personal, symbolic experiences which often act in relation to a perceived sense of prior self (Mol 2002). This led to some interesting interpretations which could often be considerably different to the presentation of illness laid out by a medical discourse.

For example, Janet, a woman in her late 50's, and her husband were enthusiastic but not ambitious, walkers who would spend a great deal of their time together walking the various footpaths of the local area. They lived what could be described as a slightly dysfunctional life. Janet received an ABI through a rare condition called Chiari Malformation meaning that the skull was too small for the brain. As a result of her condition, Janet felt pain in her legs and backside. In fact, it was this pain

that alerted them to any sense of there being a problem in the first place with no indication that the issue may lie in the head or brain. It took a great deal of time and several trips to various doctors before the issue was located and configured as a brain condition. Janet underwent several operations to alleviate the pressure and in doing so, the side effects mean that Janet experiences difficulties with concentration, understanding and anxiety (traditional ABI territory). However, for Janet, whilst these issues are problematic, they are manageable. Her prior identity was slightly chaotic and her new self is a more exaggerated version of this. That is not to say that she does not find these issues distressing, only they have less severe impact on her than they might for others. For Janet, her ABI configuration is, and has always been, located in her backside. This is where the problem started, currently lies and this is where she is most affected as the pain in her legs means she can no longer take part in her true passion of walking with her husband. She does not find a medical discourse helpful in the slightest for understanding her condition. Not only does the location of her problem, the brain, appear to be misplaced, but she has little familiarity with medical concepts and reinterprets the discourse in order to suit her own understandings. For example, in interpreting the division of labour between a neurologist and a surgeon, she explains:

*The surgeon cuts you open, he does the paper work.*

When her operation had to be repeated when the installed shunt failed and had to be replaced, she says that:

*They got the first one from Aldi and the second from Marks and Spencer's.<sup>24</sup>*

By using concepts she is familiar with, Janet removes the situation from the medical into a discourse she is more comfortable with allowing her to understand and be able to explain her situation to others. Similar to Liz, Janet also finds scores and measures unhelpful for representing her issues. Taking up the undeserving narrative, the fact that the condition came without a specific insult to the brain and prevents her walking is something that Janet and her husband find difficult to come to terms with. In the same interview, her husband Graham stated:

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<sup>24</sup> Aldi is regarded as a budget supermarket whilst Marks and Spencer's is considered to be at the higher end of the grocery market.

*This is the thing because it's not everybody's cup of tea. I mean people watch football and whatever and that's fine but we have always been active and it's good healthy exercise. If you are being asked to give up class A drugs or cake well, then you think okay, fair enough, you know I shouldn't really be doing that. But you know what's more healthy than walking especially because round here is so gorgeous? That's what we find so hard to take.*

Perceptions akin to the sick role again play a crucial part here. Janet is blameless for her injury and both she and Graham feel this deeply. Janet feels that she has a lot of trouble in understanding the consequences of her injury without having a clear explanation as to why it happened in the first place. This is an important part of configuring self in relation to illness and is absent thereby leading to a chaos narrative. The lack of a coherent narrative means that she might struggle to use traditional markers to configure herself as 'patient'. There was no event that led to a biographical disruption, no clear distinction between a prior and a current self. There is also a bitterness that the injury is preventing what would be typically regarded as a healthy practice; walking. The sense of injustice was particularly difficult to come to terms with.

The most significant outcomes of the injury might often not be constituted through markers in relation to the body directly but are more evidenced through the consequences they have on the experiencing of life by the individual (Bury 1991). Margaret, a lady in her early 60's, was home after spending several months on the neuro acute and, after a short break, rehabilitation ward. She described how the most significant effects of her injury was having to give up work as well as no longer being deemed fit to look after her elderly mother. Margaret used to work part-time as a secretary and, despite nearing retirement herself, would spend much of the rest of her time visiting her mother who lived a short walk away. For Margaret, the two most significant factors of her life for constructing her identity, ones that gave her a sense of reward and duty, were both taken away simultaneously and instantly. In an interview, she described these as the most significant outcomes of her injury:

*My whole life is changed hugely now... I am beginning to accept it now. In the beginning I hated it, when I first came home from hospital I was so, sitting twiddling my thumbs, I was just so bored.*

Here, her configuration of ABI has left the body to become something externalised. It is not a measurable score which can be improved but a set of consequences of these scores. The scores

suggested that she had poor memory and anxiety resulting in it being recommended that she take early retirement. Being 'good patient', Margaret went along with these recommendations. The difficulty here is that 'wellness' cannot be achieved in the sense that Margaret can go back to work or become a carer again. The decisions were made, with alternatives to her put in place. Therefore, the sense of rehabilitation to get back what is lost, to mend the biographical disruption (Bury 1982) is not applicable here. Margaret has to configure herself differently and use new markers to understand herself in order to present herself in a new way (Bury 1991; Castells 2003). However, she finds these new markers difficult to come by. She describes herself as becoming bored a great deal, struggling to find a sense of purpose to her day. Her ABI stripped her of the two most rewarding and defining parts of her life. Karen and Liz also commented on this. Working was so much more than merely a way of filling time or making money. It was a place which gave a sense of worth, importance and status, perhaps something they were not aware was so important until they were forced to give it up. Obviously, this would not be picked up on any brain scan yet is a far more influential part of life than the size of the original aneurysm.

So far, I have shown how patients struggle to marry up the biomedical interpretation of their injury to their lived experience, describing how others may even reject this discourse altogether. Lorenzo, a patient in his late 40's who emigrated with his family from Italy, finds it helpful to understand ABI in medical terms in specific instances but believes it is impossible to separate this from everyday life which is the context in which the consequences are carried out:

*I don't think the medical aspect is everything...as I said before I use the word holistic...Of course you need to understand (medical)... But it is not everything. You can have operations and things but there is what I call the post injury. I manage these things. It's not managing the operation. This thing, it had a significant impact on my life. There's this other aspect which is very important for me. It's really important. So it's not just that (medical) side. If the side that I suppose is initially where you're provided with information but you need a little bit more to understand exactly, perhaps I will put it under this umbrella. After an event like this where are you? What quality of life you can have? Which direction can you move?*

Lorenzo feels that rehabilitation is organised along a discourse which fixes the body but not necessarily the person. He feels the 'medical' is useful for providing an explanation for the injury but this should not be taken in isolation. Rather, it is relational and should be contextualised with true meaning of the injury understood by establishing the consequences that these changes have

produced (Pickersgill 2015). Lorenzo also believes that the medical explanation for the injury is relative to the impact it has on the particular life it has affected. For example, he recognises that he can no longer carry out his stressful job, though he believes he would have managed in another role had he been doing that at the time of his injury. The degree of injury, by measurable score as found in the occupational therapy discourse, may be the same but the impact, depending on the individual affected, can vary significantly. Therefore, the medical discourse only provides some of the story. The severity of the injury may remain constant but it is the circumstances that they affect which makes the difference.

Again, Lorenzo does not find labels very useful. He was diagnosed with epilepsy, a label which he explained that in isolation means little to him. He does not feel stigmatised by this label. However, the associated experiences he has are where he most notices a change. The medication he takes has meant that, so far, he has not had any more epileptic episodes. However, for Lorenzo, epilepsy means no longer being able to have a bath with the door locked. It also means he cannot drive. These restrictions have the potential to threaten not only how Lorenzo lives his life but the way he perceives himself and feels he is perceived by others. These are far more powerful, symbolic and prohibitive affects than the label or diagnosis itself.

An additional obstacle for Lorenzo is that he has been configured 'well' following tests after his operation. In recent discussions with healthcare professionals, he has been re-configured to that of 'worried well'. This has significant implications in terms of gaining access to financial and medical support as well as potentially being stigmatised by others. It was suggested to Lorenzo that anxiety is more to do with his coming to terms with both the massive trauma that took place and the realisation that his life has changed. It was also accepted that the anxiety may be a possible side effect from his medication. The fatigue is natural whilst he gets used to returning to work. Lorenzo does believe there to be some truth in this but, again, it is all too simplistic to assume it is a case of cause and effect. He does believe that it takes time to recover, both emotionally and psychologically, but he finds the lack of certainty, a direct result of his ABI, particularly difficult. In an interview, he describes his attempts at recovery as follows:

*I'm in a tunnel... I don't know how long the tunnel is so I cannot judge how long I have to go... You don't know where you are in this tunnel or when it will stop. You haven't got signposts to tell you you've got to go at this or that speed or another 50 miles will be the end of the tunnel. You know you are a little bit in the dark.*

I have shown in previous chapters how the patient can be re-configured and de-medicalised with their complaints being relegated to that of *'trivia'* (Jeffery 1979). Here, Lorenzo is showing the consequences of this for him and the added burden this can produce.

The outcomes of the injury might be compartmentalised in order to understand and describe but for patients, when they are applied specifically to a situation, it is the outcome which is of most importance. For example, having 'poor concentration' is just a label to Margaret but not being able to enjoy the soaps on TV is the tangible outcome which is the real issue. Similarly, having 'high levels of anxiety' is too abstract to understand in isolation. However, Margaret describes finding being a passenger in a car so worrying that she refuses to travel long journeys. Therefore, she has not managed to go on holiday this year. This is an outcome which is a very real consequence of ABI. It is the lived experience of ABI which is something fundamentally different from merely having a label named 'anxiety'.<sup>25</sup> Janet explains how she enjoys the ABI support group she visits. Her memory loss means that she has difficulties in remembering names. Memory loss on its own is an abstract term but when applied to the everyday, through the act of forgetting names, it plays out in real terms and has real consequences. Janet dislikes visiting places for fear she will appear rude when forgetting names. This, in turn, can affect her confidence. At the support group, she feels that nobody minds and, just as importantly, there are others in a similar position. Here, she can feel free of this anxiety.

Many of the patients reported having no prior knowledge of the consequences of ABI until they themselves received an injury. This lack of prior specific knowledge and experience is itself a major cause of anxiety. It adds to the complete sense of unknown as there is a lack of cultural references to draw upon for knowledge, advice and to measure expectations. As a result, many patients and family members will use their own interpretations of what an ABI might be like in order to make sense of the situation. Without specific references, they might draw on artefacts that feel as though they could help. For example, Sophie, whose husband had an ABI following a fall, explained in an interview that she would use techniques similar to those she used when her mother in law had dementia:

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<sup>25</sup> Lorenzo, stopping his stressful job is another good example of this (pg.146).

*What did help me, Colin's mother has Alzheimer's and I feel a lot of the way that Colin was, I think I would have been a bit more freaky had I not had the experience of her Alzheimer's to sort of... To understand a little bit about how Colin was.*

Sophie described how she would use techniques she had read in a book called 'Contented Dementia'. The premise of this is that the non-patient would be encouraged to play along with whatever reality the patient thought to be real. Sophie would do this on her visits to see Colin in hospital. Certain professionals would also do the same until a nurse arrived and suggested it was more appropriate "to keep Colin grounded". Despite these illnesses being quite different, without anything more concrete, Sophie would draw on these prior experiences to both understand what was happening from a medical perspective but to also understand what to do in order to help. The nurse had a different understanding of what it is to be living and adapting to living with a brain injury and, therefore, emphasised a different strategy. This is important as it shows how a different ontology can fundamentally change the experiences of the individual with ABI.

Another avenue used would be to draw on popular culture. Liz would explain that she was aware of two celebrities, the television presenter Richard Hammond and the Olympic rower James Cracknell, as two individuals who also received an ABI. She then went to some lengths to read and learn as much as she could about them and their injuries despite their particular difficulties, experiences and access to rehabilitation being fundamentally different to her own. Likewise, Winnie was aware of the TV presenter Andrew Marr having also had a stroke like her. She remembered reading how he felt he over-exerted himself doing exercises during rehabilitation leading to a further complication. This played on her mind considerably, fundamentally influencing the effort she gave to her rehabilitation. This was despite the perception this gave to fellow patients and healthcare professionals who sometimes commented that they felt she was not trying hard enough, potentially inadvertently affecting her 'performance of patient'.

One of the ironies of ABI can be that whilst many of the patients were both aware and keen to emphasise the individuality of their own ABI experience, some would still measure themselves against another in order to measure progress and effort despite regularly reporting how they disliked being compared themselves. This could be quite unhelpful at times as it meant that patients were making assumptions about self, and judgments against others, when parallels were not being drawn like-for-like. Winnie, for example, described how she had witnessed many patients come onto the ward and leave in the time she was there. Indeed she described herself as:

*“An island that has lost its ships”.*

She would witness other patients come and go, seemingly to her as recovering at a rate much quicker than herself. By using two markers, walking and discharge, as the measure of success, she felt she was significantly behind others in terms of recovery. Many of the patients she referred to had experienced different injuries to herself and, as a result, were able to walk again more quickly as this part of the brain had not been affected. Also, most were not acquiring, or able to afford, the level of adaptations which would be taking place to her home to make life easier for her when she did return. These changes were so substantial that discharge was being delayed for several months as a result. Most other patients were being discharged into more modest accommodation or were returning home as they had to try and find some form of employment to avoid severe financial hardship on the family. Without being able to appreciate this, Winnie would compare herself to others and make assumptions on her own wellness based on this.

Liz would also make sense of her injury by comparing herself to others. Whilst Liz disliked the suggestion that she was configuring patients as more deserving than others, she highlighted her observation that many men she met had received their injury through a specific event, often risk-taking behaviour, such as a road traffic accident. She felt that she, and other females, tended to be the victims of injuries or illnesses where the cause was more by chance and could not possibly be through any fault on the part of the patient, making it all the more unjust. She even likens the consequences of her injury to that of a prison sentence by rhetorically asking, *“What crime have I done?”* Patients conduct this work without even necessarily being conscious of it.

Comparison with others could also do more than become a measure of one’s own improvements. It was also used to gauge legitimacy. When Lucy collapsed in the pool as the result of an *“energy sap,”*<sup>26</sup> the extent of her de-medicalisation amongst professionals meant that she was held responsible for this (*field notes*). Winnie, on the other hand, saw it as further evidence of the difficulties that Lucy must have and, in turn, further legitimised her position. Winnie would also look

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<sup>26</sup> As commented earlier, this was another highly contested ailment amongst Lucy, her family and professionals. With no medical evidence to explain the cause of these immediate, and sometimes quite dramatic, losses of energy, they continued to be called energy saps. This was seen as both a “non-medical,” term and a by-word to suggest that it was not to be taken seriously by professionals, some of whom felt it was possibly attention seeking behaviour when other avenues for legitimisation were seen to be failing (*field notes*.)

at Leanne, a young girl opposite her, and remark upon the gains Leanne was making with some sense of pride and envy. She would often comment that Leanne was “*a remarkable girl*” who she was very proud of. Leanne, on the other hand, would look back at Winnie and configure her as illegitimate for the setting. By interpreting Winnie as lazy and de-motivated, Leanne felt Winnie was not performing ‘good patient’ well enough. She even suggested that:

*Winnie would live in hospital for the rest of her life if she could.*

By doing this, Leanne was both de-legitimising Winnie and her place in the hospital, but also legitimising herself as deserving as she was making every effort to improve by taking part in all her rehabilitation sessions.

In contrast, when expressing concerns about the lack of time nurses spend with her, Leanne explains that she understands why they spend more time with one particular patient, Vivian, because she is particularly ill. Leanne knows this because she has observed the various machines and tubes that Vivian has at her bedside; for Leanne the greater the amount and/or sophistication of technology involved in rehabilitation, the more ill the patient was. By placing significance on these artefacts, Leanne positions herself to be less in need than Vivian. Other patients, such as Winnie, often lacking technologies to display their illness in this way, do not get the same benefit from Leanne who will feel she deserves more attention.

### ***How an ABI relates to a wider consideration of self and presentation of identity***

I have established how patients attempt to configure their ABI in order to understand and come to terms with it. I now go further by considering how, through living with the outcomes of an ABI, it reflects onto a larger consideration of self and presentation of identity. No matter the intensity of the relationship between the individual and their ABI, very often, future actions and behaviours are understood in relation to having an ABI. Patients would become frustrated when things went wrong, blaming the ABI for mistakes made. For example, a member of the CBIT communications group explained her frustration at being unable to book a taxi for a night out she was planning for her friends. During the communications group, patients discussed and began to recognise that not only might they have made the same mistakes before their injury, but those without an ABI might also make similar mistakes. Many patients took great comfort from this though it took a fundamental attitudinal shift to begin to think in this way. These are not notions which are easy to reconcile when

the ABI is such a dominant component of an individual's understanding of self and requires an ontological and epistemological shift to begin to allow other factors to account for experiences (Nochi 1998; Ownsworth 2014). In the group, when a member then forgot to bring her homework for the next session, she immediately reverted back to the ABI as the cause of this showing how unstable and untrustworthy alternative accounts can be regarded.

Often, the ABI could be located to a specific point in time, constructing a moment when a pre-existing self stopped and a new self began. Many of the patients would know the exact date of their injury and several might even mark the anniversary in some way. Many would become particularly emotional as the specific date came around each year, the date becoming a symbolic marker of both remembrance and celebration. Karen notes that:

*Karen: For me I want to get this year over with.*

*Tim: Literally the year as in after December?*

*Karen: Because it happened in December, a week before Christmas so... I get quite anxious about the anniversary.*

Sometimes, the date becomes all the more important as the incident that resulted in the ABI would come with a sense of detachment for the patient. Many of the patients had no memory of either the incident or the days or weeks that followed. They would rely on family members to give them an indication of what their body experienced. These would often be harrowing highlights resulting in several patients explaining they were glad that they could not remember. However, by having no sense of belonging to such a life-changing event, this also has another consequence. It metaphorically transfers the illness from the patient onto the family members. They were the ones that suffered. From the outside looking in, the event itself provides a substantial marker in which lives would often be changed forever but for the patient, whilst there is certainly a before and after, the exact moment when these separate is less pronounced:

*Tim: Do you feel detached from it (the incident)?*

*Liz: Very much so. Very much so. It happened but it happened (pauses) too many people say it happened to me and I say no it happened to my children and my husband, I was just there and they went through it because it's now (pauses) It's now I'm going through it. It's now.*

The disruption to Liz's biography was recognised by those living with Liz before she recognised it herself. Only now is Liz beginning to realise the extent and consequences of her injury, going through the individual reconsideration of self that her relatives faced much earlier (and, in some instances, are starting to move on from). This can only add to the frustration and misunderstanding, especially in the initial stages of recovery. It also shows how other biographies, apart from Liz's, are disrupted but perhaps follow different trajectories.

### ***Negotiated concepts of wellness***

The difference between ABI and most other illnesses is that the very organ being used to make sense of the situation, the brain, is the object under scrutiny. The biological, psychological and emotional damage that comes through an insult to the brain can be perceived to fundamentally shape the patient's interpretation of self. This is not to say that the patient's view is therefore somehow incorrect. Quite the reverse; it is a perfectly valid, unique representation of self. What it does mean, however, is that for those still trying to configure recovery with markers where success would constitute a return to a previous life, this can be made all the more difficult because that understanding of self, the lens, is showing a different picture. This picture might be considered unreliable, fairly or otherwise, by professionals and others such as family members who knew the patient pre-injury. ABI patients might see themselves as a pre-injured self that, according to loved ones, is exaggerated or idealised, making a return to that pre-injured ideal almost impossible to attain. This is not necessarily exclusive to brain injury. Patients with a chronic illness can often produce concepts of a prior self that is considered to be idealistic (Charmaz 1987; Shakespeare et al. 1996; Sparkes et al. 2002). However, in ABI, additional factors such as memory loss and a reliance on others to piece together fragments of a narrative to make sense of the situation, exacerbate this further. For Janet, wellness will only be achieved when she is taking part in significant walking expeditions with her husband. According to her husband, interviewed alongside her, the difference between Janet's ability pre and post injury, whilst noticeable, is not as significant as Janet remembers. He feels her perceptions of her previous abilities and resulting configuration of self sets her up for a substantial fall as she has an expectancy which is almost certainly unattainable, including a view of previous self which, in his view, is not valid.

This romanticised prior self can be particularly problematic when it is coupled with an unwavering belief that nothing short of a complete return to a previous concept of self will be accepted. For example, Sandra felt a very strong association with work and was clearly very proud of the position

she has achieved. She has a tremendous sense of guilt that she was receiving “sick pay” whilst she was off as she felt she deserved nothing as she was not working. When her employers were advised by healthcare professionals that she was unlikely to be able to return at the level she had previously, she was offered work at a lower band. Rather than be seen as a relief, this devastated her. She claimed:

*They said they would possibly look for a job that 'I was capable of.' I'd be off the management, they would look for a suitable lower job for me that I was capable of. That hurt immensely.*

For Sandra, it was all or nothing. She felt that she had to work at the level she had always done or she had not achieved wellness. Not only that but her status and sense of self was being significantly challenged and, to her at least, was being fundamentally undermined by this new work arrangement.

As I have shown, concepts of illness and wellness are highly subjective and when trying to configure ‘patient’, it is often necessary for these definitions to be negotiated. When the very markers, the tools used as terms of reference, differ between the actors involved, this can sometimes make a successful negotiation superficial at best and impossible at worst. As discussed in chapter five, professionals might attempt to configure issues, such as anger, frustration or anxiety, in medical terms. This can sometimes be deemed unacceptable by patients, and often family members, who reject this position, favouring a more social basis. Here, Margaret describes undergoing assessments during visits to see the psychologist whilst a patient in the rehabilitation hospital:

*I've come away each time (from meetings with the psychologist) in tears and I used to like her such a lot but I was in such a state because I felt so stupid and the daft thing is I've never been good at things like that you know, like mental arithmetic. I can remember being in school and being useless at mental arithmetic so of course I'm there and trying to, especially at my age doing things that I haven't done for absolutely 100 years, I was in such a state and I used to say Julie do you think it's not my brain just I'm permanently dull?*

Here, Margaret felt that the very discourse used to configure her were misplaced and therefore misrepresentative. She bought into a medical model, to a point, though this was not to be at the expense of her own experiences and was not to ignore her pre-injured self.

The negotiation of wellness is necessary to be able to form and agree on markers which measure and establish if and when 'wellness' has, indeed, been achieved. This takes place between various healthcare professionals, family members and the patients themselves. Consensus as to the agreed markers can be made formally, through goal planning meetings etc. However, they are often also accomplished through informal arrangements, continuously being shaped and redefined through interactions between the various actors involved. To accomplish this practice, some of the most fundamental questions have to be asked which might normally go unquestioned. This might not be explicitly asked, but rather constitute an agreed set of principles that become realised through everyday talk. For example, it has to be negotiated what it is that is going to be made better. Is it an activity, a range of movement, a mood or something external such as a return to work? This is when the performance of 'patient' plays a crucial role. Even if the patient does not agree with the markers, and even if it is known that they disagree with the markers, as long as they are being 'seen to try', this can be enough. They are performing 'good patient' accordingly. This makes them trustworthy. For example, Bethan, a mother in her 30s, relished the confidence she now felt allowing her to be more outspoken. However, she attended a communications group designed to improve social interactions. This included being told when it was considered polite or impolite to express views. It may have been 'agreed' through her attendance at the group that improvement of communication was a goal to be achieved, but her story and attitude betrays this agreement. I give further evidence of this when discussing patient perspectives of ward life in the next chapter.

Another important question asked is when has 'wellness' been achieved? How can this be agreed upon? For Sandra, a return to work was not enough. It had to be the role that she previously occupied. Otherwise, wellness had not been achieved. In this instance, the defined understanding between the professional and the patient seemed to be at odds despite the initial goal, a return to work being agreed.<sup>27</sup> Putting a percentage on the extent that an individual can wash themselves or put on their clothes might be useful for professionals to measure progress but for some patients, just like the way Sandra considers work, it is all or nothing. I can either dress or I cannot.

It is important to understand that constructing the world around them in this new way takes a significant reconsideration of self. After her stroke, Winnie would rely on others to brush her hair.

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<sup>27</sup> Eventually, Sandra re-negotiated wellness with herself and decided that wellness was "not getting worse." This was a fundamental shift from the previous understanding of "getting back to normal." It is unclear what brought about this change of attitude

This was something which she desperately wanted to do for herself again. However, for Winnie, brushing hair was not a few strokes in the direction of her head before handing over the intricacies of tying it up and so on, to a professional. For Winnie she felt that unless she had accomplished the whole task, she had accomplished nothing. Winnie was previously taking a Masters degree in order to become a sport therapist. Keen on sports, she would explain how she would take part in activities such as dance, yoga and tennis in order to de-stress. They became important tools in how she came to understand herself but her physical disabilities now made participating very difficult to accomplish. This fundamental shift in understanding success did not come easy to her.

It is a complex skill to be able to reinterpret the world around you in order to break down and qualify certain activities as markers of accomplishment (very much part of a biomedical discourse). For those that do this, it means that they can be configured all the more comfortably. They are fulfilling their sick role by being in agreement as to the markers of success and acknowledging that wellness is being achieved. However, this could negatively impact on those who did not ascribe to such a perspective. Winnie, for instance, was also left unable to walk and recovering from this became almost her sole ambition. This became her primary goal to the point it became a point of conflict as she describes:

*And of course I nearly went ballistic when I saw one of them (an occupational therapist). He told me he had put me down for an electric wheelchair and I just thought I didn't come to (Rehabilitation Hospital) for this. I didn't come to go out in an electric wheelchair because it was as if they had given up on me already so I would be stuck in one of those for the rest of my life.*

The occupational therapist (OT) had configured Winnie and the wheelchair in a completely different way. To the OT, this technology represented freedom but, perhaps more importantly, it represented progress. For Winnie, however, the reverse was true. She only understood walking as all or nothing. There was no negotiation in this. This attitude occasionally provided a consideration of a re-configuration of Winnie by healthcare professionals; she was becoming potentially untrustworthy. There were differing narratives of her with some, professionals and patients alike, finding her difficult to figure. On the one hand, she presented as 'good patient'; polite, enthusiastic and motivated, yet at other times she appeared to not be making any progress, nor (perhaps more importantly) appearing willing to try to make any progress. A subsequent conversation with Winnie may go some way to understanding this further. Winnie explained that before her injury, she had

very little to do with disability. Even now, she refuses to use this word to describe herself because she felt it represented helplessness. By her account, she had always been an achiever and always felt in control. She explained that this was the first time that she felt both out of control and not able to achieve what she wanted. This relationship to her rehabilitation is a direct consequence of her previous understandings of herself and disability. For Winnie, to try elements of rehabilitation and to not succeed fully is to fail. She had not negotiated a recognisable achievement and this to her was de-motivating to the point of stifling any progress.

Similarly, Robert had issues with being associated with people he recognised as disabled. During an MDT meeting, it was commented that he had certain misgivings about a supported housing unit that he had been assigned to which was down to having to share it with other individuals in wheelchairs. Staff thought this decision by Robert was odd as it did not seem to take into account what the staff at least saw as his rather obvious disabilities. However, this is to ignore the associating factors. For Robert, being around disability meant that he had not achieved 'wellness'. He wanted to be regarded as well and, for Robert, wellness was not being associated with disability.

### ***Negotiating down***

Much of rehabilitation is about the reconsideration of self. Rather than seeing rehabilitation as 'getting back to normal', patients are often confronted with the potential necessity of having to understand a new 'normal' (Becker 1999). Learning to re-configure wellness in this way takes time and skill, often negotiated through multiple interactions between patients, professionals and family members as well as through interacting with the rituals and rhythms of the organisation of medical discourse and medical settings. When a patient first enters the ward, they might comment that their goals include wishing to play tennis again or going back to work. As discussed, rehabilitation will often break down components of these overall goals into more simple components. Prolonged exposure to this practice socialises the patient, leading to many beginning to also consider their own recovery in this way. Everyday activities, considered so trivial in normal life that they are not worthy of remark, become major landmarks. For example, Karen remembered that when she was on the ward, she became excited about being able to go to the lavatory on her own. It was a move towards independence and dignity. It humanised her. It was also symbolic in what it represented, recovery and progress. This task was something tangible. In addition, the boredom of having nothing to do on the ward meant that, for Karen, going to the loo was at least something different! She looked forward to going to the lavatory, even planning it into her morning schedule. In the CBIT anxiety

management group, Margaret reported that she had a small glass of wine at home. She did not particularly feel she wanted one but it was on her list of markers which defined steps towards recovery. She was cheered and supported by the rest of the group when reporting this news. This would have previously have been an action which would have been quite strange to specifically comment on and even stranger to cheer someone on for. The group recognition of the importance of this symbolic action was acknowledgement of progress. It also shows that the group have become socialised into this process. Margaret initially wanted to go back to work and look after her mother. She had to learn to recognise that these were not markers that others, namely her family and healthcare professionals, shared. Therefore, she had to re-configure markers of success. As a result, she was now happy that she was able to drink a glass of wine. This marker only became recognisable as progress after other markers, such as going back to work, were negotiated down.

Patients unable to define their own small markers can be encouraged to find and accept them from others, often the healthcare professionals. Geraint, a former karate instructor, now had to learn to redefine success through the act of moving several small steps using a frame, or by being able to put on a pair of trousers with minimal assistance. During a physio session, Geraint was walking up and down the social room, using markers on the floor to establish arbitrary distances. He was flanked on either side by a physiotherapist and her assistant. He is asked, *"Is it nice to be walking?"* and he agrees it is (*field notes*). Walking with a frame, assisted by two, has now become the definition of progress and success. Geraint has learned to agree with this marker.

Those that do not find negotiating down an easy concept to understand are in danger of being configured as problematic, unmanageable and eventually potentially eligible for disposal. However, it is more complex than this. The patient is not relied upon to accept this for themselves in isolation. Other actors are brought into play in order to accomplish this task. For instance, professionals themselves will 'move the goal posts' in order to achieve the desired goal as the following example shows:

*During a physio session, I observed how an individual was asked to take part initially in three activities. He struggled to complete one. After a long pause, the physio eventually said to him, "Well you did get up early today and I know its coffee time. Probably better you have your coffee today. Well done."*

This patient was de-motivated and seemed uninterested in completing the task. The situation was moved around him to ensure he continued to 'fit' the configuration of 'good patient' making progress. It also meant that the physio was continuing their role of setting suitable goals that were manageable and achievable.

Other patients such as Liz, however, had a looser connection with concepts of illness and wellness. For her, wellness was a lot more fluid with no definitive markers, other than being around to see her grandchildren. For Liz, there was less of a distinction between 'ill' and 'well', but more a continuum which she would move up and down on, often by the day. She described herself as "well enough". She used prior experiences and current life requirements to define wellness. She can vacuum clean her home and is able to devote more of her time to being a grandmother now she is not in work. She can normally achieve what she needs to do and, when this is the case, she is well and when it is not, she is ill.

### ***Is 'sickness' always undesirable?***

An important part of the sick role as described by Parsons (1951) is that the illness/ injury should be deemed an undesirable state to be in, with all steps taken to become well as soon as possible. In some instances, there was recognition amongst patients that whilst there was tremendous hardship that comes with ABI, there were fleeting elements which were occasionally reinterpreted as positives. ABI has the capacity to make the patient feel differently about themselves and their outlook on life. For example, the recognition that life could be taken away at any moment made Margaret feel that there was not enough time to worry about what others think all the time:

*I do see life in a different way. It's brought it home to me how fragile it is and how you just never know and I feel if I want to do something, I'll try and do it because life is just so short and you know I do think things now which I wouldn't have thought before. It has changed me and, in fact in some ways, it is changed me as far as I feel a bit more... I was quite shy when I meet people for the first time but now I don't feel...it doesn't worry me meeting people for the first time. I feel it's given me, well, I suppose confidence is a funny word to say really but I suppose I feel a little bit more confident. Like when I went back into (University Hospital) twice, I, you know I wasn't like shy. I could chat to anyone and I was not so bothered about what people would think then.*

A biomedical interpretation of this change of attitude may be that damage to the frontal lobes in the brain has resulted in a change of personality. A particularly common symptom of this damage would be a more outspoken and confident attitude. Here, Margaret has configured the outcome differently, equating her changed attitude to the closeness to death and the realisation that life is too short to worry about what others think of you.

In another example, a young mother, Bethan, described in a communications group (a group designed to improve communication to be aligned with social expectations) that she had always been lectured by her mother and she found this difficult to take, though she never felt able to respond. She felt this became more intense after her injury as she felt she was deemed untrustworthy, with responsibilities being taken away from her. After her ABI, she felt a new sense of confidence. On one occasion, she swore at her mother, ordering her to leave her house. Bethan explained that she was slapped by her mother and the pair had to be separated by other family members as a fight broke out. Despite feeling guilty that her children saw this, as well as believing that she deserved the assault for being rude to her mother, Bethan maintained that she was very glad to have finally stood up for herself and felt empowered by her actions, something she sees as a direct consequence of her injury. For her, ABI means a certain amount more freedom. Her configuration of ABI, as such, contained direct positives as well as negatives.

Importantly, though, Bethan felt that whilst the ABI may have been responsible for this new found sense of confidence, this was still controlled by her. Professionals and family members would put this down to neurological damage and poor insight on her part but she insists that it is due to her experiences. Such closeness to death made her feel less willing to put up with situations and people that she was unhappy with. Regardless, Bethan disliked the manner in which others would give the ABI credit or blame for her actions.<sup>28</sup> She felt that this othering, a removal of herself from her actions through a medical configuration of ABI, was both unfair and not representative of her actions. It dehumanised her, making her identity as much a construct of illness as other issues. The ABI was not separate to her but intrinsically part of her. Her actions and new beliefs were not problems worthy of attention.

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<sup>28</sup> Others in the group joked that the ABI makes for a great excuse to get away with acts which are otherwise regarded as socially unacceptable. This includes ignoring invites to parties and taking a dress back to the shop after one use claiming to forget they did not need it.

### ***Reclaiming ABI as a platform to provide meaning to identity***

As seen from the example of Bethan above, the relationship between the patient and their ABI can transcend the notion of the person and the injury being separate. The ABI can become a fundamentally defining component and the primary lens one understands themselves through. Rather than being a 'thing' which must be reacted to, it can come to be central to the very presentation of self. Several patients, especially those who have had their injury many years, reported making active steps to associate themselves with their ABI. They consider themselves as representatives of the ABI community, looking for avenues to engage with 'ABI culture'. Ironically, in the absence of typically defining constructs such as work or friendship groups, these patients turn to the very illness that prevented the traditional avenues for considering identity with ABI framing their identity instead. In short, it gave them a sense of belonging. For some, such as George (a man in his late 30's, post injury 20 years), the ABI might be alongside work but plays a different, crucial role. He says:

*Personally, I don't know about other people, I can only speak for myself, me being 20 years post injury, I think it's very much a part of me. I feel I am representing brain injury but years ago, I'm not sure I would have felt the same way.*

George feels it is his role to be as successful as possible in order to give hope to others that there is life after an injury. This was an identity and attitude which was many years in coming. This narrative, this taking on of self as the representative of a successful outcome, is a direct presentation of self alongside the chronic illness.

### ***Discussion***

In previous chapters, the importance of being seen to 'do patient' in order to accomplish legitimacy has been explored. This chapter has taken this further by considering how the patient comes to form and display their patient identity in order to make sense of their situation. This is a much more nuanced interpretation of patienthood and the chapter has shown how difficult 'doing patient' can actually be (Garfinkel 1967). Importantly, biomedicine has been shown to be unreliable as a discourse for explaining, interpreting and predicting the configuration of ABI. This also highlights the complications in attempting to use the sick role (Parsons 1951) to interpret chronic illness, particularly illness as unreliable and unpredictable as ABI. It therefore, highlights the importance of negotiation in order to achieve 'fit'.

In this chapter, thus, I have shown the importance of considering other aspects and cultural artefacts that are brought into play in order to make meaning and display identity in this setting (Becker 1999; Latimer 2000; Mol 2002). As shown, one way that the patient attempts this is by creating markers which they believe to be both valid and achievable. This has to be negotiated carefully as it cannot encroach on the overall performance of patient against the interpretation of the sick role (Jeffery 1979). Creating '*doable*' markers begins to subtly take back some power in a way that is non-threatening to the overall hierarchy of the medical domain. In many ways, it is performing good patient along biomedical grounds as it is creating a system of measures to be achieved within which 'wellness' can be negotiated. It is also done so against a backdrop of the sick role which sees illness largely as undesirable. However, if done so to such an extent that it begins to replace definitions set out by professionals, the patient can be in danger of not being deemed 'response-able' (Latimer 1999).

As discussed, narratives are an important function in order to make sense of one's situation, particularly when the traditional epistemologies of constituting patienthood are incomplete (Frank 1995). Narratives are useful ways to make sense of oneself after a biographical disruption (Bury 1982, Williams 1984) but, again, we can see in this chapter that from an illness as unreliable and unpredictable as ABI, it is difficult to form a coherent narrative that remains stability. It may be necessary for different narratives to overlap, with certain narratives being more applicable for the individual at different times.

In this chapter, I have shown the importance that patients place on considering other ways of constituting 'patient' (Latimer 1997), particularly when the biomedical discourse is felt to be unsatisfactory to be used exclusively. Alternative discourses are important as they help the patient to make sense and display identity in a way in which they can better understand (Becker 1999). However, I have shown that when configuring 'patient', these alternative discourses are less privileged than the medical discourse – and patients appear to be aware of this. Therefore, the medical discourse and the appropriate performance of patient are always kept in some focus, even by those who openly claim to have never found it helpful. Even when patients believe it to be no use, they will still use it, such as to emphasise the severity of their condition. Any alternative discourse is relational to the medical and they need to be compatible, even symbiotic, in order for the individual to remain in the medical setting.

In terms of configuring the ABI itself, we begin to see how the artefacts used to understand what it represents differs between the different actors involved (Bury 1991; Mol 2002; Castells 2003). This is very important not simply from a sociological point of view but also from an organisational perspective. For example, Sandra initially had very defined understandings that 'success' was returning to work at the level she was before her injury. By its very nature, by having alternative interpretations, assumptions and priorities as to what constitutes the ABI, this inevitably plays a significant part in negotiating wellness in terms of how and when (or even if) it has been accomplished.

### ***Conclusion***

This chapter has analysed the configuration of ABI through the perspectives of patients and, to a lesser extent, family members. I have shown how a biomedical discourse is attempted but is often found to be frustratingly inadequate in relating to the experiences of the patient. I have shown how alternative markers are used to define concepts such as illness and wellness. These are often more personal, constituted through experience rather than anything defined such as scores and measures. I have described how the markers are often determined through interactions with others, constantly be refined, negotiated and renegotiated.

As a result, each ABI and relation to it is a subjective, negotiated construct rather than something so easily definable. It is not the case that an ABI is a 'thing' that one can look at. It is not even a thing that different individuals can look at from different directions or angles depending on their perspective. Each ABI is a collection of markers, with different individuals using different markers to make up the same ABI. For the healthcare professional, it might be a grade or severity, score in a SMART assessment, completion of a specific task or the number of days in hospital. For the ABI patient, it might be a life of anxiety about having to use public transport, not being felt trustworthy to look after your own children, feeling unsafe in the passenger seat of a car or financial insecurity. For the wife or husband, it might mean giving up work, losing a partner but gaining a friend. These markers, through their fluidity, change with certain markers evolving into others, some becoming less applicable and others more so as life with an ABI progresses. This lack of 'thing' coupled with the unknowing is what can make life with ABI so difficult. In the next chapter, I explore how this differing perspective plays out in the rehabilitation setting, showing how the patient interprets and interacts with the setting through these alternative discourses in order to understand and perform an alternative presentation of self.

## **Chapter Eight: Are they moving the goal posts or playing a different game? Patient experiences in the medical setting**

### ***Introduction***

In previous chapters, I explored how ABI should not be considered as a definitive 'thing'. This is a concept of particular importance when we are attempting to understand the responses between the different actors involved. ABI is not a single artefact but a construction, understood and configured in multiple ways using fluid combinations of experiences, relations and interactions to interpret it. I have looked in particular as to how the patient, family member and professionals may construct the ABI in different ways due to these different understandings, experiences, expectations and motivations. Importantly, I have also mapped this understanding onto the organisation of ward life. An acquired brain injury cannot exist in the abstract or in isolation, and the ward plays a crucial role in both defining and refining the configuration of an ABI in the ways in which it is understood, how rehabilitation is organised, and in the manner in which it informs the notion of patient, performed and interacted with by the acquired brain injury survivor. Assuming a biomedical discourse, the ward plays a key role in configuring the ABI to become an event that can be understood as a traditional illness, allowing symptoms to be understood under a medical lens, with a narrative created being a trajectory towards 'wellness'. It also creates a suitable environment for the 'performance of patient'. It creates a set of principles, situations, rituals, tools and interactions that allows patienthood to be recognised, enacted and measured against.

In the same way that configuring ABI remains complicated and fluid, performances and interactions with ward life are similarly complex. Indeed, it makes sense that, if the understanding of ABI differs and the ward is an artefact used in making sense and performing that ABI, it figures that the corresponding interaction with the ward by the patient will also differ. The ward is a device like any other which is interpreted as a defined medical site (with its own rules and rituals) but also a space of performance, a place to interact with. This chapter explores this further. I begin by considering how medical authority remains a powerful disciplining tool in the experiences of patients and family alike. I go on to discuss how this discipline is negotiated and how patients use the rehabilitation ward as a site to be interacted with, responded to and used by the patient in order to 'do' ABI and, particularly, to perform 'patient'. I consider how this world continues to be inverted and subverted with expertise being a constant negotiation between professionals and patient. Drawing on perspectives of the staff and the patients, the most regular groups to occupy this space, I discuss how the patient looks to make sense of themselves within this alternative world. I show how

patients are not passive objects. Rather, it is quite the reverse. Many patients engage with the ward, and the ABI world they observe before them, in order to configure a set of rituals and rules of their own, presenting their own 'account' of the situation (Garfinkel 1967). Initial glances of individualism in this semi-total institution have the potential to blossom into considerable shows of individual identity (Goffman 1961). I present a case study of the Community Brain Injury Team (CBIT) groups, showing how this response is not unique to ward life. This series of negotiations and renegotiations between the healthcare professional and patient, the supposed powerful and the powerless, can be found throughout the medical encounter. I conclude by analysing how this might impact on the patient both in terms of performing identity and for their rehabilitation.

### ***Medical authority as a powerful disciplining tool***

In the last chapter, I described how medical discourse is such an influential way of understanding that it penetrates many of the experiences and attitudes of patients when it comes to describing and even embodying their ABI. However, alongside the notion of understanding the relationship between self and the body in this way comes a larger sense of deference to a medical authority as a voice of knowledge and expertise. Many recent policy initiatives within and towards the NHS are aimed at 're-addressing the balance', giving choice to the patient and allowing decision-making to be made with the professional and patient in an equal power relationship (Health and Social Care Act 2012). As admirable as these endeavours may first seem and with the best will in the world from professionals and patient groups alike, the deeply embedded understandings of medicine as a site of power means that this is incredibly difficult to accomplish. In consideration of ABI, many of the patients would seem to understand their position in the relationship as the recipient of information and instruction; that of traditional 'patient' in the power relationship with staff. This is not a personal sense of inferiority, more an understanding of the professional/patient role and their position within it. The semi-institutional role of ward life reinforces this relationship through the enactment and re-enactment of routines and practices which constantly remind the patient of the autonomy which they have had to give up as well as the authority figures, no matter how caring and kind, who hold that power. For example, as already discussed, there are rules as to who can leave the ward and who cannot, when to rest, how much exercise to do and even how to engage in conversation (with classes to assist with inappropriate behaviour.) This relationship with biomedical discourse is very difficult to relinquish, even after ward life has ended.

During interviews, patients would discuss their relationship with staff. Most explained that they had very good relationships with most staff. However, when it came to making any negative comments or telling a story of what they saw as bad practice, many patients would lower their voice. For example, when discussing her care on the intensive care unit, Liz explains that she remembers very little and relies on her family to describe events. However, she still said:

*Liz: I remember this nurse Lindsay who was very...I've got in my memory...who was very kind and so lovely and lovely Helen. There are some lovely, oh the care on D7 was just um... That's what my kids say...just absolutely fabulous they really were. Only those only... (talks a bit quieter) one that was not the thing....*

*Tim: one person or one incident or?*

*Liz: There was one incident with, I think she was Filipino the nurse, well two instances with her actually. The one time she came to check my monitors and I don't have really strong vivid memories of hospital because obviously I was sleeping a lot because my brain had to recover and that. But I had a tube in my nose that I remember and (pauses) but my monitors or the things she was looking at (pauses) she put a water bottle down on my bed and she was looking at it like this and then she picked the water bottle up and walked off and she left me soaking. So she left me soaking and she walked away and I was like (makes gesture as if she was annoyed)...*

*Tim: Did she not notice or?*

*Liz: She did not notice no but then there was another time when the lady was next to me and she was buzzing all the time and she was sat at the nursing station and she (the nurse) looked at the buzzer and carried on what she's doing and the buzzer was going for ages and ages and I was thinking she can't get out of bed this lady and I felt for her and I thought she should not just be looking at whatever thing. She should be over there and she was the only one that did that. Everyone else was just (clicks fingers) there.*

Most of these stories appeared relatively trivial yet some patients would still bookend their story with examples of very good care as if to highlight that this negative experience was very much a one off. In the above extract, Liz goes to great pains to emphasise the wonderful care she received, despite also recognising that she had very poor recollection of her stay on this particular ward. When describing the events she found less impressive, she began by lowering her voice, almost as if she was reluctant to complain. By the time she had finished retelling it, she had remembered another story and by this point, she had started to fully express herself, adding gestures to set the scene. However, she ensured that I knew that this was not typical of her experiences and her

perception of the ward was one where there was great care and attention given to the patients. Whether the unit had the highest standards of care or not is almost irrelevant here. What is important is the fact that Liz not only considers caring and attentiveness as a vital component of what constitutes good healthcare but also that she felt it important to put it across that she received it, even if she cannot be absolutely sure.

Others, such as Margaret who described her assessment experiences in the previous chapter, might present their own interpretation of a given situation as different to that of the professionals whilst still allowing room for the authority of medical discourse to be a persuasive argument. Patient interviews in this study were almost always conducted in private, in the homes of the individuals with anonymity and confidentiality assured, far away from the healthcare professionals. It is not so much that the patients lowered their voices in order to not be overheard but did so as more of a symbolic gesture in order to indicate that it might not be right to talk about someone in authority in this way. Many also expressed that they are extremely grateful to the NHS. The patients I spoke to seemed to seek to defend medicine and the NHS and, therefore, do not wish to be seen as criticising hard-working, pressurised staff.

The unbalanced power relationship between medicine and patients is a re-enactment of the expectations and status quo created by the cultural and social practices that have come to define medicine, performed particularly, but not exclusively, on medical sites. As already mentioned in the previous chapter, many patients such as Karen actually expected more instruction from the professional and were disappointed not to receive it. Likewise, family members such as Sophie (Colin's wife) felt they depended on the expertise and instruction of the professional and felt lost without it. As I describe later, this is not to say that the patient is passive, but more that they were willing to defer expertise to the professional in exchange for guidance and information as to what to do to improve. As such, there was a sense of frustration when this exchange was not reciprocated.

### ***Ward life as a site of performing patient***

In much of this thesis, the emphasis has been on considering the important role that a biomedical discourse has for configuring 'patient' and the understanding of self in relation to ABI. Professionals understand and configure the patient in this particular way. This ensures that the patient is 'solvable' (Berg 1992) from a medical perspective but also to read the patient's capacity to be 'response-able'. This ensures they are trustworthy to get along, fit in and go along with the 'moral forms' of the

setting (Latimer 1999), thus making the process more likely to be successful. The organisation of the ward provides a backdrop and interactive tool for the professional to accomplish this. However, the patient uses this space too. Using familiar cultural references and expectations, the ward becomes a site of configuration of self and performance. This can follow the expectations of what it is to do 'patient' but can also be a site where alternatives are performed.

Fixated behaviour, already a known problem after ABI, can be exacerbated when patients find themselves focusing on one activity. An event that might appear so trivial that it would escape every day attention can become a central component to life of those on the ward. Most of the time, many of the patients will sit and look. They will observe the space, making understandings and judgements on what they see before them much in the same way that anyone would. This understanding may take the form which is far removed from the assumptions of others, including the health care professionals. This may then be communicated with other patients, even with some professionals who might then give a reinterpretation of the situation. This might lead to a re-configuration of the understanding or just cloud it further. For example, Leanne would tell me how she felt that the division of labour amongst the staff was incorrect. She felt that there were too many staff on the tea run whilst there were not enough who would just come round and chat with her. This simple reinterpretation of how the tea run was organised on the ward led her to feel increasingly resentful that she was being ignored and because her injuries were not visible, she felt she was being trivialised and not configured as 'patient' sufficiently. This would be exacerbated by her observations that she felt certain patients were given more consideration and time than her as well as more help. She would be expected to make her own bed, for instance, whilst others would have it made for them. Likewise, Winnie felt it was unfair that she had not been allocated a member of staff to assist her to go into town to buy a birthday cake to share around the ward. She viewed this as non-sensical bureaucracy preventing her from doing something everyone would benefit from. Staff members on the other hand would see the likes of making a bed as both a sign of independence and a useful task for the patient to carry out (the fear of creating institutionalisation often at the forefront of their minds) and also so that they can help patients who were unable to help themselves. A trip out would be planned and negotiated between different departments, with the OT discussing with the physiotherapists how to best assist the patient. The task would be organised, a measurable distance agreed and an approximate time limit would be set. None of this work is visible to the patients (Latimer 2000). The patient sees a bed for someone else being made or another patient having a trip out and they make judgements of what they see from what they understand. They observe a small component of the organisation of the ward, often just the outcome of decisions made, and they

make a judgment based on this. This alternate understanding of the setting is the lived experience of the patients. It is their lens for making sense of their situation and can create tension against the medical discourse of organising the ward.

The rehabilitation ward can be understood as a site which promotes a way of life in its own right. It has its own rules, rituals and understandings. As discussed, the patient often needs to adapt, and adapt quickly, in order to 'do well' on the ward; they have to learn what it is to 'do patient' (Garfinkel 1967). This helps to ensure that the configuration of patient, if given to them, sticks. In chapter six, I described how the ward could be interpreted as a glorified waiting room. On a day-to-day basis, very little happens. To get used to this requires skill and socialisation. The performance of the patient in relation to this abnormal situation is important. To do 'patient' well is vital to being legitimated. This is not just the performance during key events, such as during an encounter with a medical professional, but in the everyday behaviours and interactions undertaken by the individual at the micro-level. This, in turn, creates an overall identity of 'patient'.

Whilst performing throughout the space, many patients will begin to understand it through a biomedical and organisational discourse. Routines become central to this. Difficulties following an ABI become compartmentalised by some patients (and particularly family members) in just the same way that the timetable above their bed does this. In an interview, Ellen (speech and language therapist) described her frustrations of this explaining:

*Sometimes I think families start to compartmentalise the issues and they can't see how communication impacts on daily activities the same so we're all sorts of, everything is integrated but because we're so separate as therapies I think that's how families see the problems as well. It's a little bit insular whereas I think the message is that as a service what we try get across is that everything is interlinked so that you know any activity involves communication as a therapy essentially. You know that all they tend to see is the half an hour on the timetable every week so we try to get them away from that.*

The organisation of rehabilitation directly influences the understanding of illness. The very difficulties begin to be separated as if they can be isolated, worked on and fixed independently. The conduct of life on the ward then lends itself towards defined moments such as physiotherapy sessions or drugs rounds. Patients better understand their difficulties by considering each session as a building block towards recovery, a definite act towards a pre-agreed goal. This 'grey' area of

rehabilitation, which makes up the majority of time, is less considered as a formal part of rehabilitation. Ironically, the performance in this 'empty time' is arguably more important to maintain the person's inclusion as an 'appropriate patient'.

It is not just the compartmentalising of time that is important here. The rituals of the ward in themselves begin to hold worth. For some patients, whatever event they are waiting for takes on special significance. When so little happens on the ward, the break in routine becomes highly significant. Events that might be normally considered the everyday take on a heightened sense of worth; the mundane becomes sacred. For example, particularly for the patients that are able to understand their timetable, the sessions can become the focus of the entire day. Robert once agreed to have a chat with me but only if it did not overlap with an upcoming class. The upcoming class was not for another four hours. In another example, when talking to Leanne, there was a misunderstanding, resulting in her not attending her physio session. She thought that the physiotherapist had gestured to her from across the ward that she would be collected for the session but, in fact, she was expected to make her own way there. When she did arrive, she was told that the session was due to finish soon and she would have to miss it for that day. This greatly upset Leanne. However, the reason for this did not seem to be because she was so keen to continue her rehabilitation; it was more to do with routines. Prior to the session, Leanne had told me "*the boredom is the worst part of being in hospital*" (field notes). Doing 'something else' became so symbolically important that to have it taken away from her was a crushing blow. Despite her not particularly enjoying the sessions, missing one meant that there was nothing else to look forward to that day. Leanne also understood the importance of 'willingness to try'. This was a key factor in her presentation of 'patient' and a theme that will receive more attention shortly. She may not gain anything from the class (she often missed exercises she did not fancy) but the act of attending the class was evidence of a willingness to try which for Leanne showed that she was 'doing patient' well. The interaction with ward life means that for Leanne, ABI is represented through the actions of taking part in activities which are recognised as making her better. Her ABI is intrinsically linked to the rituals of the ward in this way and without the stability and repetition of these actions, she finds it disconcerting.

So the mundane becomes sacred. However, this is not the only way in which actions on the ward become a complex part of understanding ABI. It is not just 'events' like rehabilitation sessions which define acquired brain injury. Much of ABI is defined and understood through the micro interactions and subtle behaviours which take place on an everyday basis in the spaces between defined

moments. In earlier chapters, I spoke of the manner in which the everyday is treated differently on the ward; how it can be inverted and subverted. Every day actions such as eating and sleeping are understood and positioned differently. The same can be said for events that take place which would normally be considered out of the ordinary. They are inverted by the very fact that on the ward, this behaviour becomes everyday and, if only to a certain extent is it expected, it is certainly accepted. It offers a new insight as to how the space can be reinterpreted by the patient to configure the self and creates new sets of principles of understanding. Outside the ward, these behaviours would appear highly contradictory, even challenging, yet on the rehabilitation ward, within the context of the configured 'patient', such conduct is allowed. Here, the abnormal becomes normalised through the lens of expected ABI behaviour. For example, Geraint often picked up items belonging to others and then claimed them as his own. This sometimes caused some distress on the part of other patients but overall, it is accepted by staff and patients alike as an unfortunate side effect of his ABI. He would not often be admonished or warned for his behaviour but would be one of the first patient's visited should an item of another patients go missing.

Paul will walk up and down the ward for long periods of time. He will walk quite purposefully, almost aggressively and quickly towards the exit. Once arriving he will stop, turn 180 degrees and do exactly the same, walking purposefully without a smile on his face until he reaches his bed, a distance of 30 yards. On arriving at his bed he will turn and repeat the action. This is completely ignored by staff and patients alike, often with trolleys and wheelchairs moving around him as he completes each lap. By not commenting or questioning Paul, the behaviour is normalised.

As another example, some patients may shout when on the lavatory. This could be to inform staff that they want to get off or for seemingly no apparent reason at all. The regularity again means that the action is normalised. It becomes so embedded in everyday practices that it is even occasionally encouraged by staff who asks the patient to let them know when they are ready to be assisted off the toilet.

The expected power relationship between staff and patients is well established. This does not mean that it will not be 'challenged' by the patients from time to time but there is a wider scope for interpretation of this following ABI. Consider the following field notes:

*A patient named Anne walks through the men's ward and into the staff room in the middle of a staff meeting. She explains that she needs a pot in order to 'give a sample.' It is explained to her that one would be brought to her when it was needed. She thanked the staff for their help but rather than leave, she then asked each of them their names. She explained this was important for testing her recovery. Once each staff member had given their name, she thanked them again and turned to leave. She had not gone more than half-way down the ward before returning to the room to discuss the names she had remembered and the names she had forgotten.*

This 'misreading of the situation' was seen as comical by the staff. It provided a welcome break and was accepted as a cultural norm on the ward, understood by staff as part of an ABI. This 'strategic conduct' challenged the social norms of hierarchy without being a direct threat to authority (Willis 1981).

On occasion, during the consultants' ward round, some of the patients would also join in. Here, through a reinterpretation of the interaction, patients would offer their own advice as to different types of exercises and medications that another patient could try. The consultant would sometimes be reduced to trying to get a word in in-between a full discussion between patients regarding treatments. The consultant would prefer to have the last word in these interactions but understands that new cultural norms may not always allow it here and so leave the bedside with the meeting between the two patients in full swing.

None of these activities are disruptive. By that I mean that they do not disrupt the flow and organisation of the hospital. Whilst they may not 'fit' in everyday life, they are perfectly suited here. The stealing is manageable, as are the 'breaching experiments' (Garfinkel 1967) of the patients. The striding occupies the patient and the yelling on the toilet is efficient communication. The patient is also configured by the professionals as not blameworthy for their actions. The behaviours are in themselves reinforcing the justification by the healthcare professional that they are in the right place. For the patient, often their action is defined to themselves as normal. They are interacting and making sense of the world around them as they see fit. It seems perfectly sensible to discuss medication with another patient when the mutual ambition is to get better.

However, operating in this way runs the risk of losing sight of the purpose of the overall aim of the endeavour which is to assist the individual to find a position where they can function and live in

society with the highest quality of life possible. By reinterpreting actions only in relation to the organisational discourse of the medical setting, the social values and connotations of the task can be stripped away. For example, in an interview conversation with Winnie, she discussed how food lost all of its social connotations to become a simple function for keeping alive:

*Oh dieticians. I really don't like them because I found them (pauses) I couldn't eat all that food when I was lying in bed all the time and not being able to go for a walk. I found them very threatening because they kept telling me, talking to me about putting pegs in and I said yeah okay, I just don't want to eat all this and they were saying "oh no you can't stop" and they were sort of telling me all the things that could go wrong or what they could do to make me eat and I didn't really want to eat to be honest. I just felt too full because I'm used to being able to eat and then take the dog for a walk or something. (Pause) they got much better afterwards, I think they were told not to give me such big portions of stuff. I was lying there and they kept coming to you and I came to the rehabilitation hospital and I would look up and they would start running at me with a bowl of soup (laughs) and I was thinking "not another meal" (Winnie and Tim both laugh). And it's awful lying in bed eating it. I wanted to get in a chair and eat it, that's not so bad but lying and eating it like this, you don't feel like you're eating.*

*Tim: Yes that's interesting. You don't feel like you're eating. It's a different activity altogether really isn't it?*

*Winnie: It's not social like sitting with people having a meal. I can see why they don't do it like that because some people have a lot of trouble eating and it goes all over the place so you know that's another thing that would be awful if it happened to you because it would take away one thing that you could do with your friends and family really.*

The fact that eating is referred to as 'feeding' dehumanises the process, removing any social connotations to one which is based on basic human need. The task could be broken up into smaller components, or with other technologies acting to intervene e.g. peg feed, in order to fulfil this function. In this instance, Winnie felt that the individuality of being 'patient' was removed. Different people have different appetites but with the meals being largely generic and the eating of them becoming part of a process rather than a social situation, the completion of the task takes priority over individual desires. This is, arguably, only going to be counter-productive in terms of adequately preparing the patient to life on the outside afterwards.

It could be argued that these practices, whilst probably viewed as abnormal on the outside, create an environment which is not just accepted but re-configures normality. A side effect of this, and one that patients and staff alike recognise, is that it threatens to 'institutionalise' the patient. This is a term used differently by various individuals during this study, but always with negative connotations. Institutionalisation tends to refer to a way of being that produces and reproduces a set of practices that become very specific to a particular situation to such an extent that any change to that individual's situation would be very difficult to reconcile. This could even be a change within that institution (Leanne becoming upset by missing her class is an obvious example of this). This is the complete reverse from what the organisation of the ward has set out to achieve. If nothing else, it makes the discharge of the patient all the more complicated with a greater chance of difficulties later on.

Therefore, an important question to ask is, why do these practices continue to take place, when many, professionals and patients alike, are so aware of the potential dangers it poses? The answer lies in the configuration of patient and the understanding of the rhythms and rituals that the ward accomplishes. The ward is looking to be a 'half-way' between a home and a waiting room. It hopes to achieve patient 'wellness' but in reality, it functions to make it through the day without anyone getting worse. From my observations and time on the ward it is clear to me that the staff work very hard, often under intense pressure from patients, family members and policy makers, and often with minimal staffing levels.<sup>29</sup> Maintenance becomes an acceptable target on a day-to-day level and this often means allowing repetition of practices. That repetition might mean the acceptance, and therefore repeated acceptance, of practices which would be unacceptable on the outside. By not doing any 'real harm' Geraint continues to steal without any long-term goal put in place to help him to stop this. It is, in essence, about short term survival.

By repeating these actions, and by responding predictably to the admonishment in the desired way and to the appropriate level, the patients are actually performing 'good patient'. They can be read, predicted and can easily form a biomedical narrative that explains the actions. If Anne (pg. 171) continued to disrupt the meetings, or became aggressive, she would be disrupting the basic organisational flows of the ward and would, therefore, be creating a problem. By crossing

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<sup>29</sup> It is worth mentioning again that towards the end of my field work, beds were being shut whilst there were so many members of staff absent on sick leave (50% at one time).

boundaries by just the acceptable level, she provided light relief to the pressured staff for a temporary and manageable amount of time.

### ***Who is the expert?***

As by now established, power relations play a significant role in the organisation of the ward. Power traditionally is intertwined with experience and knowledge. Another of the inverted factors impacting on rehabilitation ward life is that it is often the patients that are there for the long-term whilst it is the members of staff who are more likely leave the setting and move on first. The organising principles of many of the specialised staff means that they work on cycles of differing length meaning they can be placed at the hospital for 6 or 12 months at a time. Many patients are on the ward before the staff member arrives and would still be there after they leave. Given the long term nature of rehabilitation, patients and families often start to become 'experts'. This is not just an expertise in the illness but the tacit knowledge learned regarding organisational practises and rituals that make up ward life. Experience and building up of knowledge might, in other settings, lead to the more experienced party having more authority and this is an issue some professionals work with regularly as the following extract shows:

*Liam (nurse) arrives at Geraint's bed with his trolley. It is the same trolley with medicines and peg feed equipment that he visited P and J with.*

*Liam: Right (looking around). Geraint's wife picks up a black file and hands it to Liam, clearly aware that this is what he was looking for.*

*Sharon: Does he have meds at this time?*

*Liam: I'm just checking. I bounce back and forth between the two wards so it's always best to check.*

*Sharon: I don't think he does now.*

*Liam: No you're right.*

*Another visitor, friends with Geraint's wife, becomes involved:*

*Friend: When does he have his next meds?*

*Liam: 6 o'clock.*

*Friend: How many times does he have his meds per day now?*

*Liam: Twice.*

*Sharon: That's good. That's better.*

In this exchange, Geraint's wife is establishing her own authority in a way that also displaces that of the healthcare professional. Not only is she showing her better knowledge of the situation, but her friend is also offering approval to the new medication regime.

The relationship between staff and patient needs to be managed carefully on both sides, necessary for a successful outcome, especially in terms of negotiating 'wellness'. It would be far too simple to suggest that it would be in the interests of the professionals that the patient simply "*does what we say*", as half-jokingly remarked by Mark in the MDT meeting which is very much the relationship expected at the time of Parson's (1951) initial writings. It is certainly the case that patients and family members, who are at complete odds with the professionals, can be re-configured as challenging, with the label 'patient' often removed on grounds that the behaviour is not conducive to fulfilling their role effectively. However, those that are completely subservient are arguably viewed upon with equal suspicion. When Leanne's parents met with the neuro-consultant, the consultant was concerned that the parents seemed to have little, if any, interest in their daughters care. The consultant particularly noted that they did not have any questions when asked. Leanne was from a background of quite low economic status. She was hoping that on discharge, she may be able to return to her job as a cleaner. She possibly lacked the necessary levels of experience to conduct herself on an equal footing with medical professionals and she knew it. It is quite plausible to suggest that the parents were displaying similar issues with socialisation as Leanne, lacking the 'social capital' in order to feel they could contribute to this interaction on an even footing (Bourdieu 1979 [2010]). Leanne would often feel confused or frustrated by the way she perceived a particular situation, as if she lacked experience of dealing with, and questioning, authority in a way which was deemed acceptable. The neuro-consultant was certainly viewed as a figure of authority so perhaps the lack of questions was more a lack of questioning authority. Whatever the reason, it played a part in configuring Leanne as immature with her family situation described by the consultant as, "*not quite right*" (*field notes*). Professionals want dialogue with patients. They want consensus of agreed goals to work towards as well as joint recognition when it has been achieved. Family members also play a key role in configuring the patient. Without a two way interaction, an agreed definition of 'wellness' is all the more complicated. A patient who agrees with everything may be easier to handle but the likelihood that an embodied sense of wellness has been achieved is somewhat less likely. For the patient, it is about having *enough* interest in one's own condition to be interested and motivated to want to recover whilst understanding the necessity to hand over the appropriate amount of expertise to the professional. In Leanne's case, there was some unease as it was felt there was not enough interest in the condition amongst the parents. Alongside Leanne's performance on the ward,

the family were not deemed trustworthy, they were not 'response-able' and her legitimisation was therefore compromised.

In a similar way to the performance of 'patient', power relationships can best be understood at the micro-level through everyday interactions. It is only at this level that you can begin to see the very complex, intricate differences as to how the individual patients negotiate and renegotiate this relationship, often to obtain a little more power whilst not overstepping the mark. If the mark is overstepped, it can set the patient back for a while. The patient is disciplined through these interactions. For example, a patient, Craig, went to his OT session to find that he was the only patient in attendance, alongside Anita (OT technician). It was a woodwork session where they were making bird boxes. The session went very well with Craig and Anita, a woman of a similar age to himself, enjoying jokes at each other's expense. This showed a certain amount of closeness and familiarity between the two. Anita even went as far as to criticise the resources that they had available to make the birdhouses, blaming cut backs on the restrictions on using the power tools. This invitation to the backstage (Goffman 1959), revealing the frustrations of the staff was welcomed by Craig who would join in by rolling his eyes in agreement. Towards the end of the session, Craig asks Anita whether she might be able to adjust his electric wheelchair so that she might make it go faster. It seemed apparent that this is something he had asked for, and had been refused, previously. It seemed that he had identified this new found window to the backstage as an opportunity worth exploiting. He joked that he wanted to be able to run people over. After he asked several times, Anita explained to Craig that the use of an electric wheelchair was a luxury and it is not unheard of that patients "*who misuse their privileges*" can have them taken away (*field notes*). Her tone and demeanour shifted sufficiently so that Craig got the message. To ask once was fine but to ask a second time, by showing he was serious, meant that he had overstepped the mark and it was necessary to realign the relationship. However, it was done so in a manner that meant that Craig knew he had gone too far without any permanent damage done. In an environment such as ABI rehabilitation, staff (and most patients) realise the importance of maintaining good relationships. After he left the session, Anita explained that there is a knob under the arm of the chair which adjusts speed. He would be more than able to change the speed on his own if he knew about it!

### **Willingness to try**

Like many aspects of performing patient, a vital component of this relationship is the 'willingness to try'. The patient knows their role and what would be required of them in order to show that they are doing all they can to get better and, perhaps more importantly, doing what they are told; deferring technical expertise to the professional. I call this 'willingness to try' because that is often all that is needed. It is the *performance of trying* rather than actually doing which is important. In order for the patient to 'pass', the notion of what counts as showing acceptance is redefined. The patient may not accept the suggestion that there is anything to recover from but this framing will be accepted as long as the patient at least recognises the importance of 'performing' the role of 'patient' such as attending classes, doing their exercises or taking medication even if it is performed at its most basic level. The following example shows this well:

*Graham (OT) arrived on the ward to see Leanne who I thought was asleep. He said "Oh well done, I'm impressed," and she said, "I've been doing it for hours haven't I Tim!" I joked, "Yes, hours at least!" before admitting that I actually had no idea what she was doing.*

*It turned out that they were talking about practicing the exercises that she had been given previously by the OT which involved stretching out her fingers using a wooden rod. She had clearly picked it up to coincide with the impending visit from Graham who was scheduled to take her off to her OT session.*

Leanne had learned that it was important to be seen to be doing the exercises far more than it was important to actually do them. In another example, Richard shows how he understands, superficially at least, that it is important to show ambition and motivation in recovery when talking to the professional:

*Earlier, Gemma (Physiotherapist) had mentioned to Robert about possibly getting elbow crutches. They were described as somewhere between a walking frame and crutches and Robert felt they were a good idea. However, now (15 minutes later), he thinks they sound like a bad idea saying "they sound a bit dodge." He said he doesn't like change.*

On both these occasions, the healthcare professional was well aware that the patient was not really doing their exercises or wanting to try the next stage of rehab. What was important, though, was that the patient recognised the importance of performing the role as 'willing to try'. Patients are not always consistent, nor are they always configured as good patient at all times and by everyone

simultaneously. I have already discussed how this works in this thesis. However, in the above examples, the 'willingness to try' was recognised as doing good patient; as doing ward life correctly.

### ***Patients are not passive objects***

Rather than being passive objects to be acted upon, patients are not only reactive to the rituals and rhythms of the ward, but are pro-active, intimately configuring the shaping of the overall organisational strategy as well as the everyday practices of the ward. Importantly, these interactions give different 'accounts' playing a crucial part in determining how ABI is configured as well as the terms in which wellness is determined. Shots of individuality will appear through this semi-total institutional setting through the smallest of micro-actions by the patient (Goffman 1961). This can be a conscious reaction, an active response in recognition that the hospital space has powerful, underlying organising principles, or as a more subtle performance of identity. I shall now address each in turn.

Some patients, particularly after discharge and perhaps, therefore, more able to reflect on their experiences from a point of removal a little more, recognise that practices akin to ward life can potentially contribute to institutionalisation. Some patients on the ward also felt this, though it was rarely articulated. Winnie, however, was an inpatient who did recognise this. She likened hospital life to "*boarding schools with meal times, planned activities and lights-out*" (field notes). Winnie claimed that by being aware of the dangers of institutionalisation, she was able to take steps to counteract it in a way that prevented this from occurring. Her reaction to the wheelchair (as described in the previous chapter) is a good example of how she felt that she achieved this. By not allowing herself to be persuaded that an electric wheelchair was in her best interests, she was able to stick to her initial remit on entry to the ward. She refused to 'move the goalposts' and settle for a negotiated form of 'wellness'. Biologically, it may well be near impossible for Winnie to be able to walk fully again with the electric wheelchair later being decided to be the best possible outcome. However, it was not so much the act of walking but the act of giving up or 'negotiating wellness down too much' that she objected to. Interestingly, these acts of defiance were quite conscious moves on the part of Winnie to maintain her independence and sense of purpose of being in the hospital. However, her comments as to how she interacted with the ward differed from observations. For example, Winnie would often take part in organised activities and whenever she did protest about a situation, she always did so in a measured way, a way which meant that she was not deemed problematic. For example, on the occasion when she asked to go into town with a nurse

to buy a birthday cake and she was not allowed, she did not complain to the staff but to me. She may have very firm understandings of how she configures 'wellness' but she is also very aware of the importance of performing 'good patient' and would spend much of her time trying to balance the two.

Other patients seem to have far less of an articulated, definitive agenda. They do not necessarily constitute the ward as a site of institutionalisation, nor do they subsequently see it as a place that requires responding to. For other patients, it relates more to making sense and coping with the world they see before them. The ward is, by design, a semi-public space. Leaving this public space might be difficult for a variety of reasons such as physical disabilities or through being determined as untrustworthy by staff and, therefore, not being given permission to leave the secured space. Some may lack the motivation or cognitive skills to understand how to leave and if they do they would not know how to return. Whatever reason someone may have for not being able to leave the ward, many patients create alternatives to leaving the ward physically by leaving the ward symbolically. Many patients use headphones, plugged into numerous electronic devices such as DVD players or televisions. Others will simply go to sleep for periods of the day. Both of these have physical implications. Headphones might be necessary as it is difficult to hear when a TV is in close proximity to another and sleeping is vital for those who become easily fatigued. However, it also has the added attraction in cutting the individual off from others. It puts the patient in charge of their own space, giving back some independence, even if only temporarily. One patient actually turned his back on the central walkway of the nightingale ward, therefore using his body to show that he wants to be left alone. Whilst these actions appear small and trivial, they are performing important functions. They are providing small opportunities for patients to display some choice and autonomy against a backdrop of rules and discipline (Goffman 1961).

Other practices would also provide evidence of independence, performances of resistance. If Winnie was resisting 'moving the goals posts', these patients were playing a different game altogether. For example, a patient named Leslie placed his order for the lunch that he wanted at the beginning of the day. However, once it arrived from the hospital canteen, he left the ward without touching the food and instead went to the tuck-shop in reception, filling up on crisps and chocolate bars. He did this with little fuss. He did not complain about the food in front of him nor did he tell staff or other patients where he was going. It was not a protest at the food he was given, free of charge of course, but an act of showing agency. By disregarding the expectations of ward life, eating the food he had ordered and was given, he was showing individualism and self-reliance. By doing this on a regular

basis, he was also creating a new ritual. Many of the patients would mention that the food offered from the hospital was not to their liking. However, most would say this with an acceptance that little could or would be done and ate whatever was given to them. Here, Leslie is responding to the situation by creating a solution as he saw fit. During the time of the study, these actions were not directly challenged by staff. It did not severely disrupt the flow of the organisation of the ward. However, he and his family were described as difficult by some during MDT meetings, though I saw no evidence of this. Possibly, this subtle act of 'defiance' was part of a bigger configuration of Leslie; that of 'bad patient'.

### ***Friendship making***

Patients do not configure and interact with the ward in isolation. They use what Goffman would call 'teamwork' (Goffman 1959). Patients need other patients in order to be patients themselves. Friendship making is a vital part of being on the ward. In some instances, patients form friendships which extend beyond the stay in the hospital. Robert was very pleased to receive a good luck card from Gracie, a patient who had since been discharged, and he would often show it to me when I visited him. There were a number of friendships between patients of the same age, gender and so on. They may have similar interests or a mutual reaction to the situation they are in. Friendships also allowed patients to be more than just 'patients'. By working together, they could perform other identities. For example, two patients, Neil and Paul, were good friends. They slept in beds adjacent to each other and would often communicate even the minutest matter to each other. On one occasion, Neil would point out to Paul when he had changed his trainers into flip flops, indicating the weather was good. Paul would respond in kind saying it was time they got tans. When Neil would return from his physiotherapy session, Paul would ask him how it went and suggest different free weights that they should use to improve their strength and, possibly more importantly, their physique. The important thing to know here is that Neil had dysphasia to the point that his vocal communication was almost entirely compromised. It would initially be impossible to follow what he was saying and he would also not necessarily respond in a manner which would follow the normal line of conversation. But, of course, this is not a 'normal' organisation, nor were the expected rules of communication always followed. It did not matter to either Paul or Neil that they quite often have two almost separate conversations to each other at exactly the same time; there was communication. After a short period, it became quite clear when Neil was pleased or frustrated, asking a question or telling a story. The fact that the words never came out was neither here nor there. Paul, amongst others, would have a conversation with him by responding to the intonations

or the mannerisms. Sometimes, Neil would leave the room instead of answering a question put to him by Paul. Interestingly, Paul would not be concerned by this. He would return to whatever activity he was previously doing, normally sitting on the bed reading a magazine or pacing up and down the ward. On an ABI rehabilitation ward, conversations do not always need words, a subject or even need a start or an end point. They are vital opportunities to practice being individuals, more than just patients who are there to be acted upon. They provide an opportunity for building camaraderie and friendship. They allow men to talk to other men about things men are supposed to talk about.

In another example, two females in their early 20s were sat having a chat in a corridor. They were firstly discussing make-up brands and how the warm weather made certain make-up disintegrate (it was a warm day.) They moved on to discuss their interests and what they did for a living. One girl was a trainee hairdresser whilst the other was working in a department store but hoping to do a degree in travel and tourism. Just as their conversation came to an end, a door in the corridor was swung open and the girls went into the room. It was a gym for physiotherapy. Without saying another word, the girls moved to their various apparatus, one in a wheelchair and the other walking with a pronounced weakness down one side of the body. They began working on certain exercises; they had clearly conducted this session many times before as they needed no prompts as to what to do. After a minute or two, the conversation started again, this time talking about boyfriends. This scenario could have taken place almost anywhere. In this instance, the friendship had extended beyond the illness and the surrounding area. ABI, disability or hospital life appeared to play no part in their discussion. You could have replaced the gym with a shop floor, a coffee shop, a seminar room in a university or a pub. In this instance, teamwork had allowed them to symbolically leave the setting. It had formed an account of belonging and group membership which was simultaneously within the healthcare setting (allowing them to cope with their situation), whilst at the same time removed from the medical altogether.

Sometimes, patients may strike up friendships out of the circumstances they find themselves where it might not be the case that they would be friends out of the rehabilitation setting. Leanne and another patient, Ahmed, might be an example of this. Leanne was a young lady who had only just turned 18. Ahmed was considerably older and did not speak English very well. She was also profoundly deaf, she had been since birth. Leanne did not speak sign language but in a matter of weeks they communicated with a mixture of hand gestures which Ahmed had taught to Leanne as well as ones that they just made up. They would be considered by staff as *“two young girls”* (field

notes) by the way that they would often be found giggling on Leanne's bed, normally as they had either got completely confused by a breakdown in communication or they had successfully indicated something private to each other which no-one else had been made privy to. In contrast to Paul and Neil, this sometimes led to a little suspicion on the part of the staff that this friendship was disruptive to the organisation of the ward. Perhaps sometimes they had good cause to do so as the other component which bonded Leanne and Ahmed was a mutual dislike for some nurses. It seemed that the reasons for this were as confused as they were varied but it built a bond between the two patients who, at face value at least, seemed to enjoy their own private world which they had been successful in excluding others, especially the nurses. In this instance, the friendship acted as a mechanism for taking ownership of the situation for Leanne and Ahmed by regaining some of the power from the disciplining practices of ward life.

Leanne told me that there would be particular staff that she would trust and others which she felt could not be trusted. Trust was very important to her. In a process such as rehabilitation where definitive scores and figures are pursued but are difficult to maintain as a constant, Leanne, and her lack of good performance as 'patient', would often become confused and frustrated by the lack of consistency. She wanted definitive answers yet she had entered a discourse where scores were privileged but timescales were less concrete. She wanted promises of improvements she would make yet they could not be guaranteed. Leanne could not understand why certain patients received certain levels of assistance and she would not. As discussed, Leanne knew the importance of performing 'patient'. She would appear to be participating in groups, "doing her homework" as she put it and taking her medication but she had not been socialised into the more subtle intricacies of participating in ward life. Whilst she appeared deferential to staff, she was unable to be consistent with this. She would often be caught out and deemed disruptive. For example, on one occasion, she was asked to leave a group as she was laughing when someone fell out of their wheelchair. She felt this was unfair as she felt that the inappropriate laughing was part of her condition and this had not been understood. The professionals would later discuss between themselves that they did recognise 'emotional lability' as an outcome of her ABI yet they still had to manage it to ensure the sessions did not lose structure. Leanne could not understand this and another benefit of her friendship with Ahmed was that she could use it as a coping tool as she had found another person who would at least tolerate her frustrations and complaints.

Adapting and recovering from an acquired brain injury can be a lifelong process. Whilst I have largely concentrated on rehabilitation whilst in hospital, individuals with an ABI may continue to interact

with healthcare professionals and biomedical discourse long after they have left the setting, either formally or informally. I conclude this chapter by analysing a particular example of this by considering the community brain injury team.

### ***Case study of CBIT Groups***

Some patients would be referred to the Community Brain Injury Team (CBIT) on discharge. As well as ward life, this is also an important site which presents opportunities for patients to perform identity and interact with both their own condition and organised systems of healthcare, albeit in a slightly more informal setting. The community brain injury played the unique role of being a medical site in a life-world which is now largely lacking any regular, direct medical interaction as patients here would have been discharged from hospital.

As discussed, not everyone who is discharged from hospital is eligible for intervention from CBIT. There are several reasons why a patient may or may not be referred including geographical location, deemed appropriateness and the preference of the patient. One of the services CBIT arranges are groups/meetings organised around a particular topic. Patients who are invited to attend CBIT meetings are sent up to three letters and if they do not respond after the third attempt, they are discharged. It might be presumed that this system is unlikely to favour those with dysfunctional lifestyles, those who may have memory loss and organisational problems and those who are unsupported. Whilst there are some mechanisms in place to help, it could be argued that the system deployed to enrol patients already ensures that those most in need are the most likely to lose out.

In a similar set of negotiations to those which allow the patient to 'pass' onto the ward, moves are made to configure patients as legitimate or not. The negotiations regarding referral in themselves form a crucial part in configuring the patient and their ABI. For example:

*Next new patient from inpatients was considered.*

*Eliza (Speech and Language Therapist): She's 'out of area.'*

*Laura (Psychologist): Shame. She would have been ideal.*

Although this patient could not be accepted due to geographical boundaries, she would have been accepted because she was deemed an "ideal" patient. Here, the professionals have a clear idea of what 'good patient' looks like.

This small team is made up of several disciplines such as occupational therapy, physiotherapy, psychology and speech and language therapy. Due to financial constrictions and logistics, CBIT are unable to cover as large an area as the hospital itself. Therefore, some patients will be eligible for this service whilst others would not be. For those who are eligible and do participate, they often describe the service as vital. In fact, during one group session observed, many patients showed an enthusiasm to be involved in lobbying the necessary health boards to ensure the service could be extended to those who were currently unable to receive it. Of course, those who have this view are those who are not only eligible but are motivated and able to attend.

The team was initially set up in recognition that much of rehabilitation takes place in the home after discharge from hospital. It was also identified that much of rehabilitation is to come to terms with issues on an individual level, both physically and mentally. As highlighted in previous chapters, the artificiality of the ward means that many patients only realise that they cannot make a cup of tea or make a decision about where to go to buy food until they are faced with it, something that they may not need to do whilst in hospital. Despite these initial goals, staff shortages and financial restrictions has meant that many of the CBIT services offered takes place in larger groups, often back on the hospital site. CBIT will run courses of varying lengths with specific difficulties focussed upon. For example, this could be a communications group, anxiety management or fatigue management. There is also a longer, more generic course called the 'cognitive skills group' which provides an overview of the typical difficulties experienced after ABI and is usually recommended as the first course which a patient should attend. This course will also provide a summary of other areas such as the biology of the brain. Groups usually take part in the recreation hall, a wooden hall separate but within the grounds of the rehabilitation hospital, or the committee room which was also used by the staff to have the MDT meetings. The numbers attending each of the groups varies but is normally around 8-10. Staff will invite as many as 30 to attend safe in the knowledge that whilst this would be far too many to be practical, brain injury is by its very nature self selecting meaning at least two thirds will not turn up. Average numbers fluctuates and the staff are unsure as to why one cohort will really endeavour to attend regularly whilst other sessions have consistently poor numbers despite demographics and the course being the same. The gender divide is typically in favour of females to males which is not in keeping with national statistics of ABI sufferers but is more in keeping with those who attend ABI rehabilitation.

A typical session will be two hours long with a half hour break. The group are often encouraged to walk around if they feel the need and to use the lavatory whenever they want to. Despite this, most

will not take the initiative and only taking advantage of this offer when the group leader makes the decision to break. The session runs in a similar fashion as one might expect in a classroom. It often begins with a presentation from the front by the group leader. There will often be slides on a projector to accompany the talk. There might be questions intermittently directed at the group which, depending on the style of the group, may be interpreted as an invitation to talk about a whole manner of different things. In a communication group designed to help teach appropriate turn taking when talking, the question and answer session that ensued meant that we never left the first slide of the presentation for the rest of the session!

At some point, the presentation will stop and the group will be set activities. This could be individually, in pairs or in groups. Sometimes the group decides how the division of labour of the task will be divided, despite instructions from the leader that it is to be done individually! Worksheets will accompany the task and after an amount of time, the group will come back together and discuss answers. Confident members of the group might dominate this part, as they did in the Q&A during the presentation, and the group leaders often have to work hard to encourage less confident members to speak up whilst asking bolder members to *“maintain their enthusiasm whilst giving others a chance”* (field notes). The answers to questions might be personal opinions or may have more finite answers. Either way, the general attitude of the staff is that there is no such thing as a ‘wrong answer’. However, this sometimes means that they have to work very hard to make an answer from some of the patients ‘right’. At the end of the session, the group are given homework to do. This will often be the chance for the topic in question to be applied in some form to the everyday lives of the group. For example, during the anxiety group, the patients are asked to keep a diary. When they are about to face an event they are required to rate their stress level from 1-10. They are then asked to attempt the event, using one of the strategies they have learned in the session. They are then to evaluate themselves by again scoring how stressful it was. This would be discussed at the start of the following weeks meeting. Often, many of the patients would forget to complete the homework or would find it too difficult. Some may fill it in at the start of the session, somewhat missing the point of the exercise. This is normally excused by the group leader as acceptable. The ‘goal posts are moved’ to not only recognise patient ‘willingness to try’ but to also ensure the patient is ‘recovering’ as it symbolises progress.

The above description could easily be recognised as typical of most education settings. The ergonomics of the room, the timetabling and scheduling of the activities and the unwritten rules of

behaviour (such as sitting until a defined break) could come from most educational establishments.<sup>30</sup> It is instantly recognisable to most that enter this setting and as a result, acts as a site which encourages a reproduction of certain performances. Perhaps more importantly, it inadvertently discourages other forms of interactions. It is not the most satisfactory organisational framework for learning, especially given the difficulties that ABI brings, and the staff are fully aware of this. It requires the performance not so much of 'good patient' but of 'good student'. The patient needs to be able to listen, concentrate and understand what is being asked of them for relatively long periods of time in a space where there might be multiple stimuli. Many patients find this difficult. For many, this has less to do with the ABI and more to do with a lack of experience, recent or otherwise, of being in a setting such as this.

During the course of this study, I took part in five groups (each having between four and eight sessions in total). It was often the same patients that attended all groups. Some may attend only one of the groups, particularly if they were suffering an issue that the class seeks to specifically address (e.g. anxiety), but, overall, the same 8-10 individuals would attend all the groups regardless of the purpose or theme of the group. Some may even attend the same course more than once. CBIT helps different individuals in a whole variety of ways and the training sessions were only one method. However, it became apparent that for some, it became an essential component of their post-injury identity whilst for others, it would be very rare to see them after the first session. As already discussed, these groups are self-selecting on account of various challenges such as needing the ability to remember and retain information such as the time and place of something new like a course. Another issue is, given the setting, it is a space where individuals have already not performed well (as patients) and they do not wish to revisit that challenge. On top of all of these issues is the fact that many would find a traditional classroom environment, where one is required to interact in a particular way, as difficult, even alien to them.

Those that do manage to overcome these obstacles can do very well with the courses. For these individuals, it is possible that it was the educational factor that played an important part of the rehabilitation. However, I argue that it is much more nuanced than this. In some instances, I would argue that it was not necessarily rehabilitation at all which drew the same individuals to the courses but other factors. For instance, within the group itself, there are opportunities for expressions of

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<sup>30</sup> A small minority of patients may get up and walk around during the session but this is certainly not common place.

identity and different performances that might be denied to the patient elsewhere. With a few exceptions, rarely do members of the groups go back to work and, with old friends no longer visiting, the group acts as a space for this performance. Despite some of the more formal arrangements of the courses, the dynamics within groups often promote a casual nature where an individual's difficulties are recognised and (to an extent) tolerated, as long as they are within the overall parameters and structures which allow for the working of the group.

Having a recognisable structure, with expected rituals and practices, also produces a framework in which individuals can hang their identity. Similar to the ward, there are recognisable features in which performances can take place. For example, in the supportive group atmosphere that the meetings promote, an older gentleman, Tom, would almost act as 'alpha male'. When I met the group to explain the research and seek their permission to take part, he spoke on behalf of the group to welcome me and give permission for me to visit. In the same cohort, a younger male, Steve, would go to great lengths to explain to the group what an excessive drinker he was. He would bring talk about cider into nearly every discussion regardless of its relevance to the topic (or not). The session leaders would react in turn, gently putting a hand on Steve's when they felt he had talked out of turn or for too long. Steve would always be sat next to the leader around the table. Tom would be allowed to give numerous anecdotes from his position at head of the table, often going off the point of the discussion for several minutes.

Taking an example from another group, a patient in his late 60s, Jonathon, would take great pride in bringing cakes and biscuits to each session. He would take orders, remember favourites and correct new members of staff in regards as to how everyone, including other members of staff, takes their tea and coffee. He became known as "*the tea man*" and this role seemed to supersede any other reason to be at the group (*field notes*).

Jonathon, Steve and Tom had been stripped of previous roles where they would have given these performances. Steve no longer had the same groups of friends whilst Jonathon and Tom had to give up work. The sessions were interpreted to act as a gateway which gave Jonathon a sense of purpose, allowed Steve to rebel, with a suitable level of boundary in place, whilst Tom was afforded the luxury of being head of the group. Of course, the sessions were not consciously designed to serve these purposes but, in the absence of any suitable alternatives, they were adopted by the different members for these ends. It was not just Jonathon, Steve and Tom who would perform these identities. In order to perform in this way, they not only needed a stage, in this case the group

setting, but an audience. Others present, including the staff, would play a key role in the development and sustainability of these performances just as Jonathon, Tom and Steve would for others. The defined roles within the group and the safe space to give these performances acts to create a sense of group membership and belonging which, in turn, is integral to giving a sense of self to the individuals concerned (Castells 2003).

It could also be argued that the groups act as a transitional space between the medical and the social. The groups are taught techniques and strategies that they are then encouraged to apply to themselves in "*the real world*". For some this seems very successful whilst for others they can struggle a great deal. This seemed particularly true of the few who had managed to return to work in some capacity. For example, Lorenzo described how he would find it difficult to find somewhere to fit in a half hour nap when at work, as advised to him in the fatigue management group. Geoff, a builder who had his injury at work, described in another fatigue management group how his workmates would not be impressed if he left a job half finished or worked at a lesser pace. His employer had agreed to allow him to reduce his working week to three days, often in order to attend groups such as fatigue management, but he was often jokingly mocked by his colleagues for being lazy and work-shy. This was something which upset him greatly, especially since one of his colleagues was to blame for his accident. Therefore, Geoff would often work very hard when he was at work, meaning that in actuality, he was more fatigued than if he were employed full-time.

The performance of 'patient' was perfectly adequate, even encouraged, in a ward setting when patients could move in and out of it as they saw fit. However, once in a different setting, this position was not deemed acceptable and was actively shunned, often by the individual affected more than anyone else. This sometimes created a tension between what CBIT patients saw as knowledge from experts in the hospital and what they found outside. There would often be a lot of discussion during the session where the therapist would describe a coping strategy, only for it to be debated by members of the group who claim the strategy is unworkable in their particular setting. The therapist would usually concede ground by suggesting that their strategy is for a "*perfect world scenario*" and that it must be adapted to suit (*field notes*). As discussed in the last chapter, this lack of definitives or absolutes did not always sit well with some patients.

The staff stress that the importance of the group lies not in what is learned but through the interactions between members of the group which would not have been possible had they not have been 'forced' to run their sessions en-masse rather than individually as hoped for when the idea for

the team was initially conceived. Classes are allowed to become deliberately loose in order to allow for this. For example, the communications group would often become a two hour meeting more akin to a support group and whilst the course materials may not be covered in depth, the leader and members feel that the sessions have been a great success, providing a platform for discussion lacking elsewhere. The staff recognises the importance of allowing these performances to take place as they play such a vital role in the overall rehabilitation of patient far more than any taking in of information could. Again, we can see the 'moving of goals posts' by the professionals to ensure that 'patient' is being performed. By realigning what has been accomplished in the sessions as the marker of success, the professional is negotiating down. Therefore, 'progress' to the desired level is being achieved. When the patients seem to take control of the session, dictating the pace, this is then renegotiated as important for recovery. Thus, the professional has retained authority. When patients are encouraged to only use the advice they find useful, this ensures that medical advice remains credible. The advice that is less useful is relegated and forgotten. The useful advice is then kept in play, proof of the validity of evidence based medicine.

### ***Discussion***

This chapter has provided more substance and context to many of the themes already discussed in this thesis, though particularly focuses on the patient, their interaction in the everyday happenings of the ward and their corresponding performance/presentation of self (Goffman 1959). On a continuation of the theme of discipline and authority as an organising tool, we see that it not just medical discourse which is privileged (as discussed in the last chapter) but the overall hierarchy and structure of the medical domain which underpins it. Liz, lowering the tone of her voice when discussing bad care, is a good example of this. This is common within many medical accounts (Atkinson 1995, Latimer 2000; Silverman 1987; Strong 1979; Thomas 2015). Whilst the sick role may be challenged, the overall assumption of deference (or at least performance of deference) towards the care received still carries significant gravitas amongst most in this group. This chapter has shown that, at ground level, very little has changed since many of the studies cited above. Given the relatively recent emphasis on patient choice in healthcare settings, together with attempts at a more equal relationship between the professional and patient, this is a particularly pertinent issue. Perhaps one reason to account for the lack of change belongs to this underlying discourse.

Another concept, already considered but taken forward in this chapter, is the organising practices of the medical site which acts to legitimise and configure patients as shown by Latimer (1997). Here, I

show how it is not just the professionals (or the space in which the work is carried out) which accomplishes this organising work. Patients also legitimise both themselves and others in this way, bringing the ward into their collection of artefacts (Hillman 2007) in order to understand their position whilst also positioning others. An example of this was Leanne's interpretation of the sickness (and therefore legitimacy) of others in relation to the time spent with them by other nurses. This is important because it shows that, through self-regulation (Foucault 1978), many of the patients are doing the organising work on behalf of biomedicine, thus embedding the discourse further.

An overarching theme in this thesis has been the accomplishment, performance and consequences of the relationships between and within the two main groups that occupy the medical space: professionals and patients. An important focus of this chapter, in particular, has been on patient responses to the organisational practices that constitute ward life. There is synergy here with how Goffman describes the performances of inmates in *Asylums* (1961), namely in reaction to the authoritative practices that they observe around them. In the last chapter, I considered how patients, by partially setting their own goals, have reclaimed part of the agenda. Here, the actions of the patients take it one step further through a constant negotiation. This is sometimes subtle, sometimes overt, as we can see from the attempt by Craig of getting his wheelchair turned up when he felt sufficiently invited to the back stage to make this request (Goffman 1959). Unlike the previous chapter, however, these displays of asserting some level of power are not only accomplished in order to make sense of their own illness. They are also displays of autonomy which begin to separate the individual from the 'sick role' identity of patient altogether (Becker 1999). It is pushing back against the institutional practices which define them within a restrictive identity. Without overemphasising the point, this could be considered to be low-level resistance in order to be not doing 'patient', but doing 'human' (Garfinkel 1967). This is very important because it shows that, even against deeply embedded and consuming discourses, patients (even with significant cognitive deficits) will work hard to ensure they can overtly perform and display a sense of autonomy (Goffman 1963).

In terms of considering the implications for these alternative displays of identity, as discussed previously, this is acceptable, perhaps even to some degree encouraged, providing it continues to follow the expected performance of doing 'patient' (Garfinkel 1967) and has some recognised 'fit' to the sick role obligations. It assists to prevent 'institutionalisation' which can actually work against the biomedical discourse by creating additional problems that need to be dealt with. Again, from an

organisational perspective as well as from the perspective of 'configuring', the autonomy shown by the 'patients' show how important it is to be flexible in order to maintain 'fit'. These showings of resistance are acceptable as long as, at an organisational level, it is not disruptive. Additionally, it is also acceptable as long as the patient remains 'response-able' (Latimer 1999) within the setting. When the disruption becomes too damaging, threatening the organisation of the system of the power relationship, action can be taken. For the patient, this is often 'disposal' from the setting.

### ***Conclusion***

In this chapter, I have considered how biomedical discourse permeates everyday life on the ward and, in some instances, can even be seen to influence attitudes after the patient has left hospital. I have discussed how this discourse and the sick role more generally are performed by the patient and how the ward becomes an ideal site for this. In particular, I have examined how the ward has its own particular rituals and practices which these performances map onto and interact with in order to constitute 'patient'. In the context of ABI, these performances may appear inverted or subverted against assumptions of life on the outside. However, on the ward they play a vital role in the functioning and organisational practices of ward life and the overall configuration of 'patient'. I have considered that power relations and negotiations are important for the smooth running and repetition of these practices. The patient is given, or even takes, certain amounts of liberty yet nuanced, fluid micro-interactions consisting of gestures, practices and technologies as well as direct interventions, play a part in channelling this behaviour to ensure that the status quo is maintained.

What is of significant importance here is the understanding that patients are not passive. I have discussed how certain recognised, and some highly individualised, methods are adopted by patients in order to make sense of the setting and to construct/perform identity. Through the analysis of community brain injury team (CBIT) groups, I have shown how a setting can be adopted for a variety of purposes. The setting becomes a site of performing an identity rejected by others elsewhere, becoming a space that gives affirmation to an individual whilst also giving a sense of belonging and group membership. It also legitimises the position of the patient. It allows them to perform the sick role in various ways, most notably performing a 'willingness to try'.

## Chapter Nine: Conclusions and Implications

### *Introduction*

This thesis has explored the relationship between acquired brain injury and rehabilitation, paying particular attention to identity and the role it plays in the decision-making process when providing healthcare. I have focussed on the perspectives of both the healthcare professional and the patient, influenced also by family members. Having worked alongside healthcare professionals for a number of years prior to this study, there were a number of issues which were felt worthy of exploration. Two research questions were initially posed which I used as a platform for this inductive investigation. Firstly, I considered:

**Why does it seem that resources used to assist individuals with ABI are organised in such a way that those that appear to need the most assistance are the ones who may not be able to gain access or remain in the system?**

It seemed there was a discrepancy between the descriptions and experiences of patients and family members and the way their difficulties are explained and understood within the medical setting. This initial observation then led to a second question, a hypothesis worthy of examination:

**Could the objective framework for constituting 'patient' in the medical discourse be problematic and even incomplete when it comes to defining acquired brain injury and what it is to be ill?**

The answers to these two questions are undoubtedly intertwined. This thesis provided evidence to show that there is a 'lack of fit' meaning that those that appear most in need can, indeed, be the very ones most likely to be unable to 'pass' in the medical setting (Goffman 1959, Garfinkel 1967). This can include passing in terms of gaining access to the setting in the first place as well as the notion of 'passing' to mean being regarded as a legitimate patient within the setting. Those that are consistently deemed to be illegitimate are at most risk of 'disposal' from the setting (Berg 1992; Latimer 1997) with this bound up in performance(s) and what it is to 'do patient' (Garfinkel 1967).

### ***The role of the sick role***

In understanding these performances further, I have acknowledged Parsons (1951) sick role as a loose framework for understanding what it is to 'do patient'. To be successful as a patient in a

medical setting, there are certain rules and obligations that, if followed, go a long way to assist the individual in being deemed legitimate. By following these obligations, you are 'performing patient' in a way that is easily read and understood by the healthcare professional. This makes the patient more likely to be 'solvable' (Berg 1992). In exchange for following these obligations, the patient is legitimised and given certain allowances. Legitimation is vital in order for the patient to receive medical, emotional and financial assistance. As the preceding chapters have shown, patients with an ABI can struggle to accomplish this performance successfully. I now return to the obligations of the sick role in order to show this further:

*The person in the sick role is helpless and in need of help*

The lack of cultural artefacts (Munro 1999) means that the patient is not immediately understood as 'sick'. Many individuals can be regarded as 'high-functioning'. Some patients are able to drive, hold down work or even run marathons. The symptoms of ABI are not always performed in the same manner in which other illnesses might be which means the individual might not be immediately recognised and regarded as helpless or in need of help. This is particularly problematic after the individual has left the medical setting, the most stark example of this coming from Liz (chapter five) when describing her relationship with her husband. Her appearance and behaviours did not naturally lend itself to concepts of illness. Performance of patient, then, is also bound up in making the illness visible. On many occasions, the descriptions of the problems experienced may not marry up to the biomedical scores and psycho-metric measures professionals use in their attempts for visibility. For example, the reading of the brain scans in chapter five showed how complex and negotiated this process can be. This makes both diagnosing and legitimising the illness all the more complicated.

The nature of the problems experienced, such as anger problems or issues around confidence also begin to be contested. As shown when discussing Robert and Lucy, symptoms of an ABI can be brought in and out of focus, medicalised or de-medicalised, meaning that it is all too easy to strip away what it is that the person has been deemed to need help with. When de-medicalised, the person and not the illness becomes the problem meaning they are not helpless.

*The patient must be faultless for their illness*

It is quite possible that the brain injury might come as a result of an incident where the patient was, for want of a better expression, 'at fault' in some regard. For example, the person may have been drinking alcohol, drug taking or involved in other risk-taking behaviour. There was no evidence throughout this study that care was in any way influenced by the cause of the injury. In fact, it was often used as evidence amongst professionals of doing 'good medicine' in that they were providing care *despite* the avoidability of the injury. Perhaps more importantly, however, is the belief amongst patients and family members that fault (and responsibility) is a vital component of configuring the patient as legitimate. When diagnosis is difficult to achieve, this can be used to dispose (Latimer 1997) of professional responsibility. For example, when dealing with Lucy (chapters four and five), eventually *she* was regarded as the source of the difficulty. Indeed, she was manoeuvred to being at fault. By not fulfilling her obligations, by not being 'response-able' (Latimer 1999), Lucy was deemed illegitimate, misappropriated to the ABI ward, making her available for discharge. There were no alternative options for her. The 'lack of fit' between the experiences of patients and the perceived understanding of what it is to do 'patient' fail to align, thus causing conflict and various problems.

*The patient has to want to get better and be prepared to seek assistance for this as they would not have the technical capabilities to do so alone.*

Whilst the problem of blame can be somewhat exonerated if the patient commits and takes responsibility in trying to get better after an ABI, perceived lack of motivation and poor awareness is considered a major problem post-injury. Many professionals will point to this as a major barrier which prevents the patient fully committing to recovery. The very difficulties that the person is experiencing, medicalised in order to be explained and 'solved' (Berg 1992), can be used as evidence of their poor performance as patient. If sustained, this can potentially lead to de-legitimation and disposal. In addition to this, the unusually long time periods that the patient may remain in hospital causes a shift in terms of expertise with the patient often having more experience, particularly of the organisational discourse of ward life than the 'experts'. This relatively unique situation has to be managed carefully within the performance of patient to ensure that they are not being interpreted as unwilling to seek assistance to fulfil their role of doing 'patient' effectively.

This thesis has shown that the 'lack of fit' comes from the complex, fluid outcomes of acquired brain injury against the biomedical discourse that wishes to understand the body, and illness, as absolutes which can be isolated, worked on and fixed, removed from the subjective understandings and experiences of the person. As a result, this can be deeply problematic. There can be considerable

differences between the various actors involved as to what is an outcome directly attributable to the ABI and therefore worthy of intervention and what is not. Often, different symptoms can be moved in and out of focus during this negotiation process as and when it is suitable for either the patient, healthcare professional or family member. Many patients will disagree with a biomedical interpretation of their difficulties, finding it an unsatisfactory, constricting way of defining their experiences. The patient offers a different 'account' (Garfinkel 1967). This is explained further when also considering the next obligation.

*The emotional involvement bound up in the sick role means that the sickness cannot be accepted by the sick person.*

With the very symptoms that make up the ABI being contested between patient, family member and professional, inevitably this also means the attitude towards that symptoms might differ between people. The various actors involved use different artefacts to 'account' for the ABI. The patient and/or family member may feel that a certain issue should be addressed whilst the medical professional has doubts or vice versa. Again, this is evident when we consider how Lucy and her family were 'trivialised' (Becker 1993), when attempting to medicalise her pain (chapter five). Conversely, other times, the patient may disagree with the professional, and often with family members, by feeling that a particular symptom being deemed worthy of intervention was not to be viewed as negative or as part of the illness. Bethan showed this when describing her new found freedom that comes with her outspoken behaviour (chapter seven) despite her attendance at a communications group. In other instances, there may even be disagreement as to whether the issue was a result of the injury or not. For example, Margaret (chapter seven) felt that the tests she was given to ascertain cognitive functioning were unfair as she had never been competent at these tasks. Again, the understanding of the relationship of the injury to the individual is important. Certain issues assumed to be problematic may not actually be so for the patient as they were not a major part of their life previously. For example, Janet (chapter seven) described how her difficulties with organising were less important as she did not need to be too organised in her life. The pain in her backside, however, was much more important as it prevented her from going on walks with her husband. This thesis has shown that the need to negotiate what it is that constitutes the illness, and therefore the emotional attachment bound up in these negotiations, has a considerable impact in being able to determine when wellness has been achieved. As importantly, this lack of agreement has the potential to undermine the legitimacy of the brain injured patient.

### ***How 'fit' is attempted***

Against this backdrop, this thesis has gone on to show what takes place within this particular, rather unique setting, to attempt to achieve 'fit.' This is accomplished by patients, family members and healthcare professionals. It is in all their interests to do so. For the patient and family members, to 'fit' in the setting goes a long way to achieving 'passing'. As stated, this affords the patient legitimacy resulting in medical, emotional and financial support. For the healthcare professional being able to configure the individual as 'patient' means that the patient (and illness) can be defined and understood. This makes them solvable (Berg 1992) and, therefore, the professional has accomplished 'good medicine'; the individual entered the medical setting 'ill' and left 'well'. The professional has played their part in the performance, thus reproducing the social expectations of the encounter.

Additional pressures put on the healthcare system, such as the demands to reduce waiting lists, which increases throughput of beds and shortening hospital stays, means enormous pressure is put on staff to be seen to be performing their part effectively (Allen 2015). Therefore, as shown in the preceding empirical chapters, certain strategies are carried out by the actors involved in order to make sure that 'good medicine' is seen to be happening as much as possible.

In chapter four, I showed how even before the point of 'passing' into the hospital setting, the individual is already being configured and manoeuvred to aid being understood. This is vital in order to ensure discharge as a viable option at a later date. Individuals who are perceived to be a poor fit might be re-configured to that of 'person', thus restricting, or even denying them access to the setting.

In chapter five, I also highlighted how medicalisation can be both advantageous and problematic for the patient in their pursuit of 'passing'. Through medicalising symptoms and outcomes, 'moves' can be made to ensure that the doing of 'patient' is able to 'fit' into the discourse. In order to achieve this, it can sometimes mean a great deal of flexibility and reinterpretation to ensure the patient is recognised as such. Whilst flexible, if the patient is unable to be made to 'fit', they can be de-medicalised, positioned to have no mandate to remain as 'patient'. With the discourse favouring individual responsibility, it is the patient who is looked upon to have failed in their part of the contract in terms of performing 'patient'. The person is 'read' and interpreted as to whether they are 'response-able' and both medicalisation and de-medicalisation are very powerful tools in achieving this configuring work.

Chapter six onwards explored further as to how configuring is accomplished through the everyday, micro-interactions. Doing 'patient' is a fluid process, made up from a coming together of various responses and interactions with rituals, routines and technologies. This includes interaction with the space of the ward as much as it does the actors within it. I showed how common performances, such as washing and eating, are re-imagined. Corresponding components become broken down, potentially allowing the routine to become task-orientated, functional practices. This is beneficial to the professionals as it assists with the organisational practices of the ward as much as the biomedical understanding of the body as a site of intervention.

Flexibility is again important here in both understanding and configuring 'patient'. On some occasions, the 'goal-posts are moved' in order to ensure a continuation of 'fit'. For example, when the patient became disinterested in the tasks given (e.g. chapter seven), the session can be shortened with the task made easier. This ensured that the patient accomplishes what is asked of them, thus continuing on the trajectory towards wellness whilst reinforcing the legitimacy of both the biomedical discourse and the expertise of the professional. Another strategy akin to this is the concept of 'willingness to try'. By this, I mean the performance of patient which does little more than give the superficial performance of working to get better whilst, at the same time, this performance being accepted by the professional. Examples of this include Leanne and Robert agreeing and showing willingness to practice their physiotherapy (chapter eight) whilst the professionals are aware that they are not really doing so. What is important here is not so much the act of getting better but the understanding on both sides of the performance of attempting to do so. Even though the patients are not *really* attempting to get better, the performance of 'willing to try' makes them trustworthy. This, in turn, makes them more legitimate as 'patient'.

Having established the strategies and work accomplished by the staff, the latter half of the thesis focused on the perspective of the patient. Chapter seven explored how a biomedical discourse is also attempted by the patient. I showed how, amongst other things, this discourse is brought in and out of focus when being used to compare injuries with other patients, to emphasise severity and legitimacy and when trying to understand the illness. However, this discourse is often found to be frustratingly inadequate, problematic and incomplete in relating to the experiences of the patient. In many cases, alternative markers are used to define concepts such as illness and wellness, sometimes in combination with a medical discourse, sometimes by abandoning it altogether. These alternatives are often more personal, constituted through experience rather than anything defined and

generalisable such as scores and measures. Chapters seven and eight showed they are often determined through interactions with others, constantly being refined, negotiated and renegotiated.

The evidence I have presented in this thesis shows that a medical discourse is incomplete as the exclusive way to describe and explain the outcomes of acquired brain injury (ABI). As examined throughout this thesis but particularly in the latter empirical chapters, an ABI is a subjective, negotiated construct rather than something so easily definable. Each ABI is a collection of markers, with different individuals using different markers to make up the same ABI (Mol 2002). This lack of 'thing', coupled with the unknowing, is what can make life with ABI so difficult but what must be understood fully in order for any intervention to be worthwhile and meaningful.

With this in mind, as evidenced in chapter eight, it is important to understand that patients are not passive recipients of care. Certain recognised, and often highly individualised, methods are adopted by patients in order to make sense of the setting and to display identity. I have also shown how a setting can be adopted for a variety of purposes. When patients find the biomedical discourse unsatisfactory, they often adopt other discourses and performances. The setting becomes a site of performing an identity rejected by others elsewhere, becoming a space that gives affirmation to the individual as well as a sense of belonging. For example, the community brain injury team group allowed Tom to become a 'leader' (chapter eight). It is not just choice and autonomy that are expressed but also active methods of resistance. More subtly, by turning their back to the ward and using headphones, patients were able to actively show preference and autonomy in what could be defined as a semi-total institution (Goffman 1961). Ironically, many of these rituals can be redefined and might play a part in legitimising the position of the patient; the individual is providing evidence and performances which can be defined as worthy of medical intervention. This includes pacing up and down the ward (chapter seven), stealing from other patients and even breaching traditional conventions in the doctor/patient interaction by joining in the ward round (chapter eight).

Again, it is important that the configuration of patient is flexible. This thesis has provided evidence to show that these behaviours and performances are allowed, even encouraged as long as they still loosely fit around a recognisable concept of 'patient'. The differing interpretations are manageable when the frameworks used to conceptualise 'patient', 'illness' and 'wellness' are flexible enough to incorporate these differing accounts to ensure that there is still 'fit'. As long as the patient maintains some form of recognisable and manageable 'performance of patient', it is deemed acceptable. In this thesis, I capture how the flexibility of the framework is largely controlled by the professional.

However, when the configuration of ABI impacts on what it is to 'do patient' it can make the legitimisation of the patient both problematic and unstable. Examples of this include the performances of Lucy (chapter four), Geraint and Stewart (chapter six). When the negotiation cannot be agreed, when the patient cannot be made to 'fit', it might ultimately lead to 'disposal' from the setting, severely limiting the capacity of the individual to be deemed 'legitimate'.

### ***Theoretical contributions***

Though this was a practice-based study, it was underpinned by sociological theory and concepts. In turn, by using and interpreting these concepts, I have made several theoretical contributions. This thesis adds to medical sociology literature which concerns how the medical encounter organises, configures and legitimises patients (Latimer 1997). In particular, by undertaking a fine-grain analysis of everyday encounters, I have shown that there are fundamental, tacit assumptions in the carrying out of the everyday organisation and interaction between the actors involved which reproduces certain hierarchies. These underpin everything and are so embedded and taken-for-granted that it is hardly surprising that in multiple studies of medical sites in the sociological literature (e.g. Allen 2010, Atkinson 1995; Bosk 1979; Latimer 2000; Mol 2002; Silverman 1987), very little seems to change.

This thesis was heavily influenced, in particular, by the work of Erving Goffman (1959; 1961; 1963). By considering the medical domain through the lens of the 'front and back stage' (Goffman 1959), I have shown how it is useful to explore the different roles and positions of the professionals who, on the one hand, are trying to maintain a level of expertise and status whilst, on the other, feeling the pressure of the organising principles and everyday stresses of working in such a chaotic, complex, and demanding setting. This gives a richer context of the multiple strategies at play here. In addition, by interpreting the setting as made up of micro-interactions, this thesis provides insights into understanding how 'the everyday' constructs and configures relationships in terms of power, discipline and hierarchy. This is not just between professional and patient but, within both groups of people as well. This is also vital for understanding how and why decisions are made, with particular information and attitudes privileged, when configuring patients.

A particular concept associated with 'configuring' (Latimer 1997) has been the way in which I have reconsidered the role of medicalisation. It has been analysed as a process which configures and legitimises patients. I have shown how decisions to medicalise, as well as the medicalising itself, do

not take place in isolation; concepts of medicalisation interacts with social assumptions to form 'accounts' of the patient (Garfinkel 1967). This is very much in line with the work of Becker (1993). However, by doing this, I have shown that rather than always being interpreted as an intrusion, medicalising can be 'advantageous' for the patient. Not only does medicalisation lend patients legitimisation, but it can be used for the performance of 'patient' which contributes to being configured as 'response-able' (Latimer 1999). Importantly, it shows how medicalising symptoms relegates alternative options to the point that there are no other discourses realistically available. This means that if a patient is unable to have their symptoms medicalised, or if they are de-medicalised, then they are in a very vulnerable position both medically and socially in the clinical setting.

Returning to the everyday, I have considered how this disciplines and organises patients in various ways (Foucault 1978; Latimer 2000). In particular, I consider the role of space and the medical environment itself in doing this work (Latimer 1997; 2000). What are present (medical notes, the bed selected for the patient) and what is absent (personal belongings), all play a part in these disciplining practices. In addition, the ordering of the day, for example through timetables, and the accomplishment of everyday tasks being dictated by the professional, all contribute to this work. I have shown how even patients reinforce these practices, disciplining each other (Hillman 2007) as well as themselves (Foucault 1978) along the expected modes of conduct. A successful performance of patient interacts with the space in the expected way. They are 'response-able' (Latimer 1999), trustworthy to interact within the setting in a way that recognises the 'moral forms' required (Garfinkel 1967).

Focussing on the patient, a major contribution of this thesis is to add to the medical sociology literature which accounts for the construction and understanding of disease through the patient's experiential interpretation of their illness (Bury 1991; Becker 1999). In particular, I have shown how patients respond when they find the biomedical discourse ill-fitting and unreliable. Often, despite this issue, the biomedical discourse is so embedded in the everyday life of patients that they allow it to form part of the narrative, if only to be used in relation to experiences. This helps the patient make sense of their illness. Many constitute a new discourse, with different artefacts being considered for constituting 'illness' and 'wellness'. This may include biological measures but can include concepts through their personal experiences, such as ability to return to work, loss of independence or feelings of importance in relation to how they felt before their injury (Bury 1997; Charmaz 1987). Importantly, by recognising alternative configurations of illness, particularly when

dealing with chronic illness such as ABI, it can help to understand difficulties in achieving a successful negotiation as to when 'wellness' has been achieved. If the artefacts being used to constitute the illness (Mol 2002) are different between the actors, this will inevitably cultivate difficulty in negotiating not only what particular difficulty is deemed to need assistance, but when (and if) that has been achieved.

I wish to return to the use of the sick role (Parsons 1951). It is clear that the sick role is ill-fitting as an accurate description of modern healthcare practices. In particular, I have shown how it is certainly unable to define chronic illness as well as illnesses as unpredictable as ABI. That said, it has been valuable for informing my thinking in this thesis. As stated from the very beginning, using it in this way (i.e. to define the experience of chronic illness) was never my intention. I have used the sick role as a framework, a loose heuristic device to bring together various assumptions, expectations and behaviours which largely still persist in medical discourse and the organisation of the clinical domain under investigation here to produce the 'performance of patient'. By doing this, I have shown that the sick role can still play an important role in interpreting and understanding the medical arena.

Theoretically, my position has been pluralistic and this has been purposeful. Using Foucault's analogy of a toolbox (1994), I have brought together different ideas and concepts to make sense of an immensely complicated and complex world. This has been necessary because one theoretical lens, such as Parsons or Foucault, would have been insufficient to make sense of a chaotic and intricate setting. Using just one would have been an injustice and would not have permitted an understanding of a world that does not necessarily always cleave at neat points. Therefore, a final contribution I wish to highlight is that this thesis is showing the value of bringing together these different ideas.

### ***Implications***

The seeming lack of 'fit' between the patient and the organisation of acquired brain injury rehabilitation along a biomedical discourse has significant and far-reaching implications from an organisational, policy and – most importantly – patient perspective. This is largely because it plays a fundamental role in the potential for those who appear most in need being excluded from the setting. This, in turn, can restrict medical, emotional and financial support to the individual who needs it most. Aside from the logistical constraints, for the individual, this inability to 'pass' can also have damaging effects. It has the capacity to stigmatise the individual, with the lack of legitimacy causing them to doubt their own identity, sense of worth and position in society. The individual is

unable to claim they are legitimately sick, therefore being afforded the benefits of the sick role, whilst, at the same time, feeling unable to fully contribute. Having been unable to 'pass' (Goffman 1963), the onus and responsibility is put back on the individual who is held accountable for this. With an increased emphasis from policy makers on the patient/doctor interaction being one of 'co-production' (DOH 2005), this is only going to exacerbate the issue further.

In terms of organisation of rehabilitation, the important role of ground level interaction is overlooked on a day-to-day level. The 'non-heroic' level of interaction is not valued. As shown, this plays a vital role in assisting the patient to form 'accounts', make sense, interact with and experience their injury. This mundane, micro-interaction is as much a part of rehabilitation as any formal exercise routine and possibly more so. In contrast, there is a widely held recognition amongst professionals, patients and family members of the potential for institutionalisation to be felt on the ward. Rather than being treated as a site for the patient to practice what it is to be 'person', they are often performing 'patient'. This reinforces concepts of illness rather than wellness, thus making the transition all the more complicated when the time comes and, ironically, increases the chances of the individual requiring access to the medical setting in the future.

As argued throughout, it is clear that the biomedical discourse is not satisfactory to explain the entirety of ABI. Those that attempt to understand themselves and their experiences in this way are often left feeling frustrated and confused. As shown in chapter seven by Karen, Sophie and Sandra, this can often be as concerning and disorientating as the symptoms of the injury. In fact, it is often difficult to differentiate between the two. This, in turn, contributes to additional emotional distress. By continuing with this discourse, it means that even with the flexibility afforded this particular configuration of patient, it is still necessary for the performance of patient to fit a particular set of understandings. Unless a more holistic understanding of ABI and related knowledge can be brought into focus, there will inevitably be a fracture between the organising principles of ABI rehabilitation and the understandings of self following ABI.

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## Appendices

### Appendix 1

Information sheet for patients (example)



Cardiff University School of Social Sciences  
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King Edward VII Avenue  
Cardiff, CF10 3WT

Name: Tim Banks  
Telephone: 02920 226881  
Email: bankstm1@cf.ac.uk

## PARTICIPANT INFORMATION SHEET (PATIENTS)

Version 2.0 May 2012

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

### Introduction

My name is Tim Banks and I am a PhD student at Cardiff University. I am researching how decisions made during rehabilitation after acquired brain injury (ABI) are made and what influences them.

In order to achieve this, I intend to carry out a short questionnaire with ABI survivors, make observations of what goes on in rehabilitation settings and interview a small number of participants.

I am inviting you to take part in this research project. Before you decide, please take the opportunity to read the information below. This will address the important questions that you will need to know before you decide if you wish to take part. It is quite long so I do not recommend you attempt to read it all at once. You are able to keep hold of this sheet so you may come back to it for reference in the future.

If you have any queries please find my contact details at the top of this page.

### What is the purpose of the study?

Following an ABI, important decisions are made as to how best to help the individual recover. These decisions come from a variety of places, such as the doctor, specialist, family members and the survivors themselves. These can all have a big

influence on the rehabilitation that takes place. I feel it is important that this is studied in order to understand how this contributes to the success of the overall rehabilitation process.

Exploring this may lead to a better understanding of the various roles these relationships have during rehabilitation. It may offer suggestions as to how best improve the manner in which rehabilitation is carried out in the future in order to offer the best possible chance of a sustain improvement.

### **Why have I been selected?**

You have been selected as you have received an acquired brain injury and are currently involved with health care professionals e.g. speech and language therapy or the Community Brain Injury Team (CBIT) during your rehabilitation.

### **What will happen if I take part?**

Firstly you will be provided with a short questionnaire which you would be asked to fill in. This could be done either alone or with assistance from a carer if you wish. The purpose of the questionnaire would be to gain an insight into the sort of things you take part in on a weekly basis and how you might feel about them.

Secondly, I would be present for various groups and meetings that you already attend. I would be making notes as to what goes on. I would have no influence or contribution to the group whatsoever. These sessions would be part of your regular rehab and I would not take up any more time than what you would already be doing. The purpose of the observations is to see firsthand what sorts of decisions and choices come up during rehabilitation and how they are resolved.

Lastly, I may ask you to take part in an interview. There would be two in total. The first would be towards the beginning of the study with the second towards the end of your participation. Your main carer would also be invited to attend the interviews. The length of each interview would be no more than an hour and would take place wherever you were most comfortable e.g. at the hospital or at home. They would be audio recorded so that I don't miss anything important. The purpose of the interviews would be to gain a better understanding of what was observed and to understand participants view points. You may agree to take part in the study but ask not to be considered for interview. That is absolutely fine.

### **How long will the study take place?**

I intend to carry out the research for approximately 1 year. However, you would not be required to participate in addition to the groups you already attend or over and beyond the natural course of formal rehabilitation. For example, if the study started and you were discharged 3 months later with no follow up appointments, your participation in the project would finish.

### **What will happen if I decide not to take part?**

Refusing to take part will have no impact or influence on any care you receive during your rehabilitation. If I am present in a group where others have agreed to take part, you would not be observed and not be considered during data collection.

### **What if I agree to take part but decide to pull out during the study?**

If this takes place then your part in the study will cease immediately with no need on your part for explanation. I would look to keep hold of the data already collected from the study unless you expressly wish otherwise.

Pulling out of the study would have no impact whatsoever on your access to continued rehabilitation with the hospital.

### **What are the potential advantages of taking part?**

Whilst the study may be unlikely to directly benefit you personally, it is hoped that the study would add to the knowledge and expertise about how best to help survivors of an ABI and therefore improve services available.

### **What are the potential disadvantages of taking part?**

Every effort will be taken to ensure any possible distress is kept to an absolute minimum. However there is always a chance of some distress as topics which may be sensitive or upsetting may occasionally come up.

If this does happen, support can be offered by me, the nursing staff if you are an inpatient or the Community Brain Injury Team if you are an outpatient. You might also benefit from speaking to Headway Cardiff. Contact details are included at the end of this form.

### **Will my taking part in the study be kept confidential?**

All participants and places that take part in this research will be given different names and all identifiable data will be changed before publication.

Anything I use to store information e.g. laptops, notes, audio recording devices etc will be kept in a secure location.

After the PhD is complete, I will hold onto contact details for 6 months – 1 year before deleting the data. The data collected would be kept for 10 years to allow for further research but no participants would be identifiable from this data.

### **Who is organising and funding the research?**

The research is sponsored by Cardiff University but is self funded.

### **What will happen with the results of the research?**

The data collected will form the basis for a PhD thesis which I will write. It would also contribute to papers and chapters which I may write for peer-reviewed academic journals and books. However, in all circumstances, all participants and places that take part in this research will be given different names and all identifiable data will be changed before publication.

### **Will I have a chance to read the research?**

The study will be made available on request to all participants of the research in a summary form.

### **What if I wish to make a complaint?**

Hopefully there will be no problems if you decide to be involved in the study. However, if you do need to make a complaint then in the first instance please contact me on:

Tim Banks  
02920 226881  
bankstm1@cf.ac.uk

If you wish to speak to my academic supervisors then here are their details:

Joanna Latimer  
02920 876908  
LatimerJE@cardiff.ac.uk

Adam Hedgecoe  
02920 870027  
HedgecoeAM@cardiff.ac.uk

If you remain unhappy and wish to complain formally, the hospital can provide a copy of its complaints procedure which explains how to proceed.

### **What happens if I am harmed during the research?**

In the highly unlikely event that harm comes to you during the research due to negligence, you may have grounds against Cardiff University or Cardiff and Vale University Health Board. This would not affect your rights to access the NHS.

### **How do I register my interest to take part in the research?**

You may register your interest in the research by contacting me using the details below. Otherwise a healthcare professional that you are working with or I may call you or speak to you privately in order to know your decision.

### **Further information and contact details**

If you have any further questions or would like to register your interest in participating, please contact me using the details below. In addition, if you would not like to participate and would be happy to explain why, please also get in contact:

**Tim Banks**  
**Cardiff University School of Social Sciences**  
**1-3 Museum Place**  
**Cardiff**  
**CF10 3BD**  
**02920226881**  
**Bankstm1@cf.ac.uk**

**Contact details for Headway Cardiff**

**Headway Cardiff**  
**Rookwood Hospital**  
**Llandaff**  
**Cardiff**  
**CF5 1ER**

Thank you very much for taking the time to read this information



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Cardiff, CF10 3WT

Name: Tim Banks  
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## **PARTICIPANT INFORMATION SHEET (HEALTH CARE PROFESSIONAL)**

Version 1.0 Mar 2012

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

### **Introduction**

My name is Tim Banks and I am a PhD student at Cardiff University. I am researching how decisions made during rehabilitation after acquired brain injury (ABI) are made and what influences them.

In order to achieve this, I intend to carry out a short questionnaire with ABI survivors, family members and carers, make observations of what goes on in rehabilitation settings and interview a small number of participants.

I am inviting you to take part in this research project. Before you decide, please take the opportunity to read the information below. This will address the important questions that you will need to know before you decide if you wish to take part. You are able to keep hold of this sheet so you may come back to it for reference in the future.

If you have any queries please find my contact details at the top of this page.

### **What is the purpose of the study?**

Following an ABI, important decisions are made as to how best to help the individual recover. These decisions come from a variety of places, such as health care professionals, clinicians, family members and the survivors themselves. These can all have a big influence on the rehabilitation that takes place. I feel it is important that this is studied in order to understand how this contributes to the success of the overall rehabilitation process.

Exploring this may lead to a better understanding of the various roles these relationships have during rehabilitation. It may offer suggestions as to how best improve the manner in which rehabilitation is carried out in the future in order to offer the best possible chance of a sustain improvement.

### **Why have I been selected?**

You have been selected as you have been identified as someone who works with individuals with acquired brain injury on a regular basis (once or more per week).

### **What will happen if I take part?**

Firstly, I would be present for various groups and meetings. I would be making notes as to what goes on. I would have no influence or contribution to the group whatsoever. The purpose of the observations is to see firsthand what sorts of decisions and choices come up during rehabilitation and how they are resolved.

Secondly, I may ask you to take part in an interview. The length of each interview would be a maximum of 2 hours and would take place at your place of work. The interview would be audio recorded using a Dictaphone. The purpose of the interviews would be to gain a better understanding of what was observed and to understand participants view points.

### **How long will the study take place?**

I intend to carry out the research for approximately 1 year. However, aside from the one-off interview, it would be my intention to encroach on your time and everyday practice as little as possible.

### **What will happen if I decide not to take part?**

If I am present in a group where others have agreed to take part, you would not be observed and not be considered during data collection.

### **What if I agree to take part but decide to pull out during the study?**

If this takes place then your part in the study will cease immediately with no need on your part for explanation. I would look to keep hold of the data already collected from the study unless you expressly wish otherwise.

### **What are the potential advantages of taking part?**

It is hoped that the practical implications of this research would inform decision makers of the extent to which identity work and participation underpins the success of the overall rehabilitation process.

### **What are the potential disadvantages of taking part?**

There will be a minimal amount of extra time required on your part to participate in the study. Whilst observations will take place with no disruption the activity, I may occasionally request clarification of certain elements which I have observed. The interview will also take up to 2 extra hours of your time.

### **Will my taking part in the study be kept confidential?**

All participants and places that take part in this research will be anonymised and all identifiable data will be changed before publication.

Anything I use to store information e.g. laptops, notes, audio recording devices etc will be kept in a secure location.

After the PhD is complete, I will hold onto contact details for no more than 6 years before deleting the data. The data collected would be kept for 10 years to allow for further research but no participants would be identifiable from this data.

### **Who is organising and funding the research?**

The research is sponsored by Cardiff University but is self funded.

### **What will happen with the results of the research?**

The data collected will form the basis for a PhD thesis which I will write. It would also contribute to papers and chapters which I may write for peer-reviewed academic journals and books. However, in all circumstances, all participants and places that take part in this research will be given different names and all identifiable data will be anonymised before publication.

### **Will I have a chance to read the research?**

The study will be made available on request to all participants of the research in a summary form.

### **What if I wish to make a complaint?**

Hopefully there will be no problems if you decide to be involved in the study. However, if you do need to make a complaint then in the first instance please contact me on:

Tim Banks  
02920 226881  
bankstm1@cf.ac.uk

If you wish to speak to my academic supervisors then here are their details:

Joanna Latimer  
02920 876908

LatimerJE@cardiff.ac.uk

Adam Hedgecoe  
02920 870027  
HedgecoeAM@cardiff.ac.uk

If you remain unhappy and wish to complain formally, the hospital can provide a copy of its complaints procedure which explains how to proceed.

### **What happens if I am harmed during the research?**

In the highly unlikely event that harm comes to you during the research due to negligence, you may have grounds against Cardiff University or Cardiff and Vale University Health Board. This would not affect your rights to access the NHS.

### **How do I register my interest to take part in the research?**

You may register your interest in the research by contacting me using the details below. Otherwise I may call you in order to know your decision.

### **Further information and contact details**

If you have any further questions or would like to register your interest in participating, please contact me using the details below. In addition, if you would not like to participate and would be happy to explain why, please also get in contact:

**Tim Banks**  
**Cardiff University School of Social Sciences**  
**1-3 Museum Place**  
**Cardiff**  
**CF10 3BD**  
**02920226881**  
**Bankstm1@cf.ac.uk**

Thank you very much for taking the time to read this information.





Cardiff University School of Social Sciences  
Glamorgan Building  
King Edward VII Avenue  
Cardiff, CF10 3WT

Name: Tim Banks  
Telephone: 02920 226881  
Email: bankstm1@cf.ac.uk

## **PARTICIPANT INFORMATION SHEET (FAMILY MEMBERS/CARERS)**

Version 1.0 Mar 2012

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

### **Introduction**

My name is Tim Banks and I am a PhD student at Cardiff University. I am researching how decisions made during rehabilitation after acquired brain injury (ABI) are made and what influences them.

In order to achieve this, I intend to carry out a short questionnaire with ABI survivors, family members and carers, make observations of what goes on in rehabilitation settings and interview a small number of participants.

I am inviting you to take part in this research project. Before you decide, please take the opportunity to read the information below. This will address the important questions that you will need to know before you decide if you wish to take part. You are able to keep hold of this sheet so you may come back to it for reference in the future.

If you have any queries please find my contact details at the top of this page.

### **What is the purpose of the study?**

Following an ABI, important decisions are made as to how best to help the individual recover. These decisions come from a variety of places, such as the doctor, specialist, family members and the survivors themselves. These can all have a big influence on the rehabilitation that takes place. I feel it is important that this is studied in order to understand how this contributes to the success of the overall rehabilitation process.

Exploring this may lead to a better understanding of the various roles these relationships have during rehabilitation. It may offer suggestions as to how best

improve the manner in which rehabilitation is carried out in the future in order to offer the best possible chance of a sustain improvement.

### **Why have I been selected?**

You have been selected as you have been identified as someone who cares for an individual who has received an acquired brain injury and is currently involved with health care professionals e.g. speech and language therapy or the Community Brain Injury Team (CBIT).

### **What will happen if I take part?**

Firstly you will be provided with a short questionnaire which you would be asked to fill in. The purpose of the questionnaire would be to gain your opinions of the various services that are on offer.

Secondly, I may ask you to participate in an interview alongside the person that you care for. There would be two interviews in total. The first would be towards the beginning of the study with the second towards the end of your participation. The length of each interview would be no more than an hour and would take place wherever you were both most comfortable e.g. at the hospital or at home. They would be audio recorded so that I don't miss anything important. I will be making observations and taking notes at the hospital. The purpose of the interviews would be to gain a better understanding of what was observed and to understand participants view points. You and the person you care for may agree to take part in the study but ask not to be considered for interview. That is absolutely fine.

### **How long will the study take place?**

I intend to carry out the research for approximately 1 year. However, your part in the study would only involve the initial interview and 2 hour long interviews if you were selected and agreed to take part in them.

### **What will happen if I decide not to take part?**

Refusing to take part will have no impact or influence on any care your loved one receives during rehabilitation.

### **What if I agree to take part but decide to pull out during the study?**

If this takes place then your part in the study will cease immediately with no need on your part for explanation. I would look to keep hold of the data already collected from the study unless you expressly wish otherwise.

### **What are the potential advantages of taking part?**

Whilst the study may be unlikely to directly benefit you or your loved one personally, it is hoped that the study would add to the knowledge and expertise about how best to help survivors of an ABI and therefore improve services available.

### **What are the potential disadvantages of taking part?**

Every effort will be taken to ensure any possible distress is kept to an absolute minimum. However there is always a chance of some distress as topic which may be sensitive or upsetting may occasionally come up.

If this does happen, support can be offered by me, the nursing staff or the Community Brain Injury Team. You might also benefit from speaking to Headway Cardiff. Contact details are available on request.

### **Will my taking part in the study be kept confidential?**

All participants and places that take part in this research will be given different names and all identifiable data will be changed before publication.

Anything I use to store information e.g. laptops, notes, audio recording devices etc will be kept in a secure location.

After the PhD is complete, I will hold onto contact details for no more than 6 years before deleting the data. The data collected would be kept for 10 years to allow for further research but no participants would be identifiable from this data.

### **Who is organising and funding the research?**

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### **What will happen with the results of the research?**

The data collected will form the basis for a PhD thesis which I will write. It would also contribute to papers and chapters which I may write for peer-reviewed academic journals and books. However, in all circumstances, all participants and places that take part in this research will be given different names and all identifiable data will be anonymised before publication.

### **Will I have a chance to read the research?**

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### **What if I wish to make a complaint?**

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If you remain unhappy and wish to complain formally, the hospital can provide a copy of its complaints procedure which explains how to proceed.

### **What happens if I am harmed during the research?**

In the highly unlikely event that harm comes to you during the research due to negligence, you may have grounds against Cardiff University or Cardiff and Vale University Health Board. This would not affect your rights to access the NHS.

### **How do I register my interest to take part in the research?**

You may register your interest in the research by contacting me using the details below. Otherwise a healthcare professional that is working with your loved one or I may call you or speak to you privately in order to know your decision.

### **Further information and contact details**

If you have any further questions or would like to register your interest in participating, please contact me using the details below. In addition, if you would not like to participate and would be happy to explain why, please also get in contact:

**Tim Banks**  
**Cardiff University School of Social Sciences**  
**1-3 Museum Place**  
**Cardiff**  
**CF10 3BD**  
**02920226881**  
**Bankstm1@cf.ac.uk**

Thank you very much for taking the time to read this information

**Appendix 4**



Cardiff University School of Social Sciences  
Glamorgan Building  
King Edward VII Avenue  
Cardiff, CF10 3WT

Telephone: 02920 226881  
Email: Bankstm1@cf.ac.uk

## CONSENT FORM (PATIENTS): Version 1.0

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

**Name of researcher:** Tim Banks

Please read each statement carefully. If you agree with the statement, please initial the box.

Please  
initial box

- |   |                          |
|---|--------------------------|
| 1. I have been provided with, read and understood the information sheet for this study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.  | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.  | <input type="checkbox"/> |
| 3. If I withdraw from the study, I give my consent to allow any data collected so far to be used for the intended purpose of the research.  | <input type="checkbox"/> |
| 4. I acknowledge that my data may be used in the PhD thesis and academic/other publications.  | <input type="checkbox"/> |
| 5. I consent to the researcher being present and taking notes during meetings and groups I have with health care professionals. NB: this will also require consent from the relevant health care professional(s). I understand that there may be particular instances I would not wish the researcher to be present and I would be able to highlight these times as they arise. | <input type="checkbox"/> |
| 6. I agree to participate in an interview, if this is necessary, which will be audio-recorded and will be anonymised.   | <input type="checkbox"/> |

7. I acknowledge that I can request a summary of the study and its findings

I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person Giving  
Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1 for participant; 1 for researcher (original).



Cardiff University School of Social Sciences  
Glamorgan Building  
King Edward VII Avenue  
Cardiff, CF10 3WT

Telephone: 02920 226881  
Email: Bankstm1@cf.ac.uk

## CONSENT FORM (Health Care Professional): Version 1.0

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

**Name of researcher:** Tim Banks

Please read each statement carefully. If you agree with the statement, please initial the box.

- |   | Please<br>initial box    |
|---|--------------------------|
| 8. I have been provided with, read and understood the information sheet for this study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.  | <input type="checkbox"/> |
| 9. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.  | <input type="checkbox"/> |
| 10. If I withdraw from the study, I give my consent to allow any data collected so far to be used for the intended purpose of the research.   | <input type="checkbox"/> |
| 11. I acknowledge that my data may be used in the PhD thesis and academic/other publications.   | <input type="checkbox"/> |
| 12. I consent to the researcher being present and taking notes during meetings and groups I participate in. I understand that there may be particular instances I would not wish the researcher to be present and I would be able to highlight these times as they arise. | <input type="checkbox"/> |
| 13. I agree to participate in an interview, if this is necessary, which will be audio-recorded and will be anonymised.  | <input type="checkbox"/> |

14. I acknowledge that I can request a summary of the study and its findings

I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1 for participant; 1 for researcher (original).



Cardiff University School of Social Sciences  
Glamorgan Building  
King Edward VII Avenue  
Cardiff, CF10 3WT

Telephone: 02920 226881  
Email: Bankstm1@cf.ac.uk

## CONSENT FORM (Carer): Version 1.0

**Study title:** What is the relationship between identity and acquired brain injury with reference to rehabilitation?

**Name of researcher:** Tim Banks

Please read each statement carefully. If you agree with the statement, please initial the box.

Please  
initial box

15. I have been provided with, read and understood the information sheet for this study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

16. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

17. If I withdraw from the study, I give my consent to allow any data collected so far to be used for the intended purpose of the research.

18. I acknowledge that my data may be used in the PhD thesis and academic/other publications.

19. I agree to participate in an interview, if this is necessary, which will be audio-recorded and will be anonymised.

20. I acknowledge that I can request a summary of the study and its findings

I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1 for participant; 1 for researcher (original)

