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Narratives of brain injury and self-management after hospital discharge

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University of Westminster

Narratives of brain injury and self-management after hospital discharge

Professional doctorate thesis

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I declare that all the material contained in this thesis is my own work.

Abstract

Specific processes for supporting self-management, as prioritised in contemporary Western healthcare policy, generally focus on biomedical aspects of managing a condition that is constructed as a separate entity from the rest of a person's life. However, uncertainties in supporting self-management for long term conditions like traumatic brain injury (TBI) persist, including a mismatch between patient and professional contexts, and under-theorisation of the concepts 'self' and 'agency'. To better grasp these issues, I gathered accounts of TBI-related experiences since hospital discharge, using a qualitative longitudinal design. I specifically relied on narrative interviews with ten dyads, consisting of one person who had recently sustained a TBI and their chosen 'significant other' person, at two time intervals. I undertook iterative narrative analyses, initially identifying discourses portrayed by participants and tensions, conflicts or emotional connections across our interactions. I drew upon insights from Michael Bamberg's positioning analysis of the self in brief moments of talk-in-interaction, and Judith Butler's work on performativity, to explore how people are bound by positions or create possibilities within socially instituted and maintained norms and expectations. The findings illustrate how the subject position 'you *are* your brain injury' brings an agentive gap. The self is made and remade through co-constructed narrative scaffolds that shift in collaborative storytelling, enabling the (re)claiming of a desired sense of self. This research offers insights into dynamics of consistency and change, rather than the assumed disruption to the self, when cognitive and communicative functions alter following TBI. In conclusion, I suggest implications for healthcare professionals' conceptualisation of supported self-management interactions. Rather than 'having' individualistic agency that is bolstered by the clinical intervention, agency is understood as a relational co-construction, offering a shift away from positioning of the 'clinician as expert' and opening possibilities to reaffirm a sense of self.

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List of abbreviations

ABI	Acquired brain injury
ACT	Acceptance and Commitment Therapy
FAM	Functional Assessment Measure
FIM	Functional Independence Measure
GCS	Glasgow Coma Score
GOS	Glasgow Outcome Score
GP	General Practitioner
HRA	Health Research Authority
ICU	Intensive Care Unit
LTC	Long term condition
NHS	National Health Service
NICE	National Institute of Clinical Excellence
PAM	Patient Activation Measure
PROM	Patient Reported Outcome Measure
PTA	Post Traumatic Amnesia
QOF	Quality and Outcomes Framework
R&D	Research and Development
REC	Research Ethics Committee
TBI	Traumatic brain injury

List of accompanying material

Linked publications

A narrative case study based on DProf research:

Mäkelä, P., 2017. "They brought you back to the fact you're not the same": Sense of self after traumatic brain injury. *Subjectivity*, 10(4), pp.358-373

An application of DProf theoretical framework within a different healthcare context:

Mäkelä, P., 2018. "She doesn't want to go to hospital. That's one thing she hates": Collective performativity in avoidable nursing home to hospital transfers. *Journal of Evaluation in Clinical Practice*, 24(5), pp.1041-1048

DProf research topic within service improvement in clinical practice:

Mäkelä, P., Jones, F., de Abreu, I., Hollinshead, L. and Ling, J., 2019. Supporting self-management after traumatic brain injury: Codesign and evaluation of a new intervention across a trauma pathway. *Health Expectations* 2019; 22: 632– 642

Preface

“Much of Medicine is bluff” said a colleague, as we stood in the doorway of the ward doctors’ office. These words exerted an effect, at once exposing fragility in our professional identities and heightening incoherence in my own sense of self. The apparently confident clinician, somehow sustained by ‘bluff’ in the abstract system of medicine, sits particularly awkwardly within the contemporary rhetoric of people as equal partners in ‘patient-centred care’. This escalating patient-centred discourse continues to situate the patient within interactions where medical privilege allows or disallows what will be known and what will be told.

Toolkits and technical approaches to supporting ‘self-management’ have proliferated within the ascendance of patient-centred care research and practice. Without considered reflection, these approaches may paradoxically constrain rather than support patients’ ways of managing. Beyond the service that intends to support self-management, the patient-as-person continues to live with health conditions, with or without mutually supportive others, managing the complexities of the everyday, within the countless inequalities that exist beyond the scope of medicine. To assimilate intentions of patient-centred care, the clinical ‘bluff’ must shift to acknowledge that self-managing entails unknown complexities, which exist beyond the familiar props and scripts of clinical performance.

In telling the story about a colleague’s proclamation on medical bluff, I positioned myself as the passive recipient of an uncomfortable insight, yet one which I recognised and accepted. At the same time, I implied that there might be personal conflict in the interaction between my professional identity and my desired sense of self. The problem, which I would like to bring to the fore in this thesis, relates to taken-for-granted expectations that both enable and constrain us, as we create them again and again within our interactions. I am interested in Judith Butler’s question, asking how we “become available to a transformation of who we are, a contestation which compels us to rethink ourselves, a reconfiguration of our ‘place’ and our ‘ground’” (1995, p. 131).

I aim to explore how storytelling is ‘put to work’ as a collaborative activity within everyday interactions, where subjects are positioned by who they are and who they are expected to

be. Personal stories, created in the present moment of interaction, bring together fluid temporal and social contexts. By contrast, the story that is 'obtained' and transformed into a recognisable clinical product - a 'patient history' - becomes disjointed from the context of its telling. The generative potential of the telling is then extinguished, as the content of people's stories becomes categorised against foreclosed outcomes. Similarly, the professional performance may become fixed, if identity is rigidly embedded in taken-for-granted norms.

I start by introducing the broad topics of traumatic brain injury and support for self-management, whose interaction is central to this research. I then situate myself in the research by considering aspects of my background and how these might influence my changing perspectives.

A glossary of key terms is contained at the end of the thesis.

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CHAPTER 1: Introduction

In recent decades, the shift from disease-focussed medical paternalism to a more inclusive, holistic ‘patient-centred’ form of care has characterised a moral necessity in Western healthcare (Duggan et al., 2006; May and Mead, 1999; Yun and Choi, 2019). For advocates of patient-centred care, the concern is to ensure that patients are treated ‘appropriately’, respected and enabled as moral agents, and that understanding of their unique experience of illness is incorporated into clinical interaction (Entwistle and Watt, 2013; Mead and Bower, 2000). Some notion of identity is at the core of patient-centred care intentions, yet the concept remains underdeveloped in this context (Horton and Horton, 2018). The health system construct of ‘self-management’ forms a key part of person-centred care operationalisation, delivered through the support that healthcare professionals offer people using services to assist their own ways of managing.

Unlike many other long-term conditions, self-management as a framework for support is rarely considered for people after traumatic brain injury (TBI). Here, the focus on acute care at the time of the abrupt injury can obscure clinical understandings of longer-term challenges, which are rendered invisible if they escape a biomedical framing (Sointu, 2016). When used as a diagnostic label, ‘traumatic’ distinguishes an injury to the brain that has resulted from an external force, contrasted with causative mechanisms such as inflammatory, vascular or neurodegenerative pathologies (Menon et al., 2010). As an everyday term, ‘traumatic’ identifies events that are highly stressful, when “the resources of the person are overwhelmed” (Quosh and Gergen, 2008, p. 97). The trauma in the clinical label invokes a predictable set of time-limited treatment responses, while the trauma in the personal event brings unknowable sets of individual, family and social implications, often continuing throughout the lives of those involved. Considerations of identity, interpersonal relationships and “understanding the social world after brain injury” (Cassel et al., 2019, p. 43) highlight the need for a more-than-biomedical gaze in the conceptualisation of support for self-management after TBI.

I commence by considering consequences of TBI, as determined by neuroscience research and clinical practice. I consider implications of Western healthcare responses to TBI, their limitations, and the move toward person-centred intentions within service responses for the longer-term consequences of TBI. I explore intentions of support for self-management

in the broader context of long-term condition management. In Chapter 2, I bring literature together on supporting self-management specifically for people living with brain injury, as the research field the current study is situated in.

Traumatic brain injury

“The patient has a wild look, an eye much like that of a person who has long watched through apprehension and anxiety, talks much and very inconsistently...”

(Pott, 1768, p. 255)

In Pott’s description of a person who has suffered a blow to the head, three centuries ago, he conveys *change* and *incoherence*. This individual’s “wild look” is no longer in accordance with social expectations, and there is a sense of difficulty understanding talk that is incessant and “inconsistent”. These impressions prevail within contemporary framings of TBI, where the gaze of neuroscience upholds that “trauma to the brain can change the core of a person’s being—their thinking, memory, personality, and behavior” (Chen and D’Esposito, 2010, p. 11).

Early neuropsychological research on recovery after brain injury focused on understanding the “disordered mind” and mechanisms for its restoration (Luria and Solotaroff, 1987; Prigatano et al., 1984). Tyerman and Humphrey, in an influential study, reported changes in self-concept after TBI, or changes “as a person” (Tyerman and Humphrey, 1984, p. 16). Increasingly, the research field focussed on subjective experiences and mechanisms by which personality might interact with the neuropathology of brain injury. Tools and approaches were developed with the intention of supporting people to achieve ‘personally-meaningful’ activities, and social participation in roles that were considered central to their identity (Baddeley, 1992; Wilson, 1987). Cognitive and communicative rehabilitation research began to acknowledge the role of family and significant others, emphasising their role in helping to ‘reconstruct’ an identity *for* the person with brain injury (Ylvisaker and Feeney, 1998).

Within clinical practice, the severity of TBI is traditionally categorised using the Glasgow Coma Scale (GCS), ranging from ‘mild’, where there may have been a brief change in

consciousness, to 'severe', indicating extended coma or amnesia following the injury (Teasdale et al., 2014). Although the majority of traumatic brain injuries are categorised in the 'mild' range according to the GCS, individuals can go on to experience cognitive effects (for example, changes in attention, memory, information processing speed, and executive processes such as cognitive flexibility), fatigue, and emotional effects (Stocchetti and Zanier, 2016). These changes are frequently considered to lead to 'hidden disability' (Heinemann et al., 2002; Seeley et al., 2009) in contrast to changes that may be 'visible' to others, such as limb or facial weakness, and reduced balance. These changes may be associated with alterations in relationships, vocation, financial and social functioning in the long term (Mansour and Lajiness-O'Neill, 2015).

Over 40 years ago, the Glasgow Outcome Scale (GOS) was devised to assess independence in the community and provide an overview of outcome that included 'social recovery' (Jennett and Bond, 1975). The original five GOS categories were: (1) dead; (2) vegetative (unresponsive), (3) severely disabled (following commands but cannot live independently); (4) moderately disabled (can live independently but with reduced capacity to work), and (5) good recovery (independent and can work). The GOS has become "the most highly cited outcome measure in studies on brain injury" (McMillan et al., 2016, p. 2) despite inadequacies relating to its simplicity and its insensitivity to small but important changes (Nichol et al., 2011).

Other scales tend to be favoured in rehabilitation settings, which intend to provide finer-grained assessments. Within the NHS in England, a dominant assessment used for monitoring progress during inpatient rehabilitation, and relied upon for rehabilitation service commissioning, is the Functional Independence Measure (FIM) and its adjuvant Functional Assessment Measure (FAM) (Turner-Stokes et al., 2016). The FIM measures domains including sphincter control, mobility, communication, and cognitive function, while the FAM was designed to assess areas insufficiently addressed by the FIM for people with brain injury, assessing cognition, behaviour, communication and community function (Turner-Stokes et al., 1999; Turner-Stokes and Siegert, 2013). However, the 'FIM + FAM' is considered to be of limited use in detecting changes after patients are discharged from rehabilitation, in the longer term (Nichol et al., 2011).

At twelve months following TBI, cognitive consequences have been proposed to herald "potentially devastating social implications" (Cloute et al., 2008, p. 652). People living with TBI face paradoxical expectations based upon their usually intact physical appearance.

'Indirect' effects of TBI therefore result from responses of others (Bowen et al., 2009) and include attributions made by the public that, following brain injury, people are "less mature, intelligent, flexible, polite, and employable" (McLellan et al., 2010, p. 708). Speculation about 'malingering' also persists in medical discourse when persisting symptoms are deemed clinically inconsistent with the severity of the injury as assessed by measures and neuroimaging (Eames, 1992; Snell et al., 2014).

Standardised outcome measurements used by services may demonstrate the most obvious evidence of functional improvement following healthcare interventions (Levack et al., 2010) while failing to assess personally meaningful roles or activities (Cott, 2007). Changes that people after TBI perceive to be important have been found to be under-represented in outcome measures for TBI (Kean and Malec, 2014), for example changes in relationships, feeling alone, or feeling overwhelmed (Mäkelä et al., 2019). Individuals themselves describe a more complex response than that captured through standardised measures (Price-Lackey and Cashman, 1996). Alterations to self-identity have been attributed to depression, anxiety, and "a reduction in hope for a positive future" (Levack et al., 2014, p. 2). Although interventions to address 'self-identity' in the clinical environment are debated (Cantor et al., 2005; Muenchberger et al., 2008), research into the influence of approaches to support self-identity after TBI are limited. Conceptualisations of self-identity are generally related to factors such as changes in discrete functional abilities, or social roles and status after TBI (Conneeley, 2012; Kim and Colantonio, 2010).

Healthcare service responses to TBI

Acute-phase management, monitoring, physiological support and neurosurgical intervention may be life-saving following brain injury (Honeybul and Ho, 2011). Although advances in emergency management of TBI in the last two decades have resulted in significantly increased survival rates (Korbakis and Bleck, 2014), this has not been accompanied by evidence for improvement of overall outcome for survivors (Roozenbeek et al., 2013). In the UK, acute and longer-term effects of TBI are clinically managed within a treatment philosophy that focuses on physical needs and favours the management of a discrete illness episode. The acute trauma stage, of neurosurgical management, is then planned and delivered separately from long-term rehabilitation services, intending to address recovery from the acute injury and adaptation to consequences.

Patients' and family members' accounts of support after TBI typically characterise health and social care services as fragmented and difficult to access (Gladman et al., 2008). The

complex, unpredictable, longer-term experiences of patients and families are not prioritised within subsequent clinical encounters (Mansour and Lajiness-O'Neill, 2015; Seeley et al., 2009). Research on patients' and their visitors' experiences in TBI inpatient rehabilitation settings suggests they can feel avoided by professionals or have a sense of being controlled by professionals' authority (Jumisko et al., 2007). Further, when clinical interventions have been completed, people with TBI and their families frequently report a feeling of abandonment in coping with ongoing symptoms, challenges and impact on quality of life (Shneerson and Gale, 2015) due to limited provision of specialist rehabilitation services in the community (Cloute et al., 2008; Pickard et al., 2004; Turner-Stokes et al., 2015).

In the context of limited professional support for dealing with longer-term challenges after TBI, people continue in their daily lives largely away from clinical services or encounters with healthcare professionals (Cameron et al., 2018). Informal social contexts and relationships become critical to individuals' approach to adapting to daily life (Boger et al., 2015; Levack et al., 2010). However, changing relationships and routines in life after TBI may alter the "equilibrium" of the family system (Whiffin et al., 2017, p. 3), for example increased intensity of time spent with close family may become "constricting" for the individual or the family (Krahn, 2015).

A focus on social contexts after TBI aligns with the broad person-centred care discourse, seeking understanding of mechanisms through which changes in existing interrelations are negotiated (Vassilev et al., 2019). Although a need to establish a 'patient-centred' approach to partnership between people living with TBI, families and healthcare professionals has been advocated (Oyesanya, 2017), evidence for its enactment remains limited. Alternatively, the mechanism becomes one of "training family members as facilitators in the rehabilitation process...to reduce dependency on the service system" (Fisher et al., 2019, p. 854).

In England, National Clinical Guidelines on Rehabilitation Following Acquired Brain Injury (Turner-Stokes, 2003) suggest that patients should be given the opportunity to talk about the impact of brain injury in their lives with someone experienced in managing the emotional impact of brain injury. Other national guidance is similarly vague in asserting, without consideration of how it might be enacted, that:

"A good clinician is able to assist the person in the process of undertaking this work [of narrative construction] in such a way that the narrative is supportive of recovery"

In neurorehabilitation settings, consideration of communication practices between clinicians and patients increasingly highlight ‘engagement’; considered to be an important predictor of disability outcomes after brain injury, “even after accounting for education, comorbid health conditions, emotional distress, apathy, and baseline functional ability” (Williams et al., 2019, p. 1). The notion of engagement between patients and clinicians is gaining popularity in healthcare more generally, where it is commonly conceptualised as “a patient behaviour and responsibility” (Bright et al., 2018, p. 35). Where limited patient engagement is noted by clinicians, it is often attributed to cognitive impairment.

The notion of ‘therapeutic alliance’ offers a possible extension of the notion of ‘engagement’, indicating that there may be more to consider than identification of a patient’s deficits. However, limited research exists on how professionals “might develop a more positive therapeutic alliance with patients” (Kayes and McPherson, 2012, p. 1907). Studies seeking to conceptualise the nature of interaction with people with brain injury typically centre on a unidirectional professional-to-patient model. Here, clinicians’ expertise is assumed to be the key factor, for example delivered in: “well communicated information about rehabilitation potential”, or “a structured meeting where...bad news would be formally broken” (Peel et al., 2019, p. 3).

In recent years, Acceptance and Commitment Therapy (ACT) has been used within neurorehabilitation approaches for people with TBI. This approach deals with themes that dominate Buddhist thought: using mindfulness strategies to enhance one’s ability to undertake meaningful activity in the presence of distress, through a focus on valued behaviours (Graham et al., 2016; Hayes, 2002; Hayes et al., 2006). ACT views psychological inflexibility as a central feature of emotional disturbance, where psychological flexibility is considered through core processes that include “self-as-context” (Hayes et al., 2006). This idea imagines the self as a stable and enduring place that hosts a variety of emotions and thoughts and is “not dependent on the nature of the content that comprises one’s ongoing flow of psychological experience” (Hayes & Gregg, 2001, as cited in Myles, 2004, p. 494). The self-as-context process within ACT intends to teach individuals how to distinguish between physical and psychological experiences relative to the ‘self’. It has been considered particularly relevant in “complex psychosocial adjustment” (Roddy et al., 2018, p. 1) including assumed disruption to, or loss of, sense-of-self after TBI (Nochi, 1998; Tyerman and Humphrey, 1984). In proposing that ACT will facilitate people with TBI to

‘regain’ their lost sense-of-self, Kangas and McDonald suggest this will mean they will be "moving forward in terms of regaining sense-of-self and values by living in the present; rather than being fixated on the past" (2011, p.266). Intrinsic assumptions include that a sense of self can be identified, that the pre-TBI self will be problematic in the present and that agency underpins an individual’s ability to ‘move forward’ in life. These notions are central to my inquiry in this research.

In the following section, I consider the emergence of ‘supported self-management’ as strategy to meet healthcare policy aspirations of ‘patient-centred care’, before exploring potential relevance and challenges when applying the concept to support for people and their families in the longer term following TBI.

Supported self-management

Long term conditions, defined as “conditions that cannot, at present, be cured but can be controlled by medication and/or other treatment/therapies” (Department of Health, 2012, p. 3) place expensive demands on health and social care services internationally (Hedlund et al., 2019). The interconnection between long term conditions (LTCs) and self-management has become central in contemporary healthcare policy where drivers for efficiency savings implicate self-management as a means for health improvement within constrained budgets (de Silva, 2011a; World Health Organization, 2013), where “the ultimate aim is that people with LTCs feel they are confident and able to manage their condition(s)” (Department of Health, 2012, p. 10).

Definitions and approaches

Although the terms ‘self-care’ and ‘self-management’ are often used interchangeably, and both are applied in broad and varied ways (Kendrick et al., 2012), ‘self-management’ typically refers to mitigation of the effects of a long-term condition to maintain quality of life. Underpinning principles include efforts to increase patients’ knowledge of health conditions, their recognition of symptoms and when to take action recommended by professionals, and correctly identifying when to seek help. Interventions typically target individuals’ health-related behaviours (Burrell et al., 2019; de Silva, 2011b) or technical tasks of self-managing a disease (Owens et al, 2017). By contrast, ‘self-care’ generally refers to a wider set of behaviours which both the healthy and those with conditions may

undertake to prevent the onset of illness or disability, again to maintain quality of life (Thomas et al., 2014).

An emphasis on the ‘disease control’ approach to self-management reinforces the positioning of health professionals as ‘experts’ with “proficiency and judgment...through clinical experience and clinical practice” (Sackett, 1996, p. 71). These definitions arise from a recognition that people with long-term conditions have to manage by some means, and the purpose of support then seems to be that they will be able to manage more effectively. Medically driven approaches to long term condition self-management continue to predominate in Western healthcare (Hibbard and Gilbert, 2014) as: ‘systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems’ (Institute of Medicine, 2003).

An early use of the term self-management support, over 40 years ago, intended to position the patient as an ‘active participant’ in their medical treatment (Creer et al, 1976). Research into self-management originated in the context of long term conditions such as arthritis (Lorig et al., 1999; Lorig and Holman, 2003). Support for self-management generally comprised group education, in which problem-solving skills were ‘taught’ through structured programmes. The educational course, developed in the USA, comprises weekly face-to-face, lay-led small group meetings (Lorig et al., 1999; Lorig et al., 2001, Lorig and Holman, 2003). In the UK, the model that subsequently became most well established is known as the ‘Expert Patients Programme’ (EPP), with an expectation that the “expertise of patients could be harnessed for the challenge of increasing burden for the healthcare system of chronic disease” (Donaldson, 2003, p. 326).

The idea of supporting self-management may implicitly threaten conventional power relations in professionals’ expertise-dominated interactions with patients. Mudge et al proposed a need for a “paradigm shift” if clinicians are to share or let go of control (2015, pp. 9–10). In the NHS in England, supported self-management is considered to be a core part of the implementation of policy intentions for personalised care, set out in the NHS England ‘Five Year Forward View’ and ‘Long Term Plan’, (NHS England, 2019, 2014). The Long Term Plan understands a basis of personalised care in “what matters” to patients and highlights “their individual strengths, needs and preferences” (NHS England, p. 6). Personalised care is operationalised through a “Comprehensive Model” in which supported self-management is one of six components alongside shared decision making, support planning, enabling choice, social prescribing and community-based support, and

personal health budgets. NHS England proposes that all six components should be embedded into health and social care, as “personalised care should be business as usual for everyone, not a bolt on for some” (NHS England, 2019, p. 34).

The personalised care agenda is considered to represent “a new relationship” between people, professionals and the health and social care system (NHS England, 2019, p. 14). Within the Long Term Plan, the proposed mechanism for the new relationship is that of co-production: “a fundamental shift towards recognising that people who use health services can also help solve problems and take control” (de Longh et al, 2019, p. 1). Concepts of coproduction and codesign, already incorporated in healthcare quality improvement research and practice (Locock and Boaz, 2019), draw attention to social dimensions of decision-making by inclusion of practicalities as understood by those for whom services are intended (Jasanoff, 2004). However, critiques have questioned whether the shift to ‘co-’ terminology heralds a fundamental change in attitudes and power relations, or instead whether co-production is in danger of becoming “a buzzword” deployed by services (Flinders et al., 2016, p. 262). Nevertheless, in the area of social prescribing, ‘link workers’ spend time with people referred to the scheme, “to assess their needs, support them, coproduce solutions and to see an improvement in wellbeing” (Polley et al., 2017, p. 41). This represents a new area for the study of coproduction, as a potential mechanism underpinning successful ‘linkage’ between people living with long term conditions and available community resources (Husk et al., 2016; Wildman et al., 2019).

The Long Term Plan considers that, for many conditions, people are already taking control themselves. The plan sets out an intention to support for people to manage their own health, specifying discrete conditions that include diabetes and asthma (King’s Fund, 2018). Self-management is open to many interpretations and will not be constituted through one form of support. However, dominant approaches that have been derived from the Expert Patient Programme continue the biomedical discourse of “health-status monitoring, provider-recommended diet and/or exercise regimens, and/or other self-treatments (e.g., injections, inhalers, breathing machines)” (Eton et al., 2017, p. 118). Qualitative studies suggest that practitioners, reflecting on their role in supported self-management interventions, appear to lack the confidence necessary to support participants beyond a biomedical paradigm (Bossy et al., 2018; Ungar et al., 2018). Entwistle considers that clinicians may anticipate that patients might perceive their competence is doubted, risking damage to their confidence (Entwistle et al., 2018). Conversely, challenges

in implementation have been described in association with professionals' dismissal of supported self-management as "irrelevant or even problematic, especially when not consistent with, or contradicting, professional agendas" (Jones et al, 2016, p.4).

Consistent among the various interpretations of self-management is an implicit assumption that valuing of the self is linked to one's ability to continue to manage in the face of long-term health adversity. Self-management support programmes frequently target self-efficacy, defined as "the belief in one's capabilities to organize and execute the courses of action required to produce given attainments" (Bandura, 1997, p.3). Self-efficacy is a core concept of Bandura's social cognitive theory (Bandura, 1997), described as a person's self-perceived ability to perform a set of actions to successfully cope with the demands of a situation, continue activities and achieve a desired outcome. It has been considered to influence how people feel, think, and find motivation, it is task-specific, and amenable to change over time. Self-efficacy has been proposed as a key mechanism through which self-management operates, offering operationalisation of the concept of 'feeling in control' (Lorig and Holman, 2003).

Underpinning principles

Neoliberal states dissociate from the costs of care through individualising and privatising care duties (Cain, 2019). Commentators argue that the turn to 'self-management' broadly fits with a shifting of responsibility to cope with long-term health conditions onto individuals and their families, away from healthcare systems (Lemke 2001; Carter, 2015, Brijnath and Antoniadis, 2016). 'Empowerment' and 'consumerism' are embedded in the narrative of personal responsibility (Wyatt et al., 2010, p. 2), and the idea of the rational, self-interested individual is central (Prainsack, 2018). A fundamental principle of neoliberal policies is the need for individuals govern themselves and be entrepreneurial in making choices, assuming they will always try to advance themselves by making the 'right' choices, which will result in personal successes, while faltering choices may result in social decline (McGregor, 2001; Salecl, 2010). The normative assumption in healthcare policy underpinned by neoliberal principles encompasses (unacknowledged) assumptions that patients (consumers) will hold responsibility for decisions, actions, 'successes' and 'failures', rather than being passive recipients of healthcare (Brijnath and Antoniadis, 2016; Henwood et al., 2003; Kendall and Rogers, 2007). High value is given to individual efficiency, accountability and autonomy (Brahim, 2019).

Neoliberal healthcare affords power to knowledge that is measurable and can be evidenced, associated with a privileging of ‘evidence-based practice’ (Kompouros-Athanasίου et al., 2019; Martin, 2008). Supported self-management practices, when underpinned by a neoliberal philosophy of self-governance (Vassilev et al., 2017), assume that people can control their health through rational conduct. They imply responsibility for making choices and working on skills for sustaining health and wellbeing (Lemke, 2001). Neoliberal approaches can result in a moralising discourse of blame for ineffective self-management (Moore et al., 2015; Potter et al., 2018). Individualistic approaches to self-management generate the basis for systemic structural violence: “structural because they are embedded in the political and economic organization of our social world ... violent because they cause injury to people”. If individuals are expected to function as the primary agents in the creation of their own health and wellbeing (Sointu, 2005), the notion of self-management is open to interpretation as a question of how a patient is to manage on their own, fend for themselves (Demain et al., 2013), ‘get on with it’ or ‘do it yourself’ (Boger et al., 2015; Satink et al., 2014), exacerbating a sense of abandonment by health services (Thirsk and Clark, 2014). The degree to which the more vulnerable are able to meet their needs is lowered, and inequalities widen (Farmer et al., 2006, p. 1686).

Over the last decade, supported self-management has increasingly been used to refer to those behaviours that might influence an individual's ability to cope with their condition and achieve optimal quality of life (de Silva, 2011b; Entwistle et al., 2016; Morgan et al., 2017). Processes typically include activities such as goal-setting, self-reflection, self-evaluation, and managing thoughts and behaviours in response to change (Ryan and Sawin, 2009). Professionals providing support for self-management seek to enhance people's confidence to self-manage conditions and to reduce “unwanted or unnecessary dependence” on healthcare services (Owens et al., 2017, p. 8). Here, self-management uses personal and social resources as a means of enhancing control over that which health services prioritise (Kendall et al., 2011). For example, the practice of goal-setting may be used “to prioritise the most important problems and motivate the patient” (Verdoorn et al., 2019, p. 98).

Terms such as ‘responsibility’ or ‘accountability’ frame supported self-management interventions’ intended behaviour change as a choice that can be determined by the willingness, motivation and ‘correct’ attitude of those to whom support is provided. Here, “being responsible” involves the demonstration of “adherence to institutionalized obligations and moral norms” (Heavey et al., 2019, p. 2). Clinicians’ perceptions of

‘activated participants’ as partners in healthcare entwine with perceptions of positive moral character (Sointu, 2017, p. 68). ‘Good’ patients are characterised by motivation to control their condition, while ‘bad’ patients fail to act according to clinicians’ expectations of patients, challenging the ideal of self-responsibility and signifying ‘deficient’ personhood (Rose, 1999).

Broader interpretations of supported self-management encompass challenges to inappropriate service provision and finding new ways of sharing both professional-based and patient-held expertise (Entwistle et al., 2010; Hinder and Greenhalgh, 2012; Jones et al., 2013, 2016b, 2016b; Kennedy et al., 2013; Mäkelä et al., 2019; Vassilev et al., 2019). The social context of managing is also receiving increasing attention within supported self-management intentions:

“actions with family, community and the appropriate healthcare professionals, to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease”
(Wilkinson and Whitehead, 2009, p. 1145).

Influences on assessment of outcome

Perspectives on what constitutes ‘a good outcome’ following a self-management support intervention vary (de Silva, 2011), with lack of consensus regarding appropriate assessment measures or understandings of what is valued from the person’s own perspective (Boger et al, 2013). The attempt to transfer the work and responsibility of managing conditions from organisations to patients and their social networks is linked to the belief that it will help save money while improving health (May et al., 2009). This system-centred framing focuses on actions that can add value in dealing with long term conditions that policy makers consider important (Narasimhan and Kapila, 2019). When attention is directed to service use costs, the focus of self-management support turns to biomedical markers of health and the behaviours that might contribute to them. This instrumental policy focus has been criticised for categorising health conditions as seemingly isolated from broader social and cultural contexts (Atkin et al., 2010). Critique includes a questioning of this dualistic framework: the separation of cognitive from bodily elements of living with long term conditions. The assumption that increasing patients’ knowledge will promote their engagement in LTC management (Rijken et al., 2014), and the focus on patient compliance to prescribed tasks, constructs self-management support in separation from the rest of a person’s life (Hinder and Greenhalgh, 2012; Pickard and Rogers, 2012; Wilson, 2010).

Educating and motivating patients to adopt clinicians' recommendations for disease control perpetuates an instrumental view of patients without recognition of the supportive value of relationships (Entwistle et al., 2016). Implementation of tools such as the NHS Quality and Outcomes Framework (QOF), providing financial incentives to GP practices, increasingly standardise adherence to specific measurements of individuals' physical 'normality' applied to single conditions. For example, the QOF for diabetes mellitus (NICE, 2016) gave a required range of readings of blood pressure and glycated haemoglobin (a blood marker of long term glucose control) and categorises the person's feet to signify diabetic morbidity. Here, 'health' and its management are considered to be measurable and doing so is mandated for the demonstration of healthcare impact.

Interventions to support self-management risk 'playing to the test' by clinicians, if focussing on aspects of professional practice that is subject to quality assessment (Owens et al, 2017). Further, the need for healthcare services to measure and demonstrate control of biomedical parameters potentially increases 'burden of treatment' or workload for patients, resulting from activities prescribed to patients by healthcare providers (Mair and May, 2014; Ridgeway et al., 2014). Adherence-focused approaches then represent a kind of "bureaucratic self-management" (Brijnath and Antoniadis, 2016, p. 5), 'done to' recipients whose unique values and "rich and complex expertise that is emergent directly from the lifeworld" is unknown or beside the point (Pickard and Rogers, 2012, p. 120).

The emphasis in policy that seeks to move toward engaging people in managing their own health is apparent within the current enthusiasm for measuring 'patient activation' in areas of knowledge, skills and confidence in complying with professionally-recommended behaviours (Hibbard and Gilbert, 2014). The implication is that those deemed 'activated' by these measures will be eligible for self-management support, as the ones most likely to benefit. When the degree of 'activation' is determined through professionals' judgements, resultant gate-keeping to self-management support has potential to exclude those deemed ineligible, including assumptions that people are 'incapable' (Guldager et al., 2019). Certain groups may then be prioritised by healthcare professionals as those who are considered 'most likely' to benefit from self-management support following judgements about their suitability, for example leading to exclusion of those with cognitive or communicative impairment (Kendall et al., 2011). Further, it suggests certain people, lacking in some way, need to be managed differently, for their own benefit, thereby positioning them as someone who 'must be helped', and emphasising health professionals as the legitimate experts in ensuring this (Jones, 2018).

The rationale presented by advocates of 'patient activation' for self-management is that they need to be activated to acquire "sufficient knowledge, motivation, skills and confidence to properly manage their disease" (van Vugt, 2019, p.74). Four stages of patient activation have been described: (1) the patient believes that an 'active role' is important for disease management, (2) the patient has the knowledge and the confidence to take action, (3) the patient takes the action, (4) the patient can maintain this behaviour even at times of stress. These aspects are commonly captured in a standardised measure known as PAM (Patient Activation Measure), assessing patient self-reported knowledge, skills and confidence in self-management (Hibbard et al, 2004). Many healthcare organisations have built the PAM into standard processes. Patients might complete it either during the checking-in process on arrival, in the course of their consultation, or during an inpatient stay. The PAM data are then entered into the patient's medical records (Hibbard and Gilburt, 2014, p. 34). The use of PAM is becoming established in the 'evidence base' discourse for supported self-management interventions as a measure of service effectiveness (Armstrong et al, 2017). It is seen as a validated, generic tool that can produce "metrics that could demonstrate the effectiveness of person-centred care" (Armstrong et al, 2017, p. 78). However, understanding of how interventions or support should be integrated into service delivery, for patients identified by the PAM at different levels of 'activation', is not clear (Hibbard and Gilburt, 2014). If used as the basis of decisions about which services will be offered it becomes a "gate-keeping or eligibility tool...to ensure that any patient being referred is sufficiently activated to be able to benefit from such services." (Armstrong et al, 2017, p. 80).

By assigning people to levels of activation, defined by specified properties, the intention then is to help them move to a 'higher' level of activation. However, patients may not value items specified within PAM as much as other possible actions, for example maintaining their social networks or gaining support for their families to live well (Demain et al, 2013). Further, social contexts and conditions of constraint make change difficult to achieve, regardless of the level of 'activation' that has been clinically scored and documented in the medical record.

Personal connections and 'being me'

What is taken to be 'self-management' occurs within a complex network of people, spaces, and discourses. However, dominant approaches to support may fail to recognise the context of interaction, particularly individuals' interpretations and connections to social

structures. Tools used to measure effectiveness of self-management interventions have frequently been developed without input from people with long term conditions that they seek to support. Little attention is given to outcomes valued, or to a need for support that is suited to the dynamic and fluid changes experienced day-to-day (Boger et al., 2012; Ryan and Sawin, 2009).

Research on self-management of long term conditions from patients' perspectives has tended to focus on conditions such as diabetes, asthma, epilepsy, or rheumatoid arthritis (Townsend et al., 2006). A systematic review of self-management-related outcomes, identified by people with long term conditions, highlighted the importance of a positive social network. Here, two components of a positive network were described: 'informal relationships', and 'health professionals'. Authors identified that self-management might be "something co-created with family members" (although few studies reviewed had explicitly identified families' perspectives), and that the "relationship between patients and health professionals is fundamental to ensuring professional support for self-management is effective" (Boger et al., 2015, p. 14). Biomedical outcomes were considered to possibly sit alongside but in tension with a need to 'be me', which comprised factors of feeling 'normal', and that the condition or its management would not "define nor dictate their lives" (Boger et al., 2015, p. 15).

Tested theoretical models and programmes for self-management support, as described above, have emphasised the importance of a trained workforce to facilitate patients' individual problem-solving and goal setting skills, and to help patients build self-efficacy, in managing long term conditions (Battersby et al., 2010; Bodenheimer et al., 2002; Holman and Lorig, 2004). However, a reliance on the biomedical aspects of supporting self-management responds to the dominant healthcare viewpoint that there is a prioritised need 'to educate' patients before a broader range of components in living well with their condition might be addressed (Hughes et al., 2018). The appropriateness of such forms of support has been questioned, "because [it does] not seem to pursue what people ... themselves strive for, or use the kinds of strategies they have found supportive" (Morgan et al, 2017, p.244). People may prioritise maintaining valued social roles, identities and a 'normal' life, sometimes over symptom containment (Townsend et al., 2006), or "participating in life as fully as one chooses" (Manning et al., 2019, p. 3).

In contrast to support for self-management that is meaningful to the context of people's lives, services often focus on process outcomes, (for example, reduction in service use or

change in parameters measured by blood tests), without necessarily considering factors in the person's life context within interactions (Boger et al., 2015). Instead of health professionals tailoring support for self-management in interaction, what prevails is a situation that does not take into account complex relational factors. Further, understanding is required of the "aspects of a person's agency or action that support is intended to bolster" (Entwistle et al., 2016, p.7).

Exploration of self-management for people living with TBI may open a new space to consider interactional, identity and agentive aspects. Further, supporting self-management after brain injury potentially exposes a form of inequality among long term conditions that are seen as 'worthy' candidates for intervention, as no obvious outcomes exist for monitoring of the 'good self-manager' against biomedical markers of disease control and adherence (Ellis et al., 2017).

Situating myself

“Viewers are as much a part of the landscape as the boulders they stand on”

(Spurgeon, 1996, p. 172)

Situated knowledge derives from positions of interpretation (Haraway, 1988). By situating my viewpoint, I acknowledge that my life experiences impact my efforts in knowledge production (Harvey, 2017). My positions and views, shaped by contexts and changing over time, influence both how I view myself and how I am viewed by others. These viewpoints derive from many positions I have or have had, for example student, researcher, clinician, caregiver, patient, partner and so on. The positions I have not experienced are also relevant, as I am not disabled, I am not from an ethnic minority, and am not socioeconomically disadvantaged and there are doubtlessly other categories for which “I can give no account” (Butler, 2005, p. 40). I acknowledge, though, that particular views and attitudes have developed through my professional experiences, which are relevant in situating myself in this research.

The incentive for pursuing this research project arose after years of working in neurorehabilitation services with people who had experienced brain injury, and their families. An insidious component of my experience was a sense of isolation while fulfilling what appeared to be the requirements of the position, according to power relations within healthcare service delivery. To some degree, this was a sense of lacking connection with the professional identities of other members of my clinical community. I also experienced a sense of remoteness from the people accessing the services, when upholding the role required in ‘delivering’ professional expertise. The ‘clinician-as-knower’ position required particular structured approaches and styles of speech, and was constrained by the expectation of producing an account of others’ experiences in terms of ‘brain pathology’, stripping problems of their context, supposing cause and solution (Gray, 2011).

This research project started off with a critical curiosity into these tensions: “a readiness to find what surrounds us as strange and odd; a readiness to throw off familiar ways of thought and to look at the same things in a different way” (Foucault, 1997, p.325). My particular focus on the construct of supported self-management resulted from an

intention to probe its deeper meanings and contradictions while seeking to generate resources for change.

Structure

I proceed, in Chapter 2, with an exploration of literature specifically addressing support for self-management after traumatic brain injury. I seek to establish a context for my research within current healthcare approaches, to understand the theoretical underpinning of existing interventions and the focus of their evaluation. The synthesis will form the background to the potential contribution of this thesis to research and practice. Following this review, I present a critical analysis of additional concepts relating to self-management after brain injury.

In Chapter 3, I outline the research aims and objectives. I set out the methodology underpinning the research, firstly presenting ontological and epistemological considerations leading to a qualitative research approach, specifically through narrative inquiry with people living with TBI, in combination with their chosen other person in dyadic interviews and using a longitudinal approach.

In Chapter 4, I describe the research methods including the setting for this study, sampling considerations, my approach to recruitment, data generation activities of interviews and field notes, confidentiality and ethical considerations.

My intention in Chapter 5 is to describe the iterative development of my analytic processes, leading to an integrated use of Michael Bamberg's positioning analysis of narrative research with Judith Butler's work on performativity. In acknowledging my own influence on data generation and analysis, I include the role of emotional awareness within my analysis.

In Chapter 6, I present the research findings and analysis. I commence by introducing the people who took part in the interviews. I then describe interrelated areas of findings from my analysis of positioning and performativity in the interview conversations, through which navigation of change and continuity is brought about. This section includes consideration of positioning within talk about clinical interactions.

In Chapter 7, I discuss the research findings, commencing with analytic reflections and situating my analysis within the research context described in Chapter 2. I explore strengths and limitations of the research undertaken.

Finally, in Chapter 8, I consider the potential contribution of this research to policy, practice and research in supporting self-management, for people with TBI and long term conditions more broadly. I describe a strategy for practical application of this work, within a related project informed by principles of coproduction to develop a supported self-management intervention for people living with TBI (Mäkelä et al., 2019).

CHAPTER 2: Supporting self-management after brain injury

Introduction

Traumatic brain injury entails socially complex yet frequently hidden challenges. Attention to support for people after TBI brings scope for broader understandings of supported self-management, where consequences such as memory impairment are seen to collide with the very substance of 'who a person is' (Atkin et al., 2010). I commence with an assessment of existing literature exploring aspects of supported self-management for people with TBI, including methodologies applied in researching the topic. I review research into development and implementation of interventions in this field, delineate key concepts referred to, and approaches to outcome evaluation. After discussing the main literature findings, I explore gaps identified and I expand on concepts that are related to this body of literature, to consider relevance for the current research project.

Literature review¹

Guided by the review model proposed by (Arksey and O'Malley, 2005), refined by (Levac et al., 2010), I commenced with concept definition and population identification, to establish a search strategy. Specifically, I explored (1) key concepts relating to self-management after TBI; (2) healthcare interventions intending to support self-management after TBI; (3) outcomes used in the assessment of self-management support for people after TBI.

Search strategy

The framework for the review and my iterative development of a literature search strategy are shown in Appendix 1a. I applied the final search strategy for the key concepts of 'traumatic brain injury' and 'self-management support' in the MEDLINE database and then converted its format by using a combination of indexing terms and free text search with

¹ *This literature review has been developed from my University of Westminster DProf assignment FHSS804: 'A scoping review on self-management after traumatic brain injury'*

relevant subject headings identified according to each database. My sources included electronic databases, reference lists of key articles identified and individual searching of journals likely to include relevant coverage of the topic. In addition, I searched two UK ‘think tank’ organisations (the Health Foundation and the King’s Fund) resources for additional articles. In view of the potential applicability of the search to a variety of disciplines, I added databases to represent principal healthcare and psychological literature: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psych Info, Embase, Allied and Complementary Medicine Database (AMED), Cochrane library, and ProQuest Dissertations and Theses, from inception to March 2019. Finally, I performed searches using key words in Google Scholar with limitation to “since 2018”, in March 2019, to allow identification of more recent publications, which may not have been captured through database searches.

I imported citations into the bibliographic software package Zotero for data management and to facilitate removal of duplicate articles. I reviewed abstracts against the inclusion and exclusion criteria shown in Appendix 1b and then reviewed whole articles to determine their relevance. I extracted key concepts discussed by authors; interventions; outcome measures and key findings. I used an Excel spreadsheet to manage and compare the data generated, before synthesising the content to facilitate my interpretations.

Findings

A total of 590 titles were generated from the search, from which 90 abstracts were retrieved and considered for further review (Appendix 1d). Numbers of articles I identified within each phase from the databases searched, and the selection process from which I identified a total of 20 articles for full review, are shown in Appendix 1e. A summary of content from the articles included is included in Appendix 1f. In the following, I explore the themes identified, in relation to my areas of focus on concepts, interventions and outcomes used in self-management support for people after TBI.

Participants

Participants with mixed causes of acquired brain injury were included in many studies identified (Brands et al, 2014a, Brands et al, 2014b; Kendrick et al, 2012; Muenchberger et al, 2011, Backhaus et al, (2010)), as were self-reported histories of “mild TBI” (Trontel et al, 2013; Tsaousides et al, 2009), or broader, mixed neurological diagnoses of stroke, brain injury or other “monophasic neurological impairment” (Dixon et al, 2007). Patients with

traumatic brain injury were also included within a “general trauma” group by Wegener et al (2014) and by Connolly et al (2014).

Methodologies of identified studies

The papers’ approaches reflected a range of methodological perspectives, from a randomised, controlled intervention study (Backhaus et al, 2010) to in-depth interviews with narrative analysis (Price-Lackey and Cashman, 1995) or phenomenological interpretation (Schutz, 2007). Outcome assessment through questionnaires was frequently employed (Cicerone and Azulay, 2007; Tsaousides et al, 2009; Wegener et al, 2014, Brands et al, 2014a, Brands et al, 2014b). The qualitative studies highlighted an approach of seeking individuals who were considered to have self-managed their situation after brain injury particularly successfully. Authors then sought to understand how this may have been achieved.

Self-management-related concepts

Self-efficacy and coping

The predominant concept discussed within the identified literature was that of self-efficacy. Authors refer to Bandura’s concept of self-efficacy as the belief in one’s capabilities in achieving goals (Bandura, 1997). Dixon et al (2007) generated a topic guide for qualitative interviews, which they structured around Bandura’s components of self-efficacy (Bandura, 2006, 1997), and suggested that this could be used to derive a novel self-efficacy scale as a measure for use in rehabilitation settings in general, and in assessment of supported self-management interventions, in particular.

Studies looked at the relationship of self-efficacy to social participation (Brands et al., 2014a) and coping (Brands et al., 2014b; Yehene et al., 2019) after acquired brain injury and the concept of employment-related self-efficacy, specifically after TBI, was explored in four studies (Price-Lackey and Cashman, 1996; Sherer et al., 2014; Soeker, 2012; Tsaousides et al., 2009). Authors reported that employment-related and general self-efficacy positively correlated with perceived quality of life (Tsaousides et al, 2009). In qualitative exploration of return to work after TBI, Soeker (2012) identified a theme of participation in occupation that enabled ‘positive growth’. Sherer reviewed the effects of self-reported traits and environmental barriers or facilitators on employment outcomes after TBI, suggesting that findings indicated self-efficacy was ‘probably’ not predictive of employment and coping style was ‘possibly’ not predictive of employment. By contrast, self-reported well-being,

pain, social interaction and post-concussive symptoms were identified as being likely to make important contributions when predicting employment.

Two studies including people with mixed causes of acquired brain injury diagnoses (including TBI) measured self-efficacy, coping and social participation through postal questionnaires administered up to one year after acute onset of brain injury. The questionnaires included a 13-item TBI Self-efficacy Questionnaire and 'coping questionnaires' relating to responses to situations perceived to be a specific consequence of brain injury, for example: "I am very stressed when I meet people because I cannot remember their names" (Brand et al, 2014a, p. 870). Defining coping as the cognitive and behavioural efforts made to manage stressful situations (Folkman et al., 1986), the authors reported that higher self-efficacy protected against the 'negative effects of emotion-orientated coping' and suggested that, as assessed through questionnaires, self-efficacy facilitates the use of restoration-oriented behaviour (task coping). The findings suggested that self-efficacy appeared to be of less importance in 'long-term' (up to one-year post-injury) social participation.

In a more recent study exploring self-efficacy and coping following traumatic brain injury specifically, authors used a general self-efficacy scale (Schwarzer and Jerusalem, 1995), aiming to assess coping and adaptation abilities (Yehene et al., 2019). The authors proposed that self-efficacy relates to emotional outcome after TBI, through its impact on subjective stress appraisal, which affects the ability to accept one's condition. Further, authors suggested that coping after TBI "may not be different to coping with any other unpleasant life events that require adjustment" (p.5). They proposed that the underlying mechanism may be similar to that in post-traumatic stress disorder (PTSD) and recommended that clinicians should encourage people with TBI "to engage in activities that will help challenge their maladaptive cognitions and perception of how the injury has affected their lives" (Yehene et al., 2019, p. 7).

Trontel et al (2013) sought to explore "why individuals with mild TBI may complain of lingering symptoms" (p.961) by applying the concept of 'stereotype threat': a reduction in performance associated with negative stereotype about belonging to a social group. They investigated the effect of indicating to students that they had been selected on the basis of their history of (self-reported) TBI, which they considered would have the effect of making this diagnosis 'salient' (Suhr and Gunstad, 2002). Trontel et al termed the resulting scenario a 'diagnosis threat'. Under these conditions, students reported significantly lower

academic self-efficacy as measured by a questionnaire, and were more likely to misevaluate their cognitive ability than the control group, despite showing similar performances on cognitive tasks. The authors proposed that academic self-efficacy would be amenable to change, and highlighted the importance of taking into account individual self-perception within supported self-management interventions.

Schutz explored self-efficacy through a phenomenological qualitative study of nine individuals the authors considered to have made a “highly successful” recovery after TBI, selected from a cognitive rehabilitation programme, in which they were taught compensatory techniques for adaptation to cognitive impairments. This involved training in the use of external memory and time management aids and a procedure to develop self-correction skills. The patients were referred to as:

“self-therapists, taught to watch ardently for their errors, prescribe their own self-corrective procedures, and review and revise their methods continuously to upgrade the quality of their adaptive repertoire”.

(Schutz, 2007, p. 50)

The individuals considered highly successful were described by the authors as showing “uncommon persistence and self-discipline” in applying the adaptive techniques (Schutz, 2007, p. 53). These participants, when interviewed, attributed their successes to their continued reliance on, and elaboration of, the cognitive compensation strategies that they had been taught in the rehabilitation programme. Unlike their less successful peers in the programme, authors proposed that those who were most successful had demonstrated “self-corrective self-management”, which had minimised the functional impact of their deficits. They considered that these participants particularly demonstrated an “intolerance of error and embarrassment” that resulted in heightened determination to apply error-prevention strategies (Schutz, 2007, p. 53).

One study adopted a narrative approach (Price-Lackey and Cashman, 1996) within a case study of an individual who was interviewed twice, at an interval of one year. The authors intended to explore the complexity of personal approaches in rehabilitation and meaning-making over an extended time following TBI and sought perspectives on patients as ‘occupational beings’, by gathering a life history focused upon occupation/employment. The authors’ narrative analysis identified a theme that they described as “times of great change are times of great opportunity”. They suggested that the patient’s self-devised, gradually more complex occupations (including “studying, playing music, writing, computer graphics, and theater production, to...exercise creativity” (p. 306)), contributed

to her post-TBI recovery. Their analysis illustrated how potentially ‘negative’ situations might be reconfigured as positive opportunities, and ways that personal *meanings* of functional activities were integrated within a narrative of an overall life story. The individual summarised her own approach as “my self-treatment program...a work in progress...Life is, after all, an eternal process of being and becoming” (Price-Lackey and Cashman, 1996, p. 312).

Self-management interventions

Interventions in the literature identified were underpinned by an approach where forms of knowledge and ‘expertise’ were conveyed to patients. Self-management intervention formats included time-limited individual coaching sessions, delivered by an occupational therapist and psychologist (Kendrick et al., 2012); a group-based preventative intervention led by “two professional facilitators with a minimum of a master’s degree” (p.843) for people and their caregivers following discharge (Backhaus et al., 2010, p. 843); a peer or healthcare professional-led community-based programme (Muenchberger et al., 2011); or an occupational therapist delivered problem-solving-therapy framework to “teach individuals to self-manage fatigue” (Raina, 2018, p. n/p). One protocol planned a clinical trial to evaluate the effectiveness of a person and family-centred intervention to reduce unsafe events, increase self-managed activities and enhance participation after brain injury (Steele, 2017). The programme comprised of an assessment phase by a clinician followed by ‘prevention education and goal-setting’, and then ‘in-home activity training with a life skills coach’ through eight home visits. The life skills coach would provide training, compensatory strategies, and social or technical supports on selected activities. Patients and family members were to receive a personal report on their own strengths and risks (Steele, 2017).

A summary of the interventions identified to support self-management after brain injury is shown in Table 1.

Table 1 - Summary of self-management interventions for people living with brain injury

Reference	Intervention	Participants	Key features
Backhaus et al, 2010	'Brain Injury Coping Skills' group programme	People with mixed acquired brain injury diagnoses (n=20) Caregivers (n=20)	Psychotherapy, psychoeducation, stress management and problem-solving skills through Cognitive Behavioural Therapy (CBT) approaches.
Muench-berger et al, 2011	STEPS programme ('Skills to Enable People with brain injury and their communities')	People with mixed acquired brain injury diagnoses (n=52; 42% stroke)	Community-based six-session group programme for people with focus on planning a collective activity. Structured programme of 'relevant topics' facilitated by a trained local peer leader or health professional.
Kendrick et al 2012	'Acquired brain injury self-management programme'	People with mixed acquired brain injury diagnoses (n=53)	'Coaching sessions' at rehabilitation centre, with focus on symptom education, adaptive strategies, cognitive reframing, collaborative problem-solving and weekly goal setting. Eight sessions with occupational therapist and eight telephone calls with psychologist.
Connolly et al, 2014	Integrative review of interventions to increase self-efficacy to improve patient recovery post-acute injury	General 'acute injury' patient group including traumatic brain injury	Suggested self-efficacy was positively influenced by supervised educational interventions, coping strategies and/or cognitive behavioural training with feedback.
Raina, 2018	A self-management intervention called 'maximizing energy' (MAX)	34 participants were randomized to experimental (n= 20) and control (n= 14) groups. Mean duration post-TBI was 58 months.	The intervention involved a problem-solving Occupational Therapy framework 'to teach individuals to self-manage their fatigue' through two 1:1 sessions per week for 8 weeks, via web cameras. This was compared to a 'health education attention control intervention' intending to decrease post-TBI fatigue.

Outcome measures

Self-efficacy related

Cicerone and Azulay (2007) explored relations among standardised measures of “community integration, activity-related satisfaction, self-efficacy beliefs, and perceived quality of life” in people with TBI living in the community (p. 259). They used a ‘TBI Self-Efficacy Questionnaire’, which they modified from a measure designed for people with ‘chronic medical disability’. The intention was that it would relate to:

“self-efficacy to perform self-management behaviors that had the highest inter-correlations...[for] persons with diverse disabilities, and contained items that appear most meaningful for people with a neurological disability” (p.260)

This questionnaire incorporated four subscales covering social, physical, cognitive and emotional items. The adapted scale was developed by the authors for the group categorised as ‘neurological disabilities’, though they referred to the new version specifically as the ‘TBI Self-Efficacy Questionnaire’.

Similarly, Muenchberger et al (2011) implemented a scale to assess how people were managing effects of acquired brain injury (including TBI). Their group self-management programme was assessed using a ‘self-efficacy scale’ that consisted of items assessing their level of confidence in managing. The authors proposed that ‘self-management’ should be assessed separately, through use of an ‘active coping scale’. This was intended to assess participants’ capacity for coping, as well as perceived effectiveness of their coping, using questions such as, “How well do you think you will deal with any problems you are having?”. Each scale was generic, rather than specific for challenges after brain injury, having been developed for long term conditions (Lorig et al, 1989) and general ‘stress and coping’ situations (Terry, 1991) respectively.

A scale intended to assess perceived self-efficacy was developed by Backhaus et al (2010) for the acquired brain injury population, including a heterogeneous range of stroke, hypoxia, ruptured aneurysm, metabolic encephalopathy or traumatic brain injury aetiologies. Their ‘Brain Injury Coping Skills Questionnaire’ was developed to “measure a person’s perceptions about ability to both understand the effects of brain injury and cope and manage one’s reactions and coping skills” (p.844), with an example item: “I know what

kind of automatic thoughts I have and can catch myself when I have an automatic thought.”

Bergman et al (2011) developed and piloted a measure specifically for the traumatic brain injury context, by adapting a “measure originally created as a self-management measure for HIV/AIDS” (p. 144). The authors considered headache, dizziness, and memory difficulties to be common complaints after TBI, and added these to some of the existing items in the HIV/AIDS related measure: e.g., fatigue, depression and anxiety. The authors noted that the question inviting respondents with TBI (n=14) to add other symptoms through free text was “the only item not consistently used” on the questionnaire. They proposed that this was “a positive quality of the scale in that items did not need to be written in and therefore further items do not need to be added to the scale” (p.146), without acknowledgement of the known under-reporting of symptoms in this group and cognitive difficulties that can affect questionnaire completion (Kelley et al, 2014). The authors also proposed that healthcare providers should “better educate this population about what might be most helpful in terms of symptom self-management” (p.146). The strategies presented for self-management within the questionnaire were predetermined and emphasised actions such as medication compliance, accessing healthcare and seeking information.

A qualitative semi-structured interview approach was taken by Dixon et al (2007), instead of the questionnaire-based assessments discussed in the studies above. Their sample came from a neurorehabilitation setting. Interviews were conducted according to a checklist of topics informed by literature on motivation in rehabilitation (Grahm et al, 2000), and Bandura’s self-efficacy theory (1977, 1997). They reported themes identified in the interviews, such as “recognising one’s own improvements”, “vicarious experience”, and “external reassurance”, thereby closely mirroring the key components of Bandura’s self-efficacy theory (1977, 1997) of mastery, modelling, social persuasion and physiological factors, which they had used in the construction of the topic guide. Dixon et al concluded that such a measure of self-efficacy could be used in rehabilitation settings to assess “the effectiveness of interventions designed to improve self-efficacy and allow patients to make the best use of the services offered” (p.238).

Quality of life, function and impairments

Although health-related quality of life is often conflated with level of function, these represent discrete outcomes (Corrigan and Bogner, 2004). Kendrick et al (2012) assessed

the outcome of their self-management coaching intervention solely through a questionnaire-based measure of daily function (the Canadian Occupational Performance Measure (Law et al, 1990)), without assessment of quality of life. Brands et al (2014a) incorporated assessments of quality of life using the EuroQOL (1990), a standardised instrument used as a measure of health outcome that is considered to be applicable to a wide range of health conditions and treatments (EuroQol, 2015). They applied this along with the TBI self-efficacy questionnaire devised by Cicerone and Azulay (2007) which, as discussed above, had been developed for the context of neurological disabilities, rather than for self-efficacy after TBI.

The 'modified Fatigue Impact Scale' and 'Patient Reported Outcomes Measurement Information System' were used to assess fatigue impact in everyday life, without qualitative evaluation. Here, the author reported that the therapist-led fatigue self-management intervention had a sustained effect on fatigue impact as measured by these scales (Raina, 2018).

Patient 'activation'

Although none of the identified studies used the 'Patient Activation Measure' (PAM) employed in studies of readiness for self-management support in long term conditions more broadly, as discussed above (Hibbard and Gilbert, 2014), one study aimed to assess a similar notion of people with TBI's willingness to participate in supported self-management interventions (Wegener et al, 2014). The authors' reported development of an instrument based on the 'Stages of Change' model comprising pre-contemplation, contemplation, preparation, action and maintenance (Prochaska and DiClemente, 1983).

Literature review discussion

This literature review on supporting self-management with people following TBI identified limited research that brings forward perspectives of people experiencing it, changes over time after injury, or meaningfulness in daily life of the interventions delivered (Muenchberger et al, 2011; Brands et al, 2014a; Brands et al, 2014b; Dixon et al, 2007; Eghdam et al, 2012). Epistemological positions (origins and nature of knowing (White, 1982)) were not explicitly addressed within the majority of papers reviewed, but studies predominantly relied upon interpretations of standardised measures (e.g. Cicerone et al, 2007; Brands et al, 2014a, Brands et al, 2014b, Backhaus, 2010; Begrman, 2011). Studies did not explore qualitative accounts of priorities in support for self-management. Measures employed in assessing outcomes frequently focussed on self-efficacy but had

been devised for people with ‘neurological disability’, raising questions over their relevance for experiences after TBI in particular (Cicerone and Azulay, 2007; Brands et al (2014a). Additional self-management outcome measures were adapted from different conditions (e.g. Bergman et al., 2011) where a lack of attention to TBI-related fatigue or cognitive change could be relevant when participants are required to sustain written responses in extended questionnaire batteries (Kristman et al., 2014).

The studies identified focussed on individual self-management without inclusion of family and others, though Backhaus et al (2010) highlighted family as an integral component in coping with sequelae of brain injury. Research focused on family members as carers focussed on “training” them to “manage the patient better” (Fisher et al., 2017, p. 1). In a recent scoping review on the related topic of ‘brain injury education’ intended for adult patients with TBI and/ or their family members, the authors identified just one study that had incorporated elements of self-management training (Hart et al., 2018).

Programmes underpinned by Bandura’s self-efficacy principles have been suggested to be the most effective at changing psychological state and quality of life, in research on self-management support for long-term conditions (da Silva, 2011). Several of the studies identified in this review were based on Bandura’s self-efficacy theory (1977, 1997) where the assessments were based on self-reported standardised questionnaires (e.g. Dixon et al, 2007; Kendrick et al, 2012; Connolloy et al, 2014). Other studies relied upon questionnaire-based outcomes that focussed on changes in function and participation after brain injury (e.g. Kendrick et al, 2012; Brands et al, 2014b; Jones et al, 2014; Muenchberger et al, 2011). Here, researchers determined what the self-management support was intended for, designed the interventions as programmes the recipients were expected to comply with, and designed outcome measures that led to isolated categories of changes to be measured, without acknowledgement of the complexities of life and social relations after TBI.

Few interventional studies attempted to support self-management for people only after TBI but instead included people with TBI in groups of people with other forms of brain injury, neurological disorder or traumatic injuries. These interventions generally followed a group-based format (Backhaus et al., 2010; Kendrick et al., 2012; Muenchberger et al., 2011), mirroring the dominant model of ‘expert patient’ long-term condition supported self-management intervention, as I discussed in Chapter 1 (Holman and Lorig, 2004; Lorig and Holman, 2003). Limitations of group-based programmes have been acknowledged: difficulties for people in participating due to work commitments, access to transport and

symptom-related hindrances (Muenchberger et al, 2011). Further, structured content may be insufficiently tailored for situations people are dealing with, and time-limited sessions do not necessarily take account of ongoing needs beyond the programme. A lack of integration of the group format of self-management support into normal ways of healthcare working also fails to reach the broad range of patients for whom this support could be relevant (Jones and Riazi, 2011; Lawn and Schoo, 2010).

The studies identified frequently asserted that people living with brain injury could become more socially productive and more effective in their utilisation of healthcare services. These priorities reflect the endpoints considered of importance in supported self-management programmes more broadly: “health behaviour, health status, and health service utilization” (Lorig et al., 1999, p. 6). They fail to include the outcomes that people themselves have been found to value in support for self-management, such as the patient-professional relationship and a need to “be me” (Boger et al., 2015, p. 15).

Summary and implications

The increasing policy emphasis on supporting self-management in healthcare, combined with a paucity of studies specifically considering supported self-management after TBI, points to a need for further understanding in this area of research and practice. Traumatic brain injury is a long term condition with an acute onset and often lifelong implications for the individual and family (Oyesanya, 2017). The focus of existing support is on education about TBI (Jones et al., 2015). Limited evidence exists on how to develop partnership-working between patients after TBI, families and healthcare professionals, or how this could be enacted. Research into self-management support has taken relatively little account of the tensions or demands in social relations, including those with healthcare professionals.

The identified approaches to support for people living with TBI uphold the assumption that professional expertise will remediate patient deficits, placing the emphasis on what the clinician will bring to the encounter (Kendrick et al., 2012). To offer support for self-management is to intend to change a person’s situation for the better, and therefore means that judgements will be made about what would represent improvement and what trade-offs are at stake among people’s priorities and needs (Townsend et al., 2006). Here, normative standards are at work:

“[they] make claims on us; they command, oblige, recommend, or guide...When I say that an action is right I am saying that you ought to do it; when I say that something is good I am recommending it as worthy of your choice”

(Korsgaard et al., 1996, p. 8).

‘Responsibilising’ the patient to carry out professionals’ recommendations is not merely engaging them in neutral acts of self-help but can be seen as a ‘disciplining’ for them to act in certain ways to serve another end (Foucault, 1988): that of health service efficiencies where “success is the physician’s to claim, blame is the patient’s” (Thille et al., 2014, p. 103). ‘Bad’ patients who are not helped by such disciplining bring the limits of medicine into focus (Sointu, 2017). People living with TBI may therefore not only be disadvantaged by current conceptualisations of supported self-management, but can potentially expose healthcare systems’ inherent limits and deficiencies in this area.

In the following, I consider ways in which the concepts of biographical disruption, self and identity, and agency may deepen understandings of self-management, before linking these with literature on experiences following TBI, to more specifically identify the research gap to which I aim to contribute.

Related concepts

“There is the language of metrics, and value added...and of impact. And there is the language of kindness and grief, of loneliness, love and friendship, of the ties that bind, our sense of identity and of belonging”

(Unwin, 2018, p. 9)

The sociological literature is rich in studies of how people manage their lives when facing a long-term condition. The need to take account of patient – rather than medical – priorities is apparent within concepts such as ‘biographical disruption’ (Bury, 1982) or finding a ‘new normal’ (Couchman et al., 2014). These concepts align with the ‘turning point’ idea in illness narratives, viewed as an event that results in a sudden change and calls for re-evaluation of one’s lifestyle. The turning point is told through stories of life before and life after an event that constructs an identity as ‘changed’ (Hydén, 2010). The work of living with long term conditions extends, then, beyond ‘illness work’ to manage the health condition. It potentially includes the work of maintaining or reconstructing one’s biography (Corbin and Strauss, 1985, 1988). This biographical dimension broadens the focus of the self-management construct, yet it is generally excluded from clinical practices of supporting self-management for long term conditions (Murray et al., 2018), as discussed above. However, self-management support might offer a bridge between the ‘language of biomedicine’ and ‘the language of ‘life’, as conveyed by Unwin in the quote above, by acknowledging the centrality of self and identity work within self-management of long term conditions.

Qualitative research highlights personal impacts of living with TBI as a loss of pre-injury self and the challenge of re-constructing identity (D’Cruz et al., 2019; Levack et al., 2014; Martin et al., 2014; Nochi, 1998). Further, research has specifically examined concepts relating to of self, identity and their ‘loss’ following brain injury, intending to develop approaches in rehabilitation to support identity re-construction (Coetzer, 2008; Geytenbeek et al., 2017; Gracey et al., 2008), thereby becoming a target for supported self-management intentions. However, greater understanding is required of the “aspects of a person’s agency or action that [self-management] support is intended to bolster” (Entwistle et al., 2016, p. 7).

More than three decades ago, a classic study explored ‘changes in self’ after TBI (Tyerman and Humphrey, 1984). The authors assessed changes in self-concept through participants’ completion of scales of “anxiety and depression, an attitude questionnaire relating to physical disability and semantic differential ratings of present, past and future self” (seven months post-TBI, on average) (p.11). They found that self-ratings of present-self were “dramatically” different when compared with ratings of past-self (p.11). Inherent in this study design is an assumption that we can access and categorise a unified sense of self, and draw temporal distinctions in its evolution. More recently, authors have suggested that a changed sense of self is linked to poorer rehabilitation outcomes and mental health problems after TBI (Cantor et al., 2005; Thomas et al., 2014; Ylvisaker et al., 2008). The connection of TBI with an inevitable change in self raises the question of what it is that changes – and whether it does change, or in some ways remains the same.

I proceed by considering the concept of ‘biographical disruption’, leading to exploration of the broad interpretations of related concepts of personhood: ‘identity’, ‘self’ and ‘agency’ (Higgs and Gilleard, 2016). I reflect on these concepts in light of my research findings, in Chapter 6.

Biographical disruption

Over the last four decades, since Bury’s classic study of people living with rheumatoid arthritis (Bury, 1982), the concept of biographical disruption has been widely used in describing how individuals experience health conditions. Biographical disruption portrays a rupture in “the structures of everyday life and the forms of knowledge which underpin them” (Bury, 1982, p. 169). This rupture is proposed to impact narratives that people use to make sense of, and talk about, themselves, the coherence of their lives, and their identity (Charmaz, 1983). Bury (1982) initially used biographical disruption to describe how people viewed themselves in the context of a long-term illness, “disrupting” their sense of self and, for some, disconnecting them from their anticipated future. As such, the idea of biographical disruption might be understood within “efforts at life-planning or attempts to ‘colonize the future’ under the conditions of ontological in/security in late modernity” (Kenny et al., 2019, p. 60).

Bury later identified two aspects of disruption: ‘meaning as significance’, referring to impact of the condition on a person’s sense of identity and how others perceive her or him; and ‘meaning as consequence’, referring to the impact of the bodily effects of illness (symptoms, impairments, participation) in everyday life (Bury and Anderson, 1988). The

related concept of biographical reconstruction refers to narratives seeking to realign order in 'meaning as significance' through revisions of self-concept, as a "reconstruction of [a person's] changing relationship to the world in which they live" (G. Williams, 1984, p. 175). Whiffin has instead considered a more complex "narrative misalignment", as a lack of symmetry between people, events, experiences, and its impact on their interpretation (2017, p. 7).

Recently, authors have argued that any disruption resulting from illness onset is far from inevitable (Faircloth et al., 2004; Saunders, 2017; Wiles et al., 2019). Recent conceptualisations also view the disruption to take place at the level of the "habitual behaviours that govern daily life" rather than at the level of individual identity (Engman, 2019, p. 126). Others argue that the rupture of taken-for-granted expectations about our lives is itself problematic, as people instead attempt to normalise their health condition by incorporating elements of it into their life narratives (Sanderson et al., 2011).

Summarising critique of the biographical disruption idea, Williams raises caution about the "unreflexive usage or the ritual doffing of caps" for commonly accepted concepts as a fixed point of reference (Williams, 2000, p. 41). His argument is instead that illness may in fact be biographically anticipated, rather than disruptive. The effects of contextual factors have been highlighted in anticipation of such events and lessening a sense of disruption, such as age of onset of conditions (childhood versus advanced age) (Engman, 2019, p. 120). Further, recent authors argue that once contextual factors are considered, the idea of biographical *flow* becomes more relevant than disruption (Faircloth et al., 2004). Faircloth's conceptualisation of flow related to older people living with long term conditions who went on to experience stroke, reportedly viewing the stroke as part of their ongoing biography rather than as a disruptive event.

In this understanding, the abrupt onset of TBI, an unexpected event typically *unlinked* to any existing health conditions, may be seen to potentially heighten biographical disruption, due to "the problem of lost normality" (Prigatano and Pliskin, 2003, p. 315). Further, the symbolic significance of the label 'brain injured' may invoke its stigmatising potential, whereby an individual who sustains a TBI may be reclassified by others according to an undesirable and 'not normal' stereotype (Goffman, 1961). My intention is to explore disruption, or continuity, through the analysis of narratives of TBI in this study. In the following, I consider broad understandings of self and identity before further exploring their relevance when focussing on self-management and TBI.

Self and identity

The human brain is commonly understood to be the site of privileged values, including those which define individual human identity (Krahn, 2015). The term 'identity' is often used interchangeably with 'self', when authors make reference to a sense of "personal continuity and emotional coherence" (Fivush and Graci, 2017, p. 268). Harré asserts that "persons 'have' selves" (Harré, 2015, p. 3), identifying four aspects of personhood to which 'self' is applied: the *embodied self* (unity in a person's point of view the world, and across time); the *autobiographical self* (the 'hero' or 'heroine' of stories, a self that can differ from story to story); the *social self* (variable personal qualities displayed in encountering others) and *self-concept* (beliefs that people have about themselves, their qualities, and their life). Others have argued that the range of 'self'-related terms suggests that "self is not really a single topic at all, but rather an aggregate of loosely related subtopics" (Baumeister, 2010, p. 681) and further that "one begins to wonder what the term self actually means in any of them" (Leary and Tangney, 2012, p.4).

Across a broad range of academic inquiry, debates have proliferated around self-identity: old versus new identities, the foundations of - and transformations in - selfhood (Jenkins, 2014). The related concept of 'identity work' has been defined as:

"the mutually constitutive processes whereby people strive to shape a relatively coherent and distinctive notion of personal self-identity and struggle to come to terms with and, within limits, to influence the various social-identities which pertain to them"

(Watson, 2008, p. 129).

Identity work has been developed with analytic distinctions between an internal 'self-identity' and an external 'social-identity'. Tajfel defined social identity deriving from significant group membership (Tajfel and Turner, 1979), seen to provide a link between "socially available discourses and self-identities" (Watson, 2008, p. 121). The importance of social factors following brain injury is gaining increasing recognition, whereby social identity is one factor proposed to predict well-being after injury (Haslam et al., 2008; Walsh et al., 2015). Membership of social groups, for example families and or work colleagues, is considered "crucial" for identities in the context of adversities such as brain injury, through "a range of positive social interactions and various other acts of solidarity" (Walsh et al., 2015, p. 556). Consideration of the importance of social factors again

highlights questions over individualism in dominant approaches to neurorehabilitation and supporting self-management, as discussed above.

Billig proposed that “banal” aspects of social identity are those that remain largely unexpressed and yet are available to be drawn on when required (Billig, 1995). Although Billig’s initial concept focussed on a shared sense of national belonging, the idea of latent shared aspects of belonging, to draw upon at the time of stressors, could become relevant in identity work after TBI. Latent aspects of social identity will be a factor under consideration in narratives of TBI in this thesis. In addition, questions arise about power structures behind social relations and the socially-available discourses available to be mobilised in narration (Paton, 2018).

Within narratives of TBI, identity processes are often assumed to be “interrupted and thus laid bare” (Walsh et al., 2015, p. 568). In order to explore (re)negotiation of identity after TBI, I draw on Judith Butler’s theory of performativity, where identity is seen as a continuous processes of reiteration and resignification (Butler, 1990). In the following, I briefly introduce Butler’s concepts and I return to these when describing development of my analytic approach (Chapter 5).

Judith Butler’s work encompasses conceptualisations of subject formation, discourse and the nature of being and becoming. She draws on a range of theorists including Foucault, Derrida, Austin, Althusser and Lacan to interrogate understandings of identity. Importantly, Butler argues that coherence and continuity of the self are not logical features of personhood, but “socially instituted and maintained norms of intelligibility” (Butler, 1990, p. 7). Following Foucault, she describes notions of identity derived from regulatory ideals (Butler, 1993, p. 1), providing ideal norms which people are expected to live up to, in categories which they iteratively create and recreate. Failure to cohere with societal norms precludes recognition as a particular category of person, which coherence to these norms would otherwise confer (Brady and Schirato, 2010, p. 37).

In her account of performativity (which I expand on in Chapter 5), Butler utilises the notion of an “interpellative call”, originally outlined by Althusser as the ‘hailing’ of people into an existence (Althusser, 1971). When individuals are hailed as subjects by dominant ideologies, they are called to an identity and, upon recognising the self as the one ‘hailed’, they act in the expected manner. Interpellation involves a demand being made for an account to be given of the self that accords with the trajectory of the self in a coherent

manner. The interpellated subject then becomes positioned in relation to others through acts that the “community sees and recognises as coherent” (Meyerhoff, 2015, p. 2), described as a “matrix” in which identity positions are recognisable and stable (Butler, 1993, p. 51). Identity, then, is a “performative accomplishment compelled by social sanction” (Butler, 1988, p. 520). Performative interpellations create subjective experiences and may deny agency through passive positioning (Butler, 1997).

In the following, I consider conceptualisations of agency and autonomy in relation to the principles and assumptions underpinning the dominant approaches to supported self-management discussed above.

Agency

A fundamental social science question is “how we can understand the dynamics of human agency in conditions of constraint” (May, 2014, p. n/p). The concept of agency is “a slippery one and its definitions vary” (Jolanki, 2009, p.215). Agency is typically operationalised as decision-making but may take many forms, such as “negotiation, deception and manipulation, subversion and resistance” (Kabeer, 1999, p. 438). In common with critiques of the ‘autonomous individual’ concept, the concept of agency raises questions about how far it can be seen as individualised rather than relational (Mason, 2004).

Conceptualisations of agency through relational or dispersed processes are not broadly integrated into contemporary practices of Western healthcare where ‘reality’ remains reducible to the actions of independent individuals (Prainsack, 2018). As discussed above, prevailing practices in self-management support for those with long term conditions privilege the idea of individual rationality over relational possibilities (Hughes et al., 2018). The discourse, typically focusing on individuals’ knowledge, skills and behaviour, seems to neglect the social nature of agency and “the inherent complexity of interpersonal support and healthcare” (Entwistle et al., 2018, p. 1465). If the limits of individual agency are not acknowledged by professionals in interactions, then the intentions of ‘person-centred care’ could be at stake, through recreation of the power relations it purports to disrupt. Further, in emphasising individual agency, the idea of self-management may seem to blame those do not manage conditions successfully, according to healthcare service parameters (Rubinstein and de Medeiros, 2015).

If agency is taken as the notion that people are the “authors” of their own ideas and actions (Burr, 2003, p. 121), then human ability to ascribe meanings to life events, and to act on

those meanings, is brought to the fore. This interpretation, as captured within self-determination theory, is considered to be a psychological foundation of well-being: acting as a source of mastery for turning our lives into what we want, through behaviour that aligns with our beliefs, and preserves our sense of self (Deci and Ryan, 2012). From a narrative perspective, this understanding of agency has been considered “fundamental to rebuilding a more useful narrative of the self in recovery: Stories cannot usefully be foisted on people” (Ridge and Ziebland, 2006, p. 1052).

Challenges to this notion - the strategically rational individual - question the implication that we are somehow independent of the Other (Prainsack, 2018; Salecl, 2010). For Midgley, “we are not hard, discrete, billiard-ball-like atoms, but are organically related, members of one another” (Midgley, 2003, p. 37). Even when individuals are heralded as agential, they may not see themselves as agents if lacking sufficient availability of alternative choices or the capabilities to make them (Gubrium and Holstein, 1995). Lamb, for example, describes how older adults of low income convey “a sense of lacking agency to realize healthy aging” (2019, p. 4). Agency is intrinsically threatened by discourses of independence, where the “dependent Other is the quintessential non-actor in society” (Weicht, 2010, p. 214).

In contrast to this notion of the agential individual, feminist scholars instead highlight developments arising through relationships: “We are who we are because we relate to others” (Prainsack, 2018, p. 25). Here, the emphasis is that rational abilities developing through relationships that are viewed as a precondition for subjectivity (e.g., Gilligan 1982; Butler 1990; Prainsack, 2018). Feminist understandings of relational care diverge from an ontology that separates out the individual, instead recognising interconnectedness (Ahmed, 2004). Feminist theory seeks understanding of the ways pervasive political and cultural structures are reproduced through individual practices, and personal situations are situated in a broader, shared contexts including those that can enable or empower us in unanticipated ways (Butler, 1988).

In this thesis, I understand agency as discursively constituted, diverging from the notion of autonomy as “an individual standing outside social structures and processes” (Jensen, 2011, p. 110). Within a poststructural framework, a “device of interruption and deconstruction of taken-for-granted assumptions” (Frewin, 2002, p. 3), I consider agency to derive from the accessing of a subject position in which “one has the right to speak and be heard” (Davies, 2000, p. 66). For Butler, the possibility of destabilising an identity,

through a repetition that fails to reproduce the norm, opens the possibility to make sense of identity on the basis of an alternative set of attributes. Agency is then not seen as intentional response but instead comes from reconfiguring and *resignification* of responses and conventions, thereby “negotiat[ing] an answer to the question of who the ‘I’ will be in relation to norms” (Butler, 2005, p. 22). Agency is the freedom to recognise that positioning in discourse practices, by powerful others, cannot determine or delimit one’s identity and is “a fragmented, a transitory, a discursive position” (Davies, 2000, p. 67). Similarly, I view a sense of self as going “beyond the given meaning ...through imagining not what *is*, but what *might be*” (Davies, 2000, p. 67) (*italics in original*). I am interested in exploring how we make sense of our ‘selves’ and how we produce a desired sense of self through narration as a social process.

Research gap

In reflecting on the research discussed in this chapter, I proceed to identify gaps in research addressing supported self-management after TBI and extending to the related areas of the ‘self’ after TBI, ‘identity work’ in neurorehabilitation for people living with TBI and qualitative approaches that have been used to explore experiences of possible change in the self after TBI.

Supporting self-management after TBI

If self-management entails “complexities of managing illness, managing the self, and managing everyday life” (Brijnath and Antoniadou, 2016, p. 6), then insufficient attention has been given to the components of managing the self and managing social contexts of everyday life following TBI (Ong Bie Nio et al., 2014, p. 226). To date, research has not offered insights into ‘self-management’ from the perspectives of people with personal experience of TBI or family members supporting them. Existing literature brings to the fore the supportive aspects of interaction, by demonstrating ways in which family caregivers are vital in long-term rehabilitation (Graff et al., 2018; Lefebvre et al., 2008). However, interpersonal tensions and their navigation has not been the focus of research that has explored supporting self-managing after brain injury. As demonstrated in the literature review of supported self-management interventions above, the approach has typically been one of providing information and education to families in a way that overlooks the potential for both fragility and power within support that unfolds in the everyday. The potential for both positive and negative aspects of family interaction in supporting self-management therefore remains underexplored.

Research on patient choice and taking control in health contexts has not focused on people during the post-acute, unpredictable stages after TBI (Wilde, 2014), including the phase of recovery immediately following discharge from hospital (Bushnik et al, 2008) and first two years in which changes in “damaged brain functions” are often anticipated clinically (Klinger, 2005, p. 9). Specific problems encountered by people during this dynamic phase have received less attention than longer-term community reintegration aspects, many years or decades later (Turner et al, 2007; Nadler et al, 2013).

‘The self’ after TBI

In contrast with neurodegenerative disorders such as dementia, abrupt injury is seen to suddenly render the brain “strange”, invoking a sense of “lost self” Nochi (1998). However, research into this experience has often privileged the account of a family member or other supporter, or presents the person with TBI separately from the voice of this other person (Cloute et al., 2008). After TBI, people may be assumed to be incapable of “narrative thought” as a tool in meaning-making (Medved and Brockmeier, 2008, p. 470), for example if they are considered to produce talk that contains “coherence disrupting elements” (Kintz et al., 2018, p. 47), or where a “void” in memory is seen as a barrier to self-understanding (Nochi, 1998, 1997). The question becomes, then, “whether the inability to tell stories about the past and to establish a plot implies a loss of identity, replaced by a void that is never to be filled again” (Hydén, 2010, p. 34).

The terms loss of self, loss of self-identity, loss of personhood and ‘identity work’ that frequently appear in brain injury-related literature are used variably within and across several disciplines. It is unclear how such concepts relate to associated terms such as self-awareness, self-esteem, self-knowledge, vulnerability of the self, self-regulation, and so on. The concept of ‘loss of self’ following TBI, when used with little explanation of intended meaning, risks perpetuation of “ambiguous terms [that] continue to confuse research results leading to theoretical and empirical obfuscation” (Markova and Berrios, 1992, p. 398). Literature on managing interaction in daily life with cognitive and communicative impairments highlights interactions between the person and other parties, for example, relatives who jointly sustaining the “social status or the personhood of the person with dementia” (Hydén and Samuelsson, 2018, p. 16). Studies that have examined the narrative experiences of the self specifically following TBI are discussed below.

‘Identity work’ in neurorehabilitation

Psychosocial consequences, or identity struggles, become a focus of rehabilitation when a person’s physical impairments or other traumatic injuries have improved and direct medical care is no longer accessible (Muenchberger et al., 2008). Research has highlighted a need for significant adjustment for individuals with TBI in relation to identity (Nalder et al., 2013). Although identity is therefore increasingly seen as a necessary ‘target’ within neurorehabilitation for people after TBI, it is generally consumed by interventions that target specific components of cognitive, physical or psychosocial functioning, with limited conceptualisation of identity (Levack et al., 2010). Attention to power relations between professionals and patients – that is, the authority ascribed to the professionals and the rehabilitation encounter - has recently led to calls for the identification of opportunities to shift away from “continually reproducing the status quo” in rehabilitation that aims toward idealised norms within narrow interpretations of returning people to “productive citizenship” (Fadyl et al., 2019, p. 7) or, alternatively, “fostering realistic expectations” when professionals have determined that productive citizenship will be unattainable (Peel et al., 2019, p. 1).

Neurorehabilitation approaches draw on a generally positivist paradigm seeking a unification of the “self” after TBI (Prigatano, 2000). This field of research upholds healthcare’s conventional assumptions in seeking ‘objective’ portrayal of reality, or the ‘true’ version of events (Sbordone et al., 1998). The implication is that person with TBI’s account cannot be considered credible if periods of reduced consciousness and fragmented or displaced memories are considered to have reduced narrative coherence and allowed ‘inaccuracies’ to enter. The tendency to take accounts from others to ‘establish’ the meaning of events for the person with TBI overlooks the possibility that particular aspects of self are not inevitably shared by others in a family or broader kinship system after TBI - or at any time. Interpersonal tensions, shared telling or emergent sense-making are not acknowledged when capturing the ‘true’ account from one family member (Oddy, 1995). For example, in relatives’ intentions to support the person with TBI in ‘self-managing’, they may directly talk about the person’s ‘independence’, despite also providing personal, financial or social support for them.

Narrative approaches after TBI that seek to help people to form a ‘coherent life narrative’ (Neimeyer, 2000) or ‘reconstruct’ a sense of self (Prigatano, 2000) assume a singular self that it is lost for them to start with, and that someone else will know what will bring their coherence back. The search for narrative coherence leaves little space for the unsettling

insecurities and ambiguities that are inevitably part of the complexity of our lives (Siegl, 2019). I proceed to consider approaches to qualitative inquiry into experiences of TBI, beyond - but potentially relevant to - the focus on self-management.

Qualitative research in experience of TBI

Interest in identity recognised within and through language is apparent in varied analytical methods, including conversation analysis and approaches within the broad field of discourse analysis. Both study talk-in-interaction and postulate that identity is an active, discursive accomplishment that is maintained by, and can be transformed within, interactions (Korobov, 2001). Conversation analysis starts with the notion that “ordinary language can be analysed as a vehicle through which we perform interpersonal actions” (Wooffitt, 2005, p. 19). By contrast, foundations of discourse analysis are the ideological meanings attached to language (Wetherell and Potter, 1988). Discursive psychology combines analysis of talk with “an interest in the organisation of the broad, social and culturally resonant interpretative resources participants draw on” (Edley and Wetherell, 2001, p. 441). Here, “ideological dilemmas” are considered to be dilemmas portrayed as participants try out, resist, or uphold versions of culturally available argumentative threads (Korobov, 2001). The site of analysis is the identification of tension between competing interpretive repertoires, referring to culturally familiar and habitual lines of argument drawn from recognisable themes (Edley, 2001). However, critiques suggest that this analytic tool, the interpretative repertoire, itself represents a mere template attached by researchers to participants’ talk (Wooffitt, 2005).

Cloute et al (2008) drew on discursive psychology to identify interpretive repertoires in talk between people with brain injury and one or two significant others. Interpretive repertoires, “building blocks speakers use for constructing versions of actions, cognitive processes, and other phenomena” form a key component of this stream of discourse analysis and are considered to be internally consistent (Wetherell and Potter, 1988, p. 172). In seeking to identify interpretive repertoires employed by people with TBI and significant others across timeframes (pre- to post- injury), the authors used the approach of semi-structured interviewing “to elicit conversation around lived experience over time, from before the injury to future aspirations” (Cloute et al., 2008, p. 655). These accounts were gathered through single time-point interviews, calling for participants’ reflection on change over time and a topic guide structuring temporal narration of events. The authors identified interpretative repertoires that they considered to inform participants’ identity: “Medical model referencing” (the passive positioning of individuals with TBI in relation to

memory loss), “dependence as intrinsic to TBI”, “TBI as deficit” and “progression and productivity as key life-defining features” (p. 651). Here, single time-point approaches, and the search for internal consistency, preclude the potential for accounts to vary across times of telling, with different, contradictory or inconsistent versions of characters, motives, states of mind and events, and the opportunity to explore affordances at particular times and in different interactional contexts.

One study, using a positioning discourse approach, explored how people are positioned and position the self after TBI (Glintborg, 2015). This researcher used semi-structured interviews at two time points after TBI: the first was described as a short conversation while people were still in hospital and the second was a follow-up interview after one year. The same topic guide was used to structure each interview. The content of transcripts was then ‘condensed’ and thematic analysis was undertaken on the condensed format, rather than analysis of full interactional content. Glintborg portrays the case study of one man who ultimately asserts in an interview: “I do not think I have changed” (Glintborg, 2015, p. 14) despite the dominant highlighting of ‘disabling’ physical change by clinicians working with him. Glintborg proposed the potential for use of narrative approaches therapeutically to transform identity after disruption from TBI.

By employing several narrative techniques, Medved and Brockmeier aimed to:

“investigate how the participants experienced the symptoms of their changed brains, how this might have influenced their sense of self, and how this again impacted the experience of their symptoms” (2008, p. 473).

The authors found that people with TBI emphasised *sameness* and an unbroken connection between their pre- and post-injury selves (though authors noted that some of the stories “lacked cohesion”). The authors postulated that these individuals “felt they did not have to recover their former sense of self because they subjectively seemed to have never lost it” (p. 469). The finding of “narratives of unbroken senses of self” (p. 476) counters the dominant narrative of disruption within research into sense of self after brain injury. The difference has been attributed, by some observers, to Medved and Brockmeier’s inclusion of participants displaying ‘anterograde memory impairment’ (reduced ability to form memories of events since TBI), according to standardised neuropsychological assessment. Others speculate that this may have precluded participants’ ability to convey accounts of change in self across time (Glintborg, 2015). The authors, however, maintain that this change in functioning would itself be anticipated to create a “a loss of mooring in an autobiographical past” and yet instead, in the stories told, “an amazing sense of

continuity came to the fore” (Medved and Brockmeier, 2008, p. 476). They proposed that ‘narrative memory techniques’ underpinned the continuity: memory importation (memories that were shifted from before to after the injury), memory appropriation (presenting someone else’s memory as one’s own), and memory compensation (shifting attention from a ‘gap’ in memory instead to the active search for it, for example by saying I “wonder”; thereby normalising the conversation) (p.475).

The discrepancies outlined within these qualitative research examples point to the need for further understanding of constructions of sense of self after TBI, particularly if interventions seek to ‘fix’ a sense of self that was not (previously) experienced as subjectively ‘broken’. I proceed to discuss the implications of the gaps identified in research, in the shaping of the current project.

Implications for current research

Considering dominant assumptions that the self is ‘lost’ after TBI as discussed above, my intention is to instead focus on the processes of managing a sense of self when living with TBI, and identity as shared with others. I seek to undertake a critical examination of the assumptions underlying conceptualisations of self-management and person-centred care that derive from a “a unitary imagining” of identity (Horton and Horton, 2018, p. 2). Little research has addressed the influence of professional power or impact of interactions themselves, on experiences of change or consistency in the self.

If self-management support is to be achieved through clinical interactions, then an understanding is required of each party as “coherence-creating or coherence-declining agent[s]” (Blix et al., 2018, p. 10). In contrast to the ‘coherence paradigm’ of narrative research, which may neglect the telling of challenging stories and may marginalise those who tell more fragmented stories (Hyvärinen and Watanabe, 2017, p. 7), I instead seek to include the potential for such fragmentation in this narrative inquiry and avoid a ‘smoothing out’ of narrative content. By emphasising the social nature of narratives and their broader generation within personal, social, temporal and cultural relations (Esin et al., 2014), I seek insight not into ‘what happened’, but into the social function of stories, within broader sociocultural contexts (for example, shared norms of NHS healthcare) and the local, interactional situation of the research interview. (Heavey et al., 2019). I discuss my approach within my methodology in the Chapter 3, after setting out my aims and objectives.

Research questions, aim and objectives

Iterations of research questions develop alongside “researchers’ capacities to examine their own roles and perspectives in the inquiry process” (Agee, 2009, p. 432). In progressing my understandings of the literature and conceptualisations related to this research area, I have become increasingly interested in exploring individual and relational aspects of everyday identity work, sense of self and agency to expand understandings of self-management and approaches to its support. Attention to agency, and recognition that people may be significantly constrained by their relational circumstances and their normative social context, brings a ‘broader’ set of potential mechanisms of self-management into view (Entwistle et al, 2016). I pursued the following research questions:

1. How can concepts of self, agency and relationship within ‘self-management’ be understood through narratives of traumatic brain injury?
2. How can social interactions support or challenge sense of self and agency, following traumatic brain injury?

It is not that I began with these questions; they became more focussed iteratively, as I progressed through the research in accordance with my aim and objectives:

Overall Aim

Following traumatic brain injury (TBI), to explore the ways people and their significant others construct stories about managing in everyday life, after discharge from hospital.

Objectives

- To gather stories from people admitted to hospital after TBI and a significant other, at two time points over the course of one year.
- To explore changes in narratives of TBI over time in the context of everyday living in families, social relationships, and in healthcare encounters.
- To seek understanding of co-construction of narratives of experiences, challenges and tensions following TBI.
- To provide a nuanced account of sense of self and agency following TBI through which to understand and inform development of any specific intervention for supporting self-management for people living with TBI and families.

- To examine stories within the wider literature of neoliberal critique of self-management concepts, to understand constraining and liberating approaches to self-management.

CHAPTER 3: Methodology

Research methodology encompasses “the processes that grow out of the researcher's ontological and epistemological stance” (Varpio et al., 2017, p. 42). I begin by describing the ontological paradigm and my epistemological considerations, before setting out my rationale for following a qualitative methodology and, more specifically, narrative inquiry. In describing my methodological decisions, I acknowledge that “in a way I did not know what I was doing (though I thought I did). To the extent it appears that I did, this is because of subsequent revisions on my part” (Voysey, 1975, p. 60).

Ontology and epistemology

“Something called data cannot be separate from me, ‘out there’ for ‘me’ to ‘collect’”

(St. Pierre, 2013, p. 226)

Ontology, the study of being, encompasses assumptions about the nature of reality (Blaikie, 2007). Through medical training and clinical work in the English National Health Service (NHS), I have been immersed in an ontological paradigm which is positivist, where it is thought that “reality is constant and can be measured” (Broom and Willis, 2007, p. 20) and where “real” facts and subjective values are held as separate and distinct (Bacchi, 2016; Malterud, 2016). Epistemology, concerned with the character, origin, limits and substantiation of human knowledge (Hofer and Pintrich, 2001), has doubtlessly been shaped by my professional work in neurorehabilitation, “a world where the spotlight has commonly turned away from context, power, co-production of meanings” (Weatherhead and Todd, 2013, p. xi). This positivist heritage might be considered to raise questions about my interpretations of knowledge, following institutional practices in which I was required to attend to ‘objective evidence’ and adhere to scientific imperatives: “‘Quantify!’, ‘Medicalise!’, ‘Biologise!’” (Hacking, 2007, p. 306). Moving to a position as qualitative researcher, I am expected to explicitly trade in currencies of subjectivity. I consider that these potentially contrasting epistemological assumptions are themselves imperfectly distinguishable, and may hold generative potential:

“the actual business of interpreting human experience is messier. As researchers we find ourselves drifting, often profitably, from one paradigm of inquiry into another. We do not cross borders as much as we traverse borderlands.”

(Clandinin and Rosiek, 2007, p. 58)

In common with much sociological research into experiences of living with long term conditions, I broadly follow the epistemological tradition of social constructionism (Pickard and Rogers, 2012). I situate this within a relational ontology, where “entities do not ontologically pre-exist relationships, but rather that entities come into being through human and more than human relationships” (Murriss and Bozalek, 2019, p. 2). That is, instead of thinking about stable objects and language to represent them, phenomena - an ongoing process between matter and meaning – become constitutive of reality (Barad, 2007). The phenomenon in this study, of self-management after TBI, is attached to specific meanings of brain injury that are situated in a framework of cultural understanding that you *are* your brain (Krahn, 2015).

Social constructionism poses a challenge to an individualistic model of the person, replacing it with a social account personhood (Burr, 2015). It assumes that knowledge is produced between people in everyday interactions as we speak, write, reminisce and talk to others (Burr, 1998; Wetherell and Potter, 1988), rather being grounded “in an observable and definable external reality” (Burr, 2015, p. 2). Individual experience comes to have specific meanings, are produced, through “historical a priori that is cultural, historical, politically situated, and *collective*” (Alcoff, 2005, p. 45) (emphasis in original). As knowledge and meanings are situated, contextual and evolving (Musto and Rodney, 2016), something that we regard as knowledge is one construction among many possibilities. For example, concepts of illness are fluid, having changed significantly over time and varying varied across different cultures, thereby sustaining some patterns of social action while excluding others (Burr, 2015). Shared meanings and understandings do not need to be redefined each time they are used in everyday conversation; instead they come to assume a reality which is largely taken for granted (Andrews, 2012).

Constructionism pays attention to power relations within stories (Esin et al., 2014), and language (as social construct) is “a magnifier that selects, intensifies, exaggerates, and distorts” (Ray, 1996, p. 676). Contrast can be drawn between constructivism, in which the individual is “actively engaged in the creation of their own phenomenal [sense-perceptible] world” and social constructionism, which emphasises our understandings of

the world as the “product of social forces” (Burr, 2003, p. 19). This distinction becomes relevant when considering the methodology of narrative inquiry, which I discuss below. The essence of narrative may be used by constructivists as a cognitive, intrapersonal schema. Instead, I follow a constructionist interpretation of narrative as a dialogic performance with others (McNamee, 2004), where identities are negotiated through daily social interaction. A fundamental argument underpins constructivist and constructionist orientations, however, that it is through sense-making in language and interaction that we talk ourselves into being (Bamberg, 2014).

Post-structuralism is seen as one of the social constructionisms (Korsgaard, 2007). Foucault-influenced post-structuralism describes power as productive, shaping particular sorts of subjects (Weedon, 2004). In a classic example, Foucault challenged understandings of ‘madness’ by focussing on the forces that shape it, arguing that madness did not exist as an entity outside of the practices that constitute it – that is, how ‘the mad’ were treated (Foucault, 2013). These practices “problematized” madness (Bacchi, 2016). Following Foucault, I consider that the categories of ‘the brain injured’ and ‘the self-manager’ can be seen to be produced through the practices that have established them as recognisable entities, in which they are then measured or monitored within healthcare practices. The categories, and the practices that create them, exert influence on people as “subjects” through complex relations (Bacchi, 2015). I use post-structuralism as lens to problematise what can be taken-for-granted in the application of these labels (Charteris, 2016). I return to post-structuralist ideas when describing the evolution of my analytic approach (Chapter 5).

Qualitative methodology is considered suited to exploring complex and potentially contested themes in the study of people, cases, phenomena, social situations and processes, where:

“...individuals and their behaviours are unique, context-dependent and largely non-generalisable. Hence, what is needed is not reductionism but ‘thick description’ of purposefully selected small samples or cases”

(Yilmaz, 2013, p. 317).

Qualitative research methodologies are traditionally informed by an epistemological lens that views people’s talk as reflection of their underlying conceptualisations and seeks to access these by using questionnaires, interviews or experimental designs assuming that

talk is relatively transparent, offering a window into meaning-making (Bamberg, 2014). The positivist view of the process of interviewing is something that is controlled within a uniform structure of standardised questions from “neutral interviewers, as this is the only way in which to elicit unbiased and replicable responses” (Smith and Elgar, 2012, p.6). Within research with people who are living with brain injury, participants have been found to report on their experiences differently when freely narrating in a spontaneous manner in contrast to responding to structured questions (Villemure et al., 2011). With this in mind, I chose narrative interviewing instead of a semi-structured approach underpinned by predetermined questions.

My specific approach of narrative inquiry intended to allow exploration of self-portrayal, confrontation, contradiction and negotiation of meaning within interaction, including that within the research interview (Bamberg, 2006). Through narrative inquiry, I sought to recognise meaning-making processes that may be diverse and multiple: “at once emergent, slippery, and changing” (Charmaz, 2002, p. 323). I recognise my personal impact within interview interactions and analysis, as described in the following.

Epistemology of emotion

“The intertwining of the social with emotion...constitute[s] missing pieces in making sense of how social representations and stereotypes suffuse and shape a field explicitly heeding the ideal of scientific objectivity”

(Sointu, 2017, p. 64)

The silencing of emotion in Western modernity in general, and in clinical medicine in particular, also pervades health research inquiry, including through qualitative methodologies. In clinical and research practice, suppression of emotion requires its active management through emotional labour that seeks to protect self-esteem and maintain our “status shields” (Hochschild, 1983, p. 173; Twigg et al., 2011). The suppression of professional emotion contributes to the asymmetrical relationship in clinical interactions with patients, as “the power of biomedical discourse is embodied in the affective clout that biomedical diagnosis and treatment possess” (Sointu, 2016, p. 317).

An ‘epistemology of emotion’ integrates emotion within the research process in a way that intends it to contribute to understanding (Holstein and Gubrium, 2003). Emotions can

become central to choices we make through our perceptions of ourselves, of others and the world. Confronting others can force us to confront ourselves, thereby surfacing emotions that may then elicit an inauthentic response in interaction - as an escape strategy from confronting emotion (Sartre, 2014). If attended to in research analysis, emotions might have explanatory function through development of intuitive insight into occurrences of (in)authenticity (Burkitt, 2012; Holtan et al., 2014). These deeper insights will require such occurrences to be “digested, symbolised, processed” (Hollway, 2015, p. 4).

Emotion is intimately tied to the key concerns within this research project: identity, sense of self, kinship, legitimation and interaction (Denzin, 2001). By acknowledging the influence of emotion within my findings, I aim to acknowledge Sointu’s “missing pieces” in my interpretation, by making visible the taken-for-granted in analysis (Knowles, 2006). Emotions can be understood as individually experienced feelings that we sometimes share but “despite taking place ‘within’ concrete individuals, and thus having roots within concrete psychical and organic systems, are also socially constructed” (Cantó-Milà, 2016, p. 1). Ahmed further highlights a ‘split’ in theories of emotion: that emotions are primarily linked to bodily sensations, or to cognition and involving judgements, which “rehearse [our] associations that are already in place” (2004, p. 5).

When referring to an epistemology of emotion, I refer to emotional awareness within interaction, as a relational flow that produces subjectivities and shapes the co-construction of narratives. The integration of emotional awareness within analysis requires identification of those embodied aspects that cannot be sensed by listening to the audio or reading the transcripts to simply seek linguistic markers as evidence of emotive reactions, through verbal expressions that relate to feelings (for example, happy, relieved, overwhelmed) (Strauss et al., 2019). Emotional awareness is not easily captured textually and transcripts do provide a “transparent window” into emotionality (Holmes, 2010, p. 62). It is instead “woven into the fabric of the interactions we are *engaged in*” (Burkitt, 2012, p. 459; italics in original).

I suggest that awareness of, and processing of one’s emotions during and subsequent to a research interview is useful additional data, in terms of critiquing the taken-for-granted within steps of interpretation (Holtan et al., 2014). This interpretation involves reflecting on emotional associations to determine their significance within the context of the interaction (Habermas, 2018). I attended to particular moments that brought about some

emotional significance within interviews (which may be a vague feeling, for example, of frustration). I describe my approach to processing these within the analysis (Chapter 5).

In the following, I continue by briefly introducing the broad field of narrative inquiry and I consider epistemological tensions in the use of narrative to explore concepts of the self, identity and agency. I highlight factors influencing my decision-making when building my approach to narrative analysis in this study.

Narrative inquiry

Narrative provides a primary structure through which human existence becomes meaningful (Polkinghorne, 1988). There is broad consensus we typically see, live or experience our lives as a narrative of some sort, “or at least as a collection of stories” (Strawson, 2004, p. 428). Narrative inquiry, when taken as a metaphor for life and experience, has been described as “a game changer, triggering the big change for the turn to narrative in the social sciences” (Bamberg and Demuth, 2016, p. 24). However, definitions of narrative are varied and many approaches to its examination have been described (Hydén and Brockmeier, 2008). Frank asserts: “*Narrative* is like the elephant in the fable of the five blind men, each grasping a different part of the beast and saying with certainty what sort of animal it is, based on that grasp” (Frank, 2018, p. 107) (emphasis in original). Brockmeier and Harré (2001) raise caution over escalation in the range of applications of narrative in research, proposing that there is a risk of losing its analytic force.

There is a long tradition of using narrative as a site for understanding the self and identity (Bruner, 1987, 1986), where the connection between the narrator, stories and the self is key (Hydén, 2008a). Such approaches define narrative as a concept of social epistemology through which we “come to know, understand, and make sense of the social world, and it is through narratives and narrativity that we constitute our social identities” (Somers, 1994, p. 606). Narratives of identity formation are situated within the power relations of the local setting and the broader forces that shape language and experience (Langellier, 1999; Squires et al., 2015): we are located “within narratives *rarely of our own making*” (Somers, 1994, p. 606) (emphasis in original). Further, Foucault’s influential work informs understandings of power relations that shape regimes of knowledge or discourses (e.g.

Foucault, 2001, 1982), where a discourse “is to be understood as an institutionalised use of language and language-like sign systems...to know anything is to know in terms of one or more discourses” (Davies and Harré, 1990, p. 52). Discourses shape conditions of what is said, thought, acknowledged or dismissed (Foucault, 2001).

Within traditional narrative identity research, the analytic focus is often on the “life story model of identity...a person defines him- or herself by construing an autobiographical story of the self” (McAdams, 1990, p. 148). In this model, the story is conceived as a clearly identifiable and coherent entity, embedding identity in time and spatial relationships. Stories of the narrator’s life events often contain an account of life before a turning point, a turning point itself, and life afterwards (Hydén, 2018, 2010): “something happens, and life at the end is substantially changed from how matters stood at the beginning” (Frank, 2018, p. 119).

In influential work on personal experience narratives, Labov generated narratives of past events in response to the question, ‘Have you ever been in danger of death?’ (Labov, 1972). Labov’s analysis treats the elicited story as a text that “recapitulate[s] the told in the telling” (Mishler, 1995, p. 92). This focus on narrative’s function as the telling-of-events has widely informed definitions of narrative (Patterson, 2008). The assumption is that storied events have ‘actually happened’ and the narration will form a more-or-less accurate representation of these ‘real’ events. For Frank, this assumption is:

“one of the elephants in any room where narrative is discussed, which is the veracity/fictionality of stories; how does a story represent what actually happened in some then-and-there?”

(Frank, 2018, p. 109).

The onset of a health condition may be considered to be landmark life event that evokes a life story (Frank, 1997; Riessman, 2003). Narrative has gained importance as a means for understanding illness experiences and negotiation of life situations with the “problems of identity that chronic illness brings with it” (Hydén, 1997, p. 51). Narrative inquiry into living with long term conditions has been linked to changing power relations in healthcare or epistemic injustice: “a wrong done to someone in their capacity as a knower” (Fricker, 2007, p. 1). However, if “the meaning of the narrative is thought to be found inside the narrative” (Hydén, 2008b, p. 50), then the assumption is that the story will contain a coherent plotline and will convey a perspective to a particular audience who will understand its meaning (Ochs and Capps, 2001).

Critics suggest that expectations of linearity in narrative chronology becomes a way to “convince ourselves that things are simpler than they are” (Rosiek and Snyder, 2018, p. 3). Further, if coherent narration is taken as a marker for coherence in sense of self, then those not demonstrating such coherence may be disregarded. Researchers pursuing the coherent narrative may seek narrators who can provide the correct form that upholds the norms of an explicit narrative. Those categorised as having cognitive or communicative change, for example following brain injury, may be excluded from narrative contribution due to assumptions of “striking listener burden” (Biddle et al., 1996, p. 447) that is attributed to:

“global coherence errors...the listener must filter through the tangential information and search long-term knowledge to fit the conceptually incongruent information into the overall representation of the narrative”

(Kintz et al., 2018, p. 48).

Their story may instead be gathered from another who acts vicariously as the ‘author’ of the story and of their perspectives (Hydén, 2008a). Researchers gathering accounts of ‘incoherent events’ and ‘tangential information’ may organise and re-story narrative in an attempt to reveal the ‘real’ chronology and causal links, which recognisably adhere to temporally-coherent norms (Creswell and Creswell, 2017; Hydén, 2018). At times of potential disruption, smoothing out narrative to create “the perfect offering” (Siegl, 2019, p. n/p) overlooks opportunities afforded through the telling: the mastering, sustaining and potentially reshaping of identities (Hydén, 2008b).

An alternative to narrative analysis that seeks a coherent, ‘real’ storyline, is an approach that prioritises narrative co-construction, attending to brief narrative activity and what stories do in the interaction; aspects which may be overlooked in traditional life story (‘big story’) narrative research (Bamberg and Georgakopoulou, 2008; Georgakopoulou, 2015). Here, narrative identity is defined as “how a sense of self comes into existence by way of relating” (Bamberg and Georgakopoulou, 2008, p. 387). This approach can be seen as complementary to, rather than competing with, traditional life story research as one flows into the other, making each type possible (Frank, 2018).

Within this research, my reliance upon narrative inquiry is not to determine the ‘true’ picture of events for participants following TBI, but to explore shared-sense-making within complex relationships. Further, time itself may be relevant in meaning-making,

through mechanisms as described by Medved and Brockmeier (2008) of importing stories of events in the past into tellings that place them in the present, thereby extending notions of temporal order as a “fundamental principle of narrative and its organization” (Hydén and Brockmeier, 2008, p. 4).

In the following, I discuss dyadic and longitudinal approaches within my research design. I return to consider brief moments of talk-in-interaction as a unit of narrative analysis when describing the development of my analytic approach in Chapter 5.

Longitudinal design

Qualitative longitudinal research is considered suited to capturing social complexities through the examination and incorporation of accounts of experiences over time (Bidart, 2013; Fadyl et al, 2016). Questions arise over analysis addressing sense of self through single time-point interviews (Hall, 2004), particularly when considering narratives after hospital discharge, where consequences and adjustments take place over time within fluctuating patterns of physical, cognitive and social change. A longitudinal design brings opportunities to explore stories across time and situation, including those that have a fluidity of movement (e.g. non-linear time configurations) within narration (Barak and Leichtentritt, 2014; Frank, 1997).

Dyadic interviewing

Dyadic interviewing, referring to two participants interacting in response to open-ended questions, has been considered to ‘fill the gap’ in a continuum between one-to-one qualitative interviews and focus groups (Morgan et al., 2013). The key difference between individual and dyadic interviews derives from the interaction between participants, drawing responses from one another, in an interaction that can be quite different from the discussion of focus groups and instead, in some ways, reflecting everyday conversational practices (Hydén, 2010).

Within the field of family research, dyadic interviews focus on interviews with pairs of people who share a pre-existing role relationship, where foundations of joint meaning are explored (Eisikovits and Koren, 2010, p. 1653). The inclusion of a family member or significant other within interviews can facilitate telling of stories that encompass differing perspectives, concerns and needs. Further, “even if participants do not give their silences meaning, their family and friends may” (Charmaz, 2002, p. 304).

Dyadic interviewing can facilitate socially distributed remembering, where talking about shared past experiences constructs a shared resource. Cognitive or communicative problems that may be associated with brain injury may be addressed by the dyadic partner, by complementing restricted narrative functions and thereby “scaffolding” the shared storytelling capacity (Hydén, 2017, 2011). Described in the context of impaired cognitive and communication function, ‘narrative scaffolds’ refer to processes where participants share narration responsibilities; for example, interpretations of contributions made by a partner, prompting for word-finding, or turn-taking. Such scaffolding becomes an integral part of shared meaning-making as “a deeply moral activity” (Hydén, 2011, p. 346), which may support sense of self and sustain kinship bonds. This understanding “changes impairments from an individual property, to a property of the interacting participants” (Hydén, 2017, p. 123) as a feature of the narrative collaboration (Hydén, 2011).

Acknowledging that cognitive coherence may be achieved through others with whom participants have relationships also implies the potential for tensions or misalignment within narrative scaffolding activities, for example because of “feelings of discontinuity with the survivor [with TBI]” (Salas, 2012, p. 83) and continuous definitions and revisions of “who they are in relation to each other” (Hydén and Nilsson, 2015, p. 719). Although narrative scaffolds convey meaning, they may also contain violence, as stories and ways of sharing are backed by power (Butler, 2002a), filtering and organising views of the world (Schippers, 2014).

CHAPTER 4: Methods

Research setting

On commencing this research my clinical work base, King's College Hospital NHS Foundation Trust, London, formed the setting for recruitment to this study. King's is the Major Trauma Centre for the South East London, Kent and Medway Trauma Network, where approximately 350 patients are admitted following traumatic brain injury per year (data from clinical database at King's College Hospital, 2016). My clinical work, as consultant physician in Rehabilitation Medicine within the multidisciplinary Brain Injury Team, entailed provision of support to people and families in the acute Neurosurgical and Trauma wards, inpatient rehabilitation on a specialist unit, and outpatient follow-up clinics held collaboratively with a regional branch of Headway (a brain injury charity).

Sampling

In my initial approach to sampling, I relied upon the purposeful strategy of maximum variation (heterogeneity) sampling: the selection of cases with maximised diversity that seemed relevant to the topic, to enable its exploration (Patton, 2015). I intended that each person in the sample would be different from the others according to pre-specified dimensions of severity of traumatic brain injury, age groupings, and whether the participant was employed, studying, out of work or parenting, prior to injury. The variable of requiring initial management in the Intensive Care Unit (ICU) represented a marker of severity of TBI (more severe injuries requiring initial neurosurgical management in ICU), which could be clearly established at recruitment (Bulger et al., 2002), in contrast to practical issues presented by inconsistent recording of clinical markers such as the Glasgow Coma Scale (GCS) and/or duration of post-traumatic amnesia (PTA). Using these sampling parameters, I developed an initial pragmatic sample size estimation of 8-12 individuals living with TBI. I aimed to interview each with their chosen family member or 'significant other'. My initial sampling frame, according to these parameters of variation, is shown in Appendix 2.

Evolution of sampling decisions

As my methodology developed over time, I no longer considered that the categorisations in the initial sampling frame were necessarily meaningful. Further, I began to consider my

selection of categorisations as potentially problematic, as “identities are complex...[while] simplistic analyses reduce people to identity categories (e.g. “black”, “female”)” (Taylor and Littleton, 2006, p. 24). My decisions evolved from these pre-determined categorisations to more dynamic considerations in sampling, through which I considered further recruitment by making iterative decisions (Ellingson, 2017). In later stages, my sampling intentions remained aligned with the overall ‘maximum variation’ approach, yet my decisions were based upon more fluid social situations and a narrative conceptualisation of identity to use in sampling instead of fixed parameters. For example, a narrative conceptualisation might consider changing responsibilities for family dependants or shifting social support networks that created separation from family support overseas. Using this approach to sampling, I intended to represent the complex, evolving circumstances in which people live their lives.

As I reflected on my early analyses, I became increasingly aware of the temporal fluidity in people’s talk, in contrast to linear ‘progress’ over time since injury as anticipated by a clinical framing of predicted trajectories of recovery. My sampling intentions then extended to explore the temporal component further, through inclusion of people whose injury may have occurred more than 12 months previously (the timeframe that had been my initial intention). This aspect extended temporal considerations within a longitudinal design where change over time is already a key focus (Thomson and Holland, 2003).

Recruitment

After securing NHS and University of Westminster ethical approval (detailed below), I commenced screening of people who had been admitted to hospital following TBI and I liaised with colleagues with whom I worked clinically in the Brain Injury Team, to consider and discuss potential participation in the study. The diagnosis of TBI was supported through the inclusion criterion that the participant had required admission to an inpatient hospital ward for management of traumatic brain injury at the time of their acute presentation (Turner-Stokes et al., 2005). I discussed the study with potential participants after medical and surgical stability had been reached.

If there were reasons to think that someone may not have capacity to make the decision to participate at the time of invitation or informed consent (described below), then I undertook a capacity assessment for making the decision to be take part. I undertook this

in accordance with the Mental Capacity Act Code of Practice (2005)². My intention was to include people who may have cognitive or communicative impairments following TBI, if they had capacity to make the decision to participate in the study. Those who did not have capacity to consent to participate were not included within this study. Additional inclusion and exclusion criteria are outlined in Table 2.

The criterion relating to sufficient English language to participate in narrative interviews without an interpreter was a pragmatic consideration in view of lack of funding available for this study. Further, this exclusion related to methodological considerations in cross-language qualitative studies, including the potential effects of interpreters on the narratives gained from participants and the translation of more complex concepts, which may have impacted upon the interpretation of co-constructions of narratives (Squires, 2009).

Table 2 - Primary participant inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Traumatic brain injury requiring acute hospital admission at time of presentation • Capacity to give informed consent to participate in the study • Adults of 18 years or over • Sufficient English language to participate in narrative interviews without an interpreter 	<ul style="list-style-type: none"> • Discharged directly from the Emergency Department without need for hospital admission • Lack capacity to give informed consent to participate • Insufficient English language to participate in narrative interviews without an interpreter • No telephone or email access for arrangements to be made • Current alcohol and/or substance abuse • Severe mental health problems (undergoing specialist mental health assessment or treatment)

² I had been performing capacity assessments on a regular basis for many years during my clinical work in Rehabilitation Medicine and during previous research with people living with cognitive impairment.

I provided people with a written information sheet about the research study, which I developed in consultation with four people living with brain injury and one family member. Following their feedback, I made adjustments to the information sheet to produce the final version, which these reviewers considered to be easy to follow (information sheets are included in Appendix 3).

Following a minimum of one week after providing the information sheet, I arranged time for participants to ask any questions prior to their consideration of the informed consent form (see below for consent procedure). I explained that their participation or non-participation would not affect usual NHS Care and I included a statement to this effect within the participant information sheet (Appendix 3). I arranged the research interviews at a time and location convenient for the participants.

I asked each person with TBI who agreed to participate in the study to select a family member or significant other person. I provided each significant other with the appropriate information sheet (Appendix 3) and opportunity for questions and discussion, as above. If an individual agreed to participate but preferred not to involve another person in the whole of each interview (or if the 'significant other' person was not available for the whole duration of each interview), then I made arrangements according to their expressed preferences and practical considerations.

Interview procedures

Informed consent

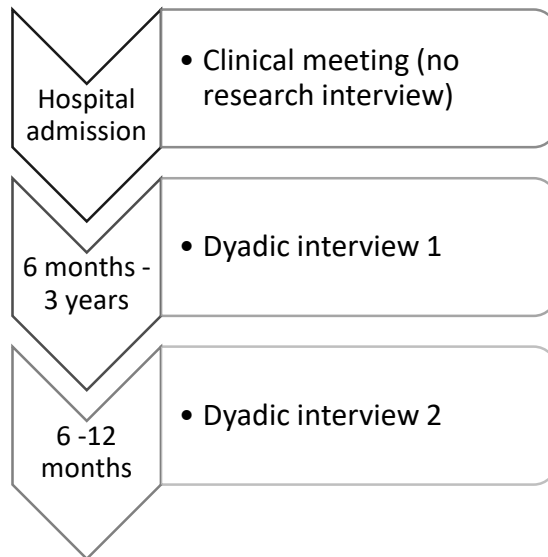
Prior to commencing the interview procedures, I gave the informed consent form to participants (see Appendix 4 for patient and 'significant other' consent forms). I reiterated the purpose of the study, what to expect, and checked that people would be comfortable with my use of a digital recorder during the interview. I also described the anticipated time required and the plan for a second, follow-up interview which would be up to twelve months later, at their convenience. I advised participants of their right to withdraw from the study (including withdrawal of their data, if they were to notify me of this prior to the analysis stage), without a need to offer explanation and without any consequences for ongoing or future care. I informed each participant's GP of study inclusion following the participant's informed consent. The informed consent form included the information that their GP would be provided with standardised information about their participation in the study (see Appendix 3 for the GP Information Sheet).

Interview processes

I followed a narrative interview approach of asking a simple opening question to elicit stories about everyday life, as an 'open' form of interview designed around what the participants wish to talk about (McCormack, 2004; Whiffin et al., 2017), intending to "follow participants down their trails" (Riessman, 2008, p. 24). I started with an informal conversation, until this naturally arrived at the purpose of my visit, when I asked one open question: "*How have things been since you were in hospital?*". After initial narration, avoiding interruptions by asking questions, I explored aspects in greater depth with prompt questions or continued in the flow of participants' own conversations. In my approach to pacing the interviews, I intended to allow each of us the "time necessary to inhabit the conversational space" (Medved, 2007, p. 607). I kept in mind the idea that the interview guide would provide an "initial framework for opening the interview conversation rather than a recipe to follow" (Charmaz, 2015, p. 1613). I added any questions of a 'closed' nature after completion of the open narrative phase, to allow participants to follow their own sequence in engaging with 'open' questions, without introducing prior potentially suggestive areas of salience (Patton, 1990). I piloted my interview approach before starting full data generation and reviewed the process with project supervisors.

Each interview lasted around 60 to 90 minutes. I checked the approximate length of time participants had available, at the beginning of our discussion. Factors affecting the length of interviews included fatigue and unanticipated occurrences such as phone calls or other issues requiring the participant's attention during the interview. Where appropriate, I paused audio-recording for such events or for a break in discussion and resumed when participants indicated they were ready to proceed. I arranged a second interview with each participant and their chosen significant other person, at an interval of six to twelve months after the first. Figure 1 shows an overview of my longitudinal approach to dyadic interviewing.

Figure 1 - Overview of longitudinal interviewing approach



I viewed the time interval between interviews flexibly, acknowledging the balance needed between practical considerations of my participants' time availabilities and my own, between employment commitments, and with awareness of the finite time available for conducting this research study. On meeting for the second interview, we talked about the last interview as and when participants referred back to it. If not, then at the end of opening discussion, I introduced areas they had raised at the first interview that had seemed to be source of anticipation during the first interview. Interview guides for each time point are shown in Appendix 5. I followed the sensitivity protocol below, where appropriate.

Sensitivity protocol

The sensitivity protocol that I implemented during interview procedures, to ensure wellbeing of participants, included:

- Discretion so that, if topics appeared to be causing undue distress, I would cease recording of the interview.
- I did not put participants under any pressure to resume discussion but sought their preferences on whether to proceed.
- In circumstances where clinical concerns arose, I left contact details for the helpline of the Brain Injury Team at King's College Hospital, who provide long-term, holistic support for people after brain injury.
- In the case of any instances of distress, I followed up with participants within a few days by phone or email, and anonymously discussed problems within the project supervision team as appropriate.

Remuneration

I referred to 'INVOLVE' guidance on good practice for recognition of participation in research (NIHR, 2017). This included reimbursement for any travel expenses that may be incurred and acknowledged the contributions by giving participants a gift voucher for £20. The approach and monetary value was determined through discussion with peer researchers who had undertaken interviews entailing similar requirements for participants in recent months. I chose the voucher after discussion with a sample of potential participants and selected a provider easily accessible within the participant's location. Consensus of discussion with colleague researchers suggested that such vouchers would be suitable for this purpose, for a range of participants. On concluding each interview, I thanked participants, discussed plans for the follow-up interview where relevant and gave a thank you card with the voucher, in acknowledgement of their contribution.

Field notes and reflexivity

Reflexivity in qualitative research typically refers to:

“a process by which we as researchers hold ourselves accountable for the assumptions we enact when we do research, a process of justifying why we are inquiring about people and the world in particular ways”

(Shaw et al., 2017, p. 1735).

Reflexivity allows for observation of the unexpected, capturing a 'quick glimpse' of something that may affect interpretation of the research. This concept aligns with the inclusion of emotional overlap within the analysis (described in Chapter 5). However, here I consider reflexivity to be linked to more overt or verbally identifiable “sticky events” (Riach, 2009, p. 361), for example the introduction of a contentious or controversial point that can be demonstrated textually within the transcript, for example if participants were to raise clinical questions to me 'as a clinician' within the course of the research interview.

Throughout the project, I reflected on my own influences in constructing the research, including choices I make in my approach to the topic and the analysis of findings. These activities contribute to a validity procedure in which my own positioning is explored, acknowledging that the researcher and the process of inquiry are not separable (Creswell and Miller, 2000), while also increasingly acknowledging a need “to admit to oneself the limits of self-understanding” (Butler, 2003, p.9; quoted in Magnus, 2003, p.93).

The time in participants' homes provided opportunities for observations of interactions in the environment where they naturally occur (Adler and Adler, 1994) This naturalistic setting provided scope for additional observations and interactions surrounding the interview itself, for example, with other family members and with pets who were also present. I recorded anonymised observations, where relevant to the study, within handwritten field notes. I made initial journal entries immediately after each interview episode, to ensure that sufficient detail could be recorded. However, I found that "information can be added at any point to create a comprehensive documentation useful in later data analysis" (Phillippi and Lauderdale, 2017, p. 6). I continued to maintain participants' anonymity and confidentiality within these notes. I also used field notes to reflect on research progression and to explore developments in my theoretical awareness (Barak and Leichtentrirt, 2014; Carter and Little, 2007).

My field notes generally comprised three key components: (1) a description as a "concrete and detailed" account of observations (Patton, 2015, p. 387); (2) personal reflections on meanings of the encounter including noticing and processing my own emotional reactions to the experience "potentially created in the intersubjectivity between participant and researcher" (Holmes, 2010, p. 166); and (3) interpretations or early analysis of what happened or its significance. The functions of my field notes are outlined in Table 3 (adapted from Phillippi and Lauderdale, 2017).

Table 3 - Field notes: overview of functions

Function	Examples
Prompting	As a tool to prompt observation of environment and interactions
Complementing	To complement data from text-focused interview transcripts To document aspects of physical environment and participants' non-verbal exchanges or movement within the setting
Reflecting	Facilitate noticing and processing own emotional reactions To provide a focus through which to consider potential biases in interpretation
Analysing	Facilitate preliminary analysis and iterative design Documenting development of theoretical awareness and steps in analysis Observations and interpretations considered in analysis

Ethical considerations

My research governance activities followed the Research Governance Framework for Health and Social Care (HRA, 2017b) and the University of Westminster's Framework for Research Governance (University of Westminster, 2016). I secured ethical and Research and Development (R&D) approvals from:

- London City and East Research Committee (IRAS ID 168036)
- R&D department of King's College Hospital NHS Foundation Trust
- The University of Westminster Research Ethics Committee
- Health Research Authority (HRA)
- R&D department of Imperial College Healthcare NHS Trust

The approval documentation for each of these bodies is included in Appendix 6.

During the course of this research project, I changed my hospital work-base from King's College Hospital to Charing Cross Hospital, Imperial College Healthcare NHS Trust. This relocation incurred significant delay in securing additional approval for inclusion of Charing Cross Hospital as a study site. On 31st March 2016, Health Research Authority (HRA) approval was introduced for all research within NHS England (HRA, 2017). As my project had initially gained NHS permission for research at King's College Hospital through a Research Ethics Committee (REC) review, the altered process meant that I was also required to apply for HRA approval to recruit patients through my new clinical base at Charing Cross Hospital. As I anticipated that the length of wait for additional approval processes would impact upon my participant recruitment timeline, I applied for and secured an honorary contract at King's College Hospital (Appendix 7). By liaising closely with the helpful Research and Development (R&D) department, I gained approval to continue recruitment to the study through patients I had worked with while based in the Brain Injury Team at King's College Hospital.

In the following, I describe particular ethical considerations for this project, including participation of participants who may be experiencing cognitive changes following TBI; a longitudinal approach to data generation through follow-up interviews; decisions around exclusion of non-English speakers; the inclusion of another person within dyadic

interviews; potential burden of study procedures for participants; and considerations about my clinician/researcher roles.

Cognition considerations

During the first weeks after TBI, patients often experience a phase of post-traumatic amnesia (PTA), “representing the length of time from injury until return of orientation and continuous memory for events” (Ponsford et al., 2016, p. 997). Patients who were assessed as being ‘in PTA’ were not approached regarding the study, until this was deemed to have resolved (for example at a later stage of clinical interaction, such as outpatient follow-up review).

People with brain injury may be excluded from research about their own experiences, due to the perception that persistent cognitive impairments caused by the injury (after the phase of PTA) limit their provision of ‘meaningful information’ (Paterson and Scott-Findlay, 2002). The ethical concern here relates to the concept of ‘a wrong done to someone specifically in their capacity as a Knower’ (Fricker, 2007, p. 1). When inviting and including people to participate who may be considered to be experiencing cognitive changes, I implemented strategies to facilitate discussions, including taking account of fatigue by building in breaks as guided by participants and taking an informal conversational approach, not requesting responses to pre-structured questions, but instead determined by participants’ preferences in the discussion.

Dyadic and longitudinal approach

When discussing study procedures with participants, I asked if they would be willing for the interview to take place jointly with their chosen ‘significant other’ person. Many people after TBI prefer to have a family member or other supporter involved in discussion, especially if they have experienced memory impairment since their injury. If the family member or significant other requested to speak privately and if the issue to be discussed did not relate to the research interview, I would offer guidance back to standard clinical processes (see ‘sensitivity protocol’, below).

Longitudinal research can make considerable demands on the participants, through repeated interview participation. I sought to minimise the impact of my research on participants by limiting to just one follow-on interview.

Potential burden of participation

The need to make journeys to unfamiliar settings can frequently seem overwhelming to people and might particularly be an issue following TBI. I therefore offered the option of meeting participants at home for interviews, if they preferred this to travelling to a meeting venue. I adhered to King's College Hospital NHS Foundation Trust's lone worker policy when visiting participants in their own homes. Although the majority of participants preferred to meet in their own home or the home of the significant other joining the discussion, two participants chose to meet in cafés, which I considered may raise ethical concerns about confidentiality and possibilities of being overheard. However, together we took measures to choose seating which would enable privacy for our discussion. I confirmed comfort level with the arrangements for each participant intermittently through our conversations. Within interviews, I was guided by participants' indications of time for breaks and for overall duration of the interview, according to fatigue.

My potential conflict of interest

My dual roles as both a healthcare professional and researcher introduced the potential for conflict of interest within research with patients who had experienced the service in which I was employed. This study was a non-interventional, qualitative study, seeking knowledge that may inform future service improvement initiatives. The discussions I held with people with TBI and their family members/significant others in clinical practice already had emphasis on the complex, longer term considerations and effects of the injury on function and quality of life when people return home, rather than the biomedical treatment focus of the acute Major Trauma Centre more generally. I introduced the purpose of this research to study participants within this framing, including the intention to seek understanding of people's experiences after leaving hospital and when they are often coping without access to specialist healthcare services. No therapeutic promises or expectations were made regarding participation, and no coercion exerted. Where any matters arising indicated a participant's wish to pursue clinical management-related discussion, I offered redirection to usual care processes, as discussed within the 'sensitivity protocol'.

I was aware that my identity categories as doctor and researcher could construct power imbalances. I paid attention to possible verbal and non-verbal (for example, body language or tone of voice) cues that might indicate participants' reluctance to continue in an interview, or particular aspect of a discussion. I consider potential conflicts between my

roles as clinician, researcher, and other positions, alongside my analysis of interview findings (described in Chapter 5). In brief, I found that distancing myself from the role of clinician within research encounters gradually required less conscious monitoring as my experience of the qualitative researcher role expanded. I became aware of a change in my own approach when allowing interactions to unfold without the constraints and expectations of a clinical gaze.

Anonymity, confidentiality and data storage

Confidentiality

I maintained confidentiality of information regarding participants in this study in accordance with the Data Protection Act, NHS Caldicott Guardian, The Research Governance Framework for Health and Social Care, and the Research Ethics Committee Approval. I stored patient-identifiable data in NHS premises in password-protected files, in locked drives, and no patient-identifiable data was shared beyond the direct care team. Information with patient-identifiable data was securely destroyed at the end of its use; hard copy material was shredded and electronic medium was deleted. Anonymised transcripts will be retained for ten years after DProf completion.

My initial intention had been to use professional transcribing services. However, after piloting initial interviews, I decided that I would undertake transcription myself, to facilitate my immersion in, and familiarisation with, the data and also to provide opportunity to make notes on non-verbal aspects that I recalled from interviews. I replaced names, places and other identifiers within transcripts with pseudonyms and made changes to other potentially identifiable content within narratives, through substitutions intending to minimise impact on original meanings (Vainio, 2013).

Further considerations

NVivo to Scrivener

In commencing my analysis, I followed qualitative research norms in using the computer assisted qualitative analysis software package NVivo (QSR International) for data management and to facilitate analysis (Bazeley and Jackson, 2013). Over time and when moving through the analytic process described, I began to consider that my use of NVivo was creating a reiterative practice in which I felt distanced from data, components of the

data felt compartmentalised from each other and there seemed to be a risk that people and interactions would become reduced to objective codes. Similarly, Malterud notes that “software intended to support qualitative analysis seems to encourage decontextualization and fragmentation rather than recontextualization, synthesis and understanding” (Malterud, 2016, p. 127). I began to use ‘Scrivener’ (Literature & Latte, 2019), a programme that provides an interface which enables organisation, reorganisation and synthesis of information. In contrast to NVivo, Scrivener facilitates a sense of fluidity in thinking-and-writing, contrasted with the linear containment I experienced within NVivo.

During second and third readings of transcripts, I highlighted salient excerpts according to the analytic components outlined above and used Scrivener to detail my observations on what I thought was occurring with use of linkage function to create connections, disconnections or shifts between longitudinal interviews. In this way, I was able to use functions within Scrivener to connect analytic reflections across storytelling times and situations, opening up possibilities for a theoretically-inspired analysis to become something new, instead of repeating my old or established interpretations. Scrivener facilitated making meaning in non-prescriptive ways and supported my efforts to keep analysis ‘on the move’. I include a screenshot to illustrate my use of the Scrivener software in Appendix 8.

Saturation

My intention was not to reach a point of ‘data saturation’ in this study. The notion of saturation derives from the grounded theory approach described by Glaser and Strauss, intended for generating sociological theory from empirical textual data by comparing events sequentially until further information no longer adds to conceptual categories developed (Glaser and Strauss, 1965). The saturation idea is frequently mentioned in sample size considerations in qualitative research as concepts are identified in data to guide participant recruitment to further explore those concepts (Malterud et al., 2016). However, as a general marker of quality, it remains unclear what saturation means in practice for other qualitative approaches (Hennink et al., 2017; Malterud et al., 2016). Instead of data coding to reach “saturation” through sameness, I instead sought difference within and between participant’s expressions (Jackson and Mazzei, 2013). I consider the potential of the “available empirical data to provide access to new knowledge by means of analysis and theoretical interpretations” (Cohen and Crabtree, 2008; Malterud et al., 2016, p. 1759). I describe the process of seeking new connectives, between theory to data, within the development of my analytic steps (Chapter 5).

Validity

Validity, in the context of qualitative research, has been defined as “how accurately the account represents participants’ realities of the social phenomena and is credible to them” (Creswell and Miller, 2000, p. 124). Similarly, Tracy (2010) argues that a key criterion for ‘quality’ in qualitative research is ‘credibility’, suggesting this to refer to the “trustworthiness, verisimilitude and plausibility of the research findings” (p842). Tracy goes on to suggest that one route to credibility may involve the researcher “seeking input during the process of analysing data” (p844). Member validation, or checking, generally refer to processes where participants are sent for their review and/or correction: (a) a transcript of their interview, (b) a copy of findings, or (c) a draft research report (Thomas, 2017, p.23). Although these processes have traditionally been recommended as a specific validity procedure in qualitative research (Lincoln and Guba, 1985), some authors have further proposed that member validation may elicit narratives which participants may have felt unable, or reluctant, to tell in the original research interview (Kirkpatrick and Byrne, 2009). However, the concept of member checks in enhancing the credibility or trustworthiness of qualitative research has been questioned (Varpio et al., 2017), including concerns over “additional intrusion for participants [with] little or no substantive changes in research findings” (Thomas, 2017, p.39). Member checking may also support the idea of there being one identifiable ‘truth’ to be collected by the researcher (Angen, 2000).

Mazzei et al argue more forcibly that processes traditionally pursuing ‘validity’ tether research to a plane of consistency (Mazzei et al., 2018), thereby losing the “radical possibility in the unfinalized” (Jackson and Mazzei, 2013, p. 271). Within the constructionist paradigm (outlined in Chapter 3), I anticipated that variations in narration would be both inevitable and valuable. Creswell and Miller broaden validity intentions to the acknowledgement of researchers’ paradigm assumptions, beyond specific procedures that have been used (2000). As described in my analytical rationale, I sought understandings of version-making in drafts of the self rather than an “attempt to catch the most authentic (as in true or real)—or even the most recent edition” (Bamberg, 2011a, p. 18).

Addressing the notion of “plausibility of the research findings” (Tracy, 2010, p. 842), I discussed transcript extracts with project supervisors from commencement of data generation and throughout the development of my interpretations during the reiterative analytic processes. In addition, I ‘tested’ my analytical ideas with academic audiences by

presenting several conference papers on work-in-progress (my contributions to conferences are shown in Appendix 9). In these fora, I gained feedback about whether my interpretations seemed plausible in relation to the narrative extracts shared and whether the listeners described a sense of being “made to rethink a stance or opinion” (Winter et al., 2000, p. 35). These varied perspectives and aspects of feedback became integrated into my thinking about the research and ongoing development of the analysis.

CHAPTER 5: Analytic approach

Introduction

My analytic approach evolved from project conception through data generation, transcribing and interpretation, in response to learning from earlier parts of the study (Given, 2008). My early intentions were to gain a holistic picture of how people manage in daily life after hospital discharge following traumatic brain injury. As I considered using an inductive thematic analytical approach (Braun and Clarke, 2006), I became aware of potential critiques, whereby “themes, by definition, represent a loss of attention to detail, a loss of the idiosyncratic” (Peck, 2015, p. 3). Retention of the integrity of participants’ responses represents a pervasive challenge for qualitative researchers (Bailey and Jackson, 2003). Further, conventional coding methods often focus on the meanings that the interviewees attach to their experience, yet “it is reasonable to infer that it is extremely difficult to attach a meaning to something that is not intentional” (Huyard et al., 2018, p. 4). In seeking to identify meanings that participants attach to their experience, we may also ‘smooth out’ inherent contradictions and tensions. Further problems with coding data involve the risk that the categories of findings generated become, in some way, predictable.

Acknowledging that qualitative research takes place with language or in language, I required an approach “that unravels the connection between experience of the world and the role that language plays within that” (Peck, 2015, p. 1). Michael Bamberg proposes an approach that intends to avoid the imposition of analysts’ concerns onto participants. It has been proposed that Bamberg’s positioning analysis (Bamberg, 1997) can avoid “the overly top-down trappings of CDA [critical discourse analysis] or the overly myopic technicalities of CA [conversation analysis] because it derives from neither orientation” (Korobov, 2001, p. 8). Bamberg’s concept of “narrative positioning” is influenced by Positioning Theory, which addresses how people use words and discourse of all types to locate themselves and others (Davies and Harré, 1990; Harré, 2015; Harré et al., 2009) and where “selves are located in conversations as observably and subjectively coherent participants in jointly produced story-lines” (Davies and Harré, 1990, p. 48). Positioning theory offers a lens to examine what is said, how it is said, and effects on (and from) the social world (Harré, 2015; Harré et al., 2003).

I commence by describing my rationale for focussing on everyday components of talk-in-interaction within narrative analysis (Bamberg, 2014, 2006; Bamberg and Georgakopoulou, 2008). I briefly consider alternative (and overlapping) narrative approaches that could alternatively have been applied within this analysis. I then expand the theoretical orientation with an outline of Bamberg's positioning analysis and a framework for its application within my analytic steps. Finally, I describe my application of Butler's theory of performativity as a sensitising device within the analysis. I demonstrate the interrelated steps within an encompassing analytic model.

Narrative analysis

"I think we are more than walking narratives"

(Bamberg and Demuth, 2016, p. 21)

My intention in analysis of data generated through interviews is to focus on what people do when they tell stories, where narratives are "sites for social and individual meaning construction and not just as the carriers of what may be considered as socially and individually meaningful" (Bamberg, 2008, p. 184). Storytelling can be viewed in variable and diverse forms including those highly integrated into ongoing conversations and therefore less easily circumscribed as a discrete entity from an analytic perspective (Ochs and Capps, 2001).

In Chapter 2, I discussed tensions surrounding the concepts of sense of self and loss of self, and their potential relevance when considering 'self-management'. 'Small stories' are "the rough, inchoate, in situ stories that comprise much of ongoing experience" (Freeman, 2017, p. 23): the term captures a range of narrative activities under-represented in conventional narrative analysis, includes talk about ongoing events, hypothetical events, shared events, and also incorporating prior telling or refusals to tell (Ochs and Capps, 2001). Such stories are 'small' in length and are also seen to counter the tradition of 'big' stories – autobiographical narrative, which tend to "equate life and story...assuming that narrators have a self and an identity ...locatable in the 'big stories' they tell" (Bamberg, 2008, p. 184). The term 'small stories' instead locates the means of identification and analysis of transcript at the level of 'smallness' of talk through fleeting moments of narrative

orientation to the world (Hymes, 1996). They allow exploration of how sense of self might be claimed through talk-in-interaction in situated contexts, including “who was positioned as doing what kind of things, in relation to what, or whom” (Jolanki, 2009, p. 216). These elements of situated talk-in-interaction were central to my analytic focus. Criticism of narrative analysis of brief moments in interaction includes a claim that the very integrity of storytelling is at stake:

“[there is] a price for dissolving stories into smaller and smaller fragments until ultimately any thought seems to count as a story. The price is that the distinctiveness of the speech genre of story can get lost”.

(Frank, 2018, p. 123)

Instead of seeking units of analysis that would “count as a story”, I intended to explore ways in which these smaller fragments of interaction might “help make visible ‘big issues’” (Georgakopoulou, 2017, p. 274). By contrast with ‘big story’ (life story) research, this approach does not assume that people are aware of a ‘self’, or that the researcher might locate it within their own or others’ narratives. Instead, in interaction with others, people are considered to display a sense of self in everyday contexts (Bamberg, 2014). As a site where sense of self may be tested out, brief moments of talk-in-interaction allow consideration of the influence of the relational dynamic that occurs within the ‘here and now’ of the telling while also considering the ‘there and then’ of the events described (Bamberg, 2015).

Accounts may be shared by more than one speaker, where positions are taken up or allocated as an interactive achievement or “site where constructions take place” (Bamberg, 2004a, p. 333). This analysis attunes to local, interpersonal purposes and are not restricted to story content (Ochs and Capps, 2001). For example, talk constructed between couples where one partner is living with dementia may sustain the relationship and reaffirm personhood, even where stories may otherwise appear ‘meaningless’ (Hydén, 2017). This analytic approach includes the inconsistencies, contradictions, and moments of tension as they occur within speakers’ navigation of selfhood in situated interactional contexts (Bamberg, 2011b).

Theoretical framework

Theory refers to “a scheme or system of ideas or statements held as an explanation or account of a group of facts or phenomena” (Oxford English Dictionary, 2019). The purpose theoretical perspectives within qualitative health research is debated (Malterud, 2016). In contrast to qualitative research that predominantly uses empirical observations (asking ask what is going on in terms of events or behaviour), an application of theory intends to examine why certain things happen and how they can be explained (Maxwell, 2012). These stereotyped approaches have been contrasted as activities in which:

“the researcher gathers detailed narratives of people doing things, orders them according to broad themes, and lets the data speak for itself...[or] the researcher aims to fit aims into a predetermined theoretical account, usually developed by some en vogue theorist”

(Tavory and Timmermans, 2014, p. 1).

Rather than “forc[ing] data into predetermined codes or categories” (MacFarlane and O’Reilly-de Brún, 2012, p. 609), I sought theoretical concepts that might sensitise me to relevant interpretations, which I might not necessarily have identified through an inductive approach (Layder, 1998), while also considering how empirical findings might push theorisation in unanticipated directions. The framing of data generation as an active process depends on the joining and ‘contamination’ of data with theory through a multi-layered treatment, where knowledge might be opened up “in order to *become*”, instead of being foreclosed, reduced or simplified (Jackson and Mazzei, 2013, p. 271) (my emphasis).

By integrating theory within this analysis, I aim to open up “self-understanding in the sense of our place in the world and how society around us works” (Carrigan, 2018, p. n/p). Further, I aim to explore Burke’s concept of ‘Trouble’ in narratives of brain injury, as “a violation of the conventionally expected, an upsetting of what should be taken for granted” (Burke, 1969, p. 4). I distinguish this from the concept of ‘trouble and repair’ in storytelling, where troubles may arise for the audience in hearing or understanding what the speaker is saying and the associated ‘repair’ may comprise for example, repetition, rephrasing or elaboration to clarify the cause of ‘trouble’ (Hydén, 2010, p. 340). Specifically, through an application of Butler’s theory of performativity (Butler, 2010, 1990), I test out Frank’s assertion that fleeting moments of talk-in-interaction (as opposed to ‘big’, life

stories) “lack a specific Trouble” in Burke’s sense of upsetting the taken-for-granted (Frank, 2018, p. 109) and I explore his question of whether stories “can be acts of making life liveable” (Frank, 2018, p. 111).

In the following, I describe my interpretations of theoretical insights from positioning analysis and performativity, before describing their application within this thesis.

Positioning

The concept of positioning has been widely used in narrative identity research studies on identity work. ‘Positioning’, bringing attention to dynamic aspects of interaction, has been defined as a discursive practice where selves are located in “jointly produced story lines” (Davies and Harré, 1990, p. 48). These ‘discursive practices’ impact the ways subjectivity is generated and, as discourses are contradictory, so too is subjectivity (Davies and Harré, 1990).

Bamberg’s model of positioning within talk-in-interaction provides a way to think about how people may meaningfully construct a sense of self and of each other (Bamberg, 1997; Bamberg and Georgakopoulou, 2008). The concept of positioning analysis enables exploration of “sense of self, the ideas and metaphors with which we think, and the self-narratives we use to talk and think about ourselves” (Burr, 2003, p. 124). Sense of self is explored at the level of the talked-about, and at the level of speaker, in the here-and-now of the interview situation. Each of these levels feeds into a larger positioning in social discourses that extend beyond the here-and-now, as discussed in Chapter 3.

Bamberg operationalises an approach to co-narration through a framework that explores three interrelated levels of positioning (Bamberg, 1997), as summarised in Table 4.

Table 4 - Framework for positioning analysis

Level of positioning	Explanation	Focus
Agency versus passivity	Navigation of the effects of the world upon the self, compared to the self onto the world.	<ul style="list-style-type: none">• Is speaker's role presented as active and agentive?• Sense of self: imposed by others, self-crafted, or both?• Are characters linguistically marked (for example as the agent, in control of the situation, or as the victim, at the mercy of outside forces).
Sameness or difference between self and others ('synchronic')	How the self is differentiated from others (actual or imagined audience)	<ul style="list-style-type: none">• Within interactions, do people bring up categories or make them relevant, which may be related to self or other (for example when categories of profession are made relevant to create sense of sameness or difference)
Constancy or change in self over time ('diachronic')	How the self is presented as continuous or discontinuous across time	<ul style="list-style-type: none">• How do people deal with being 'the same' or 'changed' in the 'there and then' versus the 'here and now'?• Is constancy or change variably brought to the fore within interaction? (intention is not to 'verify' the change)

In the following section, I introduce further analytic possibilities to develop my interpretations of positioning, by disrupting fixed conceptions of identity or assumptions of the unity of an 'inner' self (Langellier et al., 2001).

Performativity

In Chapter 2, I discussed the concepts of biographical flow/disruption as under-acknowledged components of the work of self-management. These concepts first present the question: what is it that is flowing or being disrupted? I seek understanding of the spontaneous acts, or expectations to act, within familiar settings, to which we do not necessarily consciously attend (Butler, 1990), generating a subjectivity as something that we *do*: an interactional accomplishment that is actively constituted and re-constituted in interaction (Bamberg, 2015). Situated accomplishments of identity-work constrain speakers by norms of communication, yet may construct the self through that does not reflect pre-existing norms (Bamberg, 2005). Identity-work, the portrayal of 'who I am', is then a "project of limited range" (Holstein and Gubrium, 2000, p. 70), as a draft that is "multilayered, fleeting, and meandering" (Brockmeier, 2015, p. 69).

Expanding on the positioning analysis described above, I integrate an analytic move through which I specifically seek to disrupt 'easy' or 'predictable' interpretations of narrative. I use insights from Butler's theory of performativity to provide a sensitising device (Gergen, 1973; Liu, 2004), bringing my attention to the performative aspects of self in questions of 'who I am' or 'who I am becoming'. I discuss my interpretation of Butler's work on performativity, before outlining how I consider these insights might deepen my analysis.

Butler's theory of performativity questions those ideas and categories that represent themselves as self-evidently 'real' and 'normal'. In her book *'Gender Trouble: Feminism and the Subversion of Identity'* (Butler, 1990), she critiques identity categorisation by uncovering exclusionary principles in conceptualising the subject, and seeks to destabilise these. The application of the theory seeks to:

"counter a certain kind of positivism according to which we might already begin with delimited understandings...[it] starts to describe a set of processes that...bring into being certain kinds of realities or lead to certain kinds of socially binding consequences"

(Butler, 2010, p. 147).

In Butler's view, compulsory repetition, or 'performativity', gives the appearance of a fixed and cohesive subject according to norms that are adopted for a viable subject to be produced (Butler, 1993, p. 232). 'Performativity' originates in Austin's 'performative utterances': an utterance "in which to say something is to do something; or in which by saying something we are doing something" (Austin 1962, p. 12). Austin's performatives bring about what they say in the appropriate context and if speaker has serious intent. Butler departs from Austin, however, for whom performative utterances are active and intentional acts by speakers (Austin, 1975)³. Searle's (1980) interpretation of Austin's (1975) speech act theory proposed that the social intention of the speaker determined the type of speech act, while Davies and Harré (1990) propose that conversation unfolds through participants' joint attempts to render their actions socially established, becoming a speech-act as far as it is taken up as such by the participants.

³ Austin (1975) differentiates between linguistic acts as locutionary (language that describes), illocutionary (language that does things in the world) and perlocutionary (language that is the effect of that doing).

Derrida extends the understanding through the concept of ‘citationality’, where the utterance has consequence or action because it is recognised by participants as a social convention, “identifiable in some way as a ‘citation’” (Derrida, 1988, p.18). For Derrida, the performative’s force is not its intention, but its citational representation: the success of a performative as it is identifiable as a model and can be repeated (Derrida, 1978). For Derrida, performative statements ‘do things’ because they are citational (Gond et al, 2015). Derrida’s argument, then, is that citation *precedes* intention. Butler upholds this assertion in her foundational argument that gender does not exist before its citation of practices that ‘bring off’ masculinity or femininity. Butler therefore uses the term ‘citation’ to describe adoption of norms (Boucher, 2006). Through ‘*Gender Trouble*’ (Butler, 1990) and ‘*Bodies that Matter*’ (1996), Butler extends Austin’s linguistic origins of performative speech acts by applying the concept to gender identity. The conceptualisation can be extended to other subjective attributes (e.g. ‘adult’) as a repeated doing, which establishes ‘the self’.

Though constituted through the expression of repetitive acts, Butler’s account of identity performativity does not refer to intentioned (performed) acts, i.e. those characterised by some degree of pretence. Critics of Butler’s work have often conflated ‘performativity’ with ‘performance’ but Butler explicitly addresses this misunderstanding in distinguishing between performance and performativity:

“Performativity is neither free play nor theatrical self-presentation; nor can it simply be equated with performance. Performativity cannot be understood outside a process of iterability, a regularised and constrained pattern of norms. And this repetition is not performed by a subject; this repetition is what enables a subject and constitutes the temporal condition for a subject”

(Butler, 1993, p. 95)

Inclusion of performance-oriented aspects in analysis of narrative identities, extending back to Goffman (1959), have been reiterated within biography research by Riessman (1993). In using insights derived from Butler’s performativity, my intentions in analysis differ from Riessman’s ‘performative analysis’, which has also been described as a dialogic analysis. Riessman’s attention is directed to examine how talk among speakers is interactively ‘performed’ as narrative (Riessman, 2008; Smith et al., 2009), where the performance of narrative may include, for example, speakers’ emphasis on words and phrases, enhancement of particular parts with narrative detail, inclusion of reported

speech, pleas to the audience, or bodily gestures and movement (Riessman, 2001). Instead, I explore sites of negotiation and struggle in narration, where 'performativity' reveals competition, conflict, or synergy in subject positions (Langellier, 1999).

Butler's work has expanded from identity categories of gender, central to her foundational work, to broader categories of social relations, particularly kinship (Butler, 2002a, 2002b), and moving "from pivotal concern with gender and sexuality to a general interest in alterity and the face/place of the other" (Segal, 2008, p. 384). Beyond Butler, 'new materialist' scholars now ask how our intra-action with other bodies, both human and nonhuman, may produce subjectivities and performative enactments that have not previously been imagined (Barad, 2003). Barad's performativity moves beyond purely discursive approaches to the materiality of performativity and has been viewed as a critical extension by considering 'more than human' entanglements (Gond et al., 2016).

Integrating performativity

Although we take theories into the field with us, these become relevant only if and when they illuminate social reality. Moreover, we tend to find very frequently that it is not a theorist's whole system which so illuminates, but his scattered ideas, his flashes of insight taken out of systemic context and applied to scattered data. Such ideas have a virtue of their own and may generate new hypotheses...Randomly distributed through some monstrous logical system, they resemble nourishing raisins in a cellular mass of inedible dough. The intuitions, not the tissue of logic connecting them, are what tend to survive in the field experience.

(Turner, 1975, p. 23)

Following Turner's metaphor of nourishing raisins, I intended to draw upon some of Butler's insights as illuminating resources. I saw performativity as a "toolbox" of ideas (Petersen, 2012, p. 17) to access interpretations of assumptions and views that I would not necessarily articulate otherwise (Davidoff et al., 2015). Through exploration of narrative interview interactions, I aimed to reframe uncertainties surrounding sense of self, its disruption, and agency, as a matters of positioning challenges and performativity, using these concepts to produce knowledge differently through the empirical data.

Importantly, my application of 'performativity' is in line with Butler's non-dramaturgical understanding, as discussed above, although the 'performance' of storytelling is an

important and related area of analysis – that is, creative use of communicative to intentionally present oneself by telling a certain type of story to the right audience in a way that establishes an identity (Hydén, 2010).

The performative framing of this analysis, following Butler, opens up questions such as, “How do performative practices and expectations confront subjectivities in everyday life following brain injury?”. To expand on my rationale: if performative acts signify what a community takes to be ‘normal’, then those living with TBI may be signified, or ‘hailed’, as ‘Other’ within a matrix of situated understanding. Following Butler’s application of Derrida’s ‘citation’ that precedes intention, I also seek understandings of ways in which stories have:

“a provisional existence as things outside of consciousness, waiting to shape nascent consciousness and then be repaid when that consciousness perpetuates the stories’ lives by retelling them”

(Frank, 2018, p. 123).

The amount of data, from ten dyadic interviews across two time points, precluded any attempt to read across the dataset using a theoretical application of performativity. In addition, an attempt to draw directly from all transcripts and field notes would risk decontextualised generalisations (Jackson and Mazzei, 2013). Instead, I followed Bamberg’s positioning analysis approach to brief moments of talk and interaction (2006), as described above. Rather than seeking stability or ‘narrative coherence’ in the data, I became drawn to data that seemed to contain tension or ‘trouble’. I considered myself part of the construction:

“If the “I” of the participant is always becoming in the process of telling, so too the “I” of the researcher is always becoming in the process of researching, listening, and writing...[I therefore] seek to unsettle the “I” of both the researcher and researched [as] a static and singular subject.”

(Jackson and Mazzei, 2013, p. 268)

By using Butler’s theory of performativity as a sensitising device, I explored ways of thinking that might help me to move away from a predictable understanding but offers one of many possible interpretations (Mazzei and McCoy, 2010). Further, ‘my’ Butler will not be the same as applications of Butler that pre-exist this work, “for they have inevitably entered into very different assemblages” (St Pierre, 2002, p. 150).

Analytic steps

I listened to audio-recording of interviews several times, including simultaneous listening alongside reading and re-reading of transcripts and field notes. As I transcribed the interviews myself, I developed preliminary analytic ideas at that stage and built on those recorded in my field notes. The analytic steps did not proceed in a linear manner but instead occurred simultaneously and re-iteratively (Figure 2). My analysis was initially data-driven, attending to instances within talk-in-interaction rather than looking for the overall ‘meaning’ or identifying the ‘big’ story, for example, the speaker’s biography. While listening and reading, I considered links between each dyads’ interviews and identified instances of tellings and retellings. The analytic unit shifted from the entity of a ‘story’ or a ‘speaker’ to the practices under joint construction in talk-in-interaction (Bamberg, 2011a, p. 107).

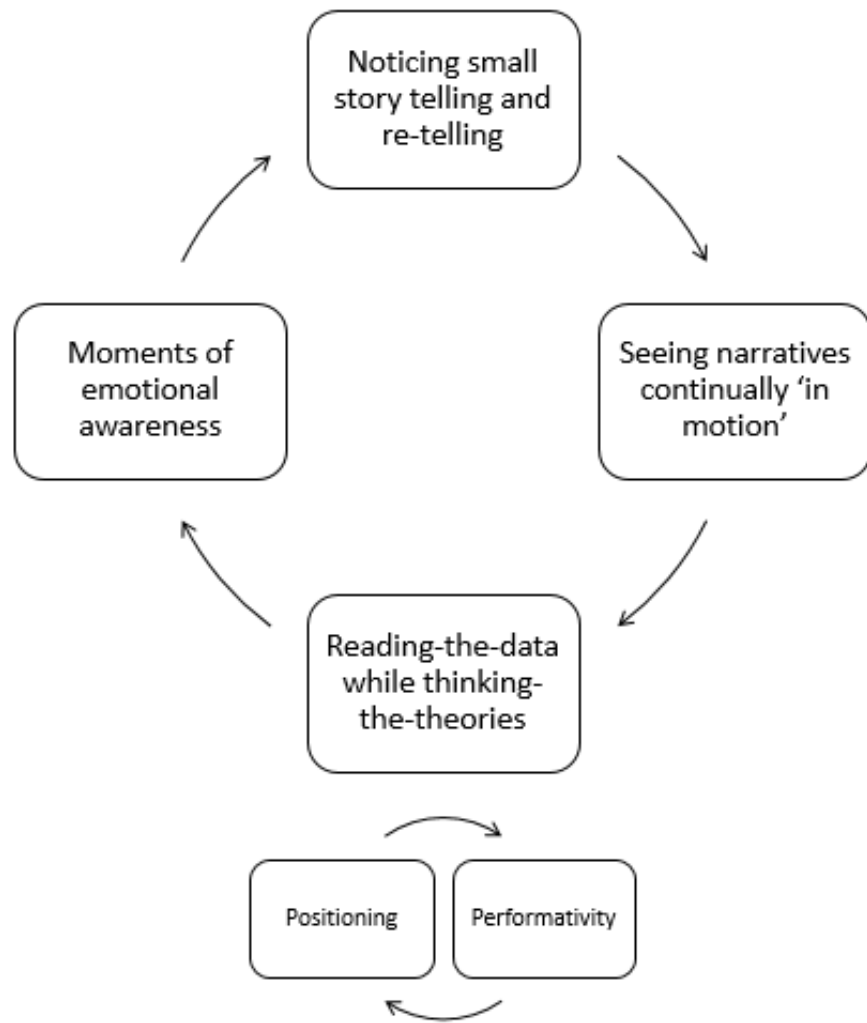
The challenge of acknowledging emotional elements (e.g. intuition, frustration, empathy) within my analytic reasoning, introduced in Chapter 3, was to make sense of - and articulate and conceptualise - the emotional content that was sensed during interview interactions, and sometimes lingered for days after the event. I cognitively attended to particular moments from my experience of the interviews that resonated as having some particular significance - for example, a vague embodied feeling - which may have suggested a form of emotional influence (Skoggard and Waterston, 2015). Viewing emotions as “fundamentally relational” (White, 1994, p. 231), I attempted to get “a sense of and narrate the insinuated, the unsaid, and the unseen” (Stodulka et al., 2018, p. 521), which I reflected on through field notes and discussions with my supervisors. I argue that the processing and scrutinising of such feelings can offer additional ‘information’ and insights into co-construction within social interactions, moving beyond the mere textually identifiable, the ‘talked about’ (Beatty, 2013).

In conceptualising analysis of emotion within qualitative research, Feldman and Mandache describe “emotional overlap” as moments when emotions of participants and researchers are uncovered and acknowledged, offering sites of epistemological reflection (p. 227). This overlap contrasts with analysis that is more typically focussed primarily on participants’ emotions, or pertains to researchers’ reflections on their own specific experiences during fieldwork (Feldman and Mandache, 2019, p. 230). I incorporate

examples of such moments of emotional overlap in the narrative of findings (Chapter 6) and I reflect on the challenges of doing so, in Chapter 7.

When identifying fragments of talk, my analysis turned to the navigation of positioning outlined in Table 4 (levels of positioning analysis). Iteratively “moving back and forth between a set of observations and theoretical generalisations” (Tavory and Timmermans, 2014, p. 4), I considered ways in which positions which are fragile, due to tensions and contradictions, and open to repeated negotiations between the self and others in the interaction. I further questioned potential assumptions within my interpretations by applying insights from Butler’s performativity. I considered processes whereby norms of everyday life were told and re-told, bringing the possibility for disruption when encountering tension between what may be expected or taken-for-granted and considering how this is navigated within talk-in-interaction. Figure 2 summarises my inter-related analytic steps.

Figure 2 - Inter-related analytic moves



(Source: Author)

Summary

Through an open narrative approach to interview interaction and its analysis, I explored talk that was co-constructed within the interview by considering of positioning of the self, and positioning of/by significant others. Sense of self, unfolding in talk-in-interaction, might be crafted within conversation by participants, imposed by others, or both. I added constructs from Butler's work on performativity to consider subjectivities that are fluid yet situated within social positions, norms and expectations. Using this application of performativity, I sought alternative understandings of agency that may provide a space for disruption of normative conceptualisations of self-management as a willed, individual act based on individual agency.

CHAPTER 6: Findings

Introduction

In this chapter, I commence by introducing the participants in the study. I then present extracts of talk that were co-constructed in the interviews across two time points, to consider the micro-processes in navigation of constancy and/or change following traumatic brain injury (Bamberg and Demuth, 2016).

Through my application of positioning analysis (Table 4), I sought to explore participants', and my own, navigation of positions within the power dynamic and social expectations of the interview between myself (identified as a researcher foremost, but also secondarily a clinician, which participants will have been aware of), the person identified as having TBI, and the person identified as their significant other. Especially, I sought to demonstrate the ways in which alternative identities may be called up and made relevant beyond the setting of the interaction, when talking about the 'there and then' in the 'here and now'.

Applying the analytic framework (Figure 2) during repeated listening to audio recordings alongside (re)readings of transcripts, I became aware of moments of 'emotional overlap' between myself and participants (Feldman and Mandache, 2019). As described in Chapter 5, these could comprise a range of fluctuating emotions, for example, frustration, unease, pride or pleasure. I particularly attended to the talk associated with such moments, which may have otherwise appeared unremarkable in textual content and yet could represent instances of work in navigating agentive positions.

I do not employ a thematic approach to presentation of findings. Instead, I seek to retain the integrity and complexity of talk-in-interaction. Here, I present illustrative sequences of key extracts, indicating the approximate time interval between the episodes of talk to situate the extracts within different episodes of interaction with each dyad. I have written the analysis in the present tense, in keeping with the unfolding, generative nature of talk-in-interaction. I use pseudonyms and include line numbers to refer to in my accompanying commentaries. I present the transcribed text in conventional written form with standard

punctuation to assist readability, acknowledging that transcription practices always represent authors' interpretations and biases⁴.

The participants

Ten participants (five males and five females; age range 19 to 80), along with their chosen 'significant other' person (parents (3)⁵, siblings (3), spouses (2) or partners (3), took part in interviews in the south of England, between February 2016 and January 2018.

When commencing this research, I considered that it would be important to record 'accurate', 'objective' information on aspects of people's injuries, details of their hospital admissions, interventions, lengths of stay, scales documenting extent of cognitive impairments and so on, in order to 'describe the sample'. To illustrate the nature of these data: six people who took part had been clinically categorised as having 'severe' brain injuries (according to the parameter of Glasgow Coma Scale (GCS) recorded to be 8 or less, at initial assessment (NHS England, 2017); as discussed in Chapter 1). By the time of the first interview, three participants would have been categorised as having 'severe' injuries, in terms of long term outcome assessed through the Glasgow Outcome Scale (GOS), where 'severe' is identified as a permanent need for help with daily living (Jennett and Bond, 1975).

Over the course of the research, I have come to appreciate Medved's observation about treating people as if

"straightforwardly categorizable...there is much that challenges this neurological segregation, which all but ignores the sociocultural process undergirding the experience"

(Medved, 2014, p. 91).

These descriptions of people, relying on categories of impairments and deficits, are constructed within normative healthcare conventions of managing 'the brain injury'. Although I collated clinical data (cognitive and communicative consequences of TBI for each participant are shown in Appendix 10, Table b), I have come to see these categorisations, and their dehumanising power (Foucault, 1973), as increasingly

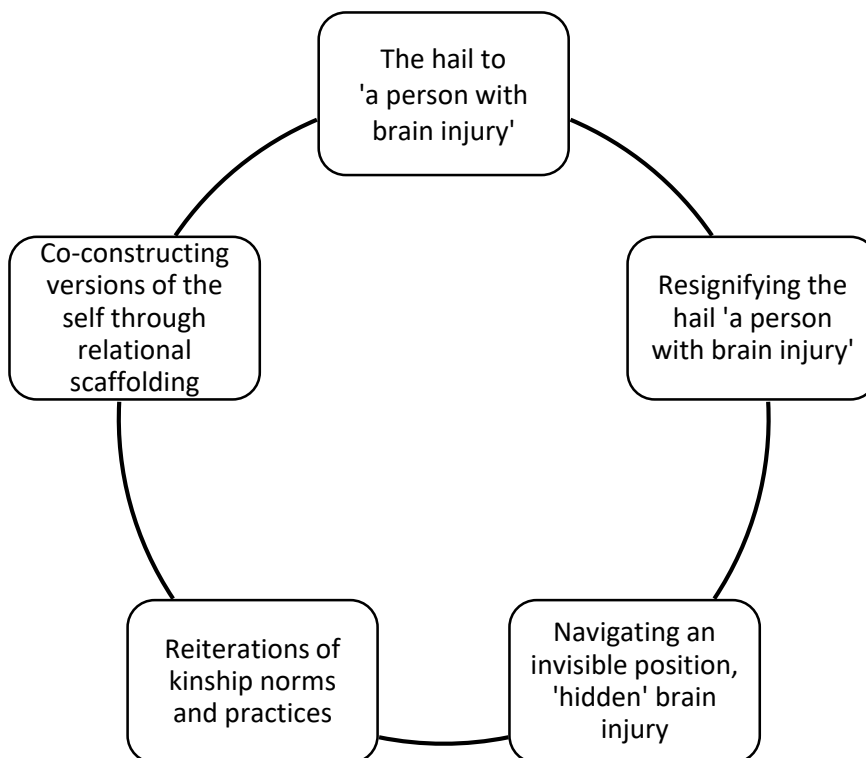
⁴ Commas indicate short pauses and full stops indicate longer pauses. No sections of the extracts have been deleted. Laughter is indicated in square brackets and italics.

⁵ One participant wished to include both parents in the first interview

problematic in this research. Instead of providing categorical descriptions and clinical characteristics, I introduce each person's situation as I present them throughout this chapter.

In the following analysis, I use a term from Butler's work on subjectivity that is underpinned by the concept of interpellation - the call that '*hails*' people into an existence (Althusser, 1971). I present extracts of talk that move through the positioning challenge of a hail to 'a person with brain injury', followed by resistance to the hail through narrative resignification. I then illustrate navigation of an invisible position as a person with brain injury with 'hidden disabilities'. Finally, I discuss co-constructed talk where kinship norms and practices are reiterated following TBI, presenting tensions and affordances in maintaining a desired sense of self within family interactions and as participants talk about encounters with healthcare professionals. I present an overview of the findings below (Figure 3).

Figure 3 - Overview of findings



Representing findings from research interviews, as Back observes, involves “making the social world hold still for its portrait [and] can seem like a gross violence, reducing its mutable flow to frozen moments” (2007, p. 17). In Figure 3, I emphasise an interrelated flow between the findings that I explore in the following section. My intention is to

illustrate the constant complexity of navigation processes; the co-construction and re-construction of a desired sense of self.

Analysis of talk-in-interaction

The hail to ‘a person with brain injury’

When Claire fell down the stairs at a party, she was far from home. Transfers between healthcare settings followed her emergency admission to a trauma centre close by, yet access to local services did not happen smoothly. Claire and her sister Rachel talk about challenges the family navigated to secure the support they felt she would need after discharge. In the extract below, Claire talks about her participation in brain injury rehabilitation, which she ultimately attended as a day patient at a specialist neurological centre. She introduces this account by emphasising that she was “very grateful” to have finally accessed this support. The service intended to rehabilitate people living in the community following brain injury, through educational group sessions led by multidisciplinary neurorehabilitation professionals.

- 1 **Claire:** I never begrudge it, it has been core to my recovery, but the intensity of that,
- 2 naturally, then puts the person with brain injury in a situation where you are not really
- 3 dealing with the repercussions of the day to day of living with the brain injury.
- 4 Because talking about it, you are constantly being reminded about it and it is discussed,
- 5 trying to get an understanding. So, the intensity of that is quite a lot to take on.
- 6 I have had different people, now I am independent, saying just like, “You are so negative,
- 7 all you do now is talk about brain injury. Can’t you talk about something else?”
- 8 You have to kind of step back and say to someone, “One, I am trying to come to terms
- 9 with the fact that I nearly died. Two, I wasn’t getting that treatment but now it is all
- 10 coming at once”, which I can never ever begrudge, and that is fundamental. So, you have
- 11 got to understand that, three or four days, or a week, being in the hospital, again and again
- 12 and again, talking about brain injury or recovery from brain injury. Well, naturally, that is
- 13 all that is going to be in your head. Specifically, because you are a person with brain injury.

Claire conveys tension between subject positions through her account of being “in the hospital, again and again and again” when attending the rehabilitation sessions (line 11-12), contrasted with trying to manage in her everyday life (line 3). She conveys an “intensity” of the period in which healthcare professionals seek to educate her about brain injury, which overwhelms her ability to incorporate this intended support into her way of being, outside those sessions. Her frustration is apparent, in trying to reconcile the

rehabilitation – which she conceives as specialist and “fundamental” – with her desired self as she interacts with others. She presents the tensions involved in being a person who is both required to talk about brain injury in the former context, whilst avoiding talk about brain injury, in the latter. Claire refers to the constant reminders from rehabilitation discourse, of an identity as someone who has a brain injury (line 4). In line 6, she describes that other people pick this identity up as her ‘new’ broken one, through the content of her talk that has been shaped by the reiterative focus of the brain injury sessions.

Claire presents the positioning in healthcare encounters as “a person with brain injury” (line 13) as a frustration of her desire to get on with everyday life. She expresses her own desire to deal with the “repercussions” of the injury (line 3) while also wanting to put aside the position of being a “person with brain injury”, to continue a liveable life. Trouble arises from a subjectivity marked out by the way she has come to view herself as “a person with brain injury”. She portrays this position as constantly reinforced in the rehabilitation sessions, yet disconnected from the repetitions of acts that could otherwise constitute her preferred, “independent” sense of self (line 6). Claire continues:

- 14 **Claire:** And the difficulty is then people don't realise and they might just assume, “Oh
15 look at her, she is depressed and whatever” and then they flip you to one side. And okay,
16 there are some appropriate emotional coping mechanisms or whatever, but there is a real
17 lack of understanding about the individual, of what the person is dealing with. Then it is
18 difficult, because everyone with brain injury differs, because no one knows what anyone's
19 brain is like, it is the most complicated organ in anyone's body, but there has to be some...
- 20 **Rachel:** Well, I think, if I can come in, Claire, we know through family members who are
21 a lot more sympathetic to Claire's condition than others, and they have had to take the
22 time to research it...
- 23 **Claire:** Or sit down and talk...
- 24 **Rachel:** Yeah, talk to you...
- 25 **Claire:** Not become too inquisitive but just to ask, “Okay, how are you?”

Claire's apparent willful dismissal of healthcare professionals in line 16, by saying “appropriate emotional coping mechanisms or whatever”, demonstrates her perception of the rehabilitation clinicians' approach as not her priority. Her sister, Rachel, begins to insert an account of family members' support (line 20), yet for Claire this intervention seems to re-emphasise a category in which her ‘new’ situation is simply to be ‘researched’ through detached resources. Instead, she advances her preference; for others to seek a

supportive understanding through talking with her on a personal level (line 23). Claire's resistance asserts that the 'researching brain injury' approach, presented by Rachel, cannot lead to an understanding which she considers could provide useful insights that open questions might achieve, like "...how are you?", for instance (line 25). This mirrors her frustration with the brain injury rehabilitation sessions, in prioritising a narrative of deficit which could potentially obliterate other thoughts and identities, if that is "all that is going to be in your head" (line 13).

Resignifying the hail

Claire and Rachel go on to discuss characteristics of Claire's speech since her injury. Since her hospital admission, areas of potential change have been brought into focus by family members and by clinicians. In the interaction below, Claire uses clinical terminology and an interpretation of what she may be experiencing, explaining that this identifies her as someone who needs to receive speech therapy. She shares a story of a friend, known to Rachel also, and apparently held in high regard for her complicated use of language:

- 26 **Rachel:** You can do the majority of things, 98%, but there are certain things that she does
27 ask, "Rachel, what does that, what word is that?"
- 28 **Claire:** I have got asphasia
- 29 **Rachel:** Yeah, dysphasia. And it's not bad...
- 30 **Claire:** It is in there somewhere, and I can give a description of what I want to exactly get
31 to
- 32 **Rachel:** And, "What's that word?", yeah
- 33 **Claire:** The word is there, but just not quite there, and that is part of the reason why I am
34 going through the set of speech therapy
- 35 **Rachel:** But it's not bad, it's just...
- 36 **Claire:** I just come out with complicated jargon
- 37 **Rachel:** Yeah [*laughs*], when she woke up from a coma she was speaking all this gobble-
38 de-gook, and it was like, all these fancy words, and it was like, okay, there is something up
39 there...
- 40 **Claire:** Yeah, but it goes back to my friend. She was always like that, it was like she was
41 Mary Poppins, she was always very califragilistic
- 42 **Rachel:** Swallowed a dictionary!
- 43 **Claire:** Yeah, she would always come out with that stuff.

Claire begins by citing a professional term but is corrected in her mispronunciation by Rachel (lines 28-29), who positions herself as the knowing witness (line 26). Frequently through the interaction, Rachel makes relevant her identity as Claire's older (and wiser) sister. Rachel shares a description of Claire's period of transition "from a coma" (line 37), recounting a time period for which Claire cannot report on herself. Claire then navigates the change in herself that is presented by Rachel as "speaking all this gobble-de-gook" (line 37), instead creating a sense of mastery (for complicated jargon), which is then reinforced with an association with a valued, '(super)normal' ability (califragilistic); an interpretation that is endorsed by the apparently erudite Rachel (line 42).

Claire's navigation of the trouble that arises, in being labelled as someone who has speech difficulties, demonstrates her resistance to this additional 'hail' to 'a person with dysphasia'. In the subsequent interview, she demonstrates re-appropriation of the valued characteristic that she had attributed to their friend in her earlier telling:

Nine months later...

- 44 **Claire:** I guess you are always worried, is someone gonna notice the scars, are they going
 45 to immediately know from me that I have had a brain injury, because you are trying to
 46 assess, right, this is me before, this is me now, which is an interesting, um, exercise to do.
- 47 **Petra:** What are some of the things you think about, when you think about that?
- 48 **Claire:** Um, not being able to express myself, in the same way I was before. So really silly
 49 things, like remembering the words for something and, um, I know the word is in there
 50 somewhere but being able to identify what it is, and not have to say to someone, "What is
 51 that called again, I know it begins with A". And then, even when you are trying to express
 52 yourself in conversation, it can be quite frustrating.
- 53 But then, I don't know if that is partially because my friend used to say I was like Mary
 54 Poppins, making up my own, like I had swallowed a dictionary, and making up own
 55 phrases, and words and stuff. So, I don't know if it's that, I don't know if it has stemmed
 56 from that.

Claire's re-attribution of being "like Mary Poppins" (lines 41 and in the re-telling, line 53-54), from her friend to herself, demonstrates that the 'true' owner of this characteristic is beside the point. This is a reiterative use of a story as a resource that transforms others' labelling of her speech as problematic. Claire identifies that being like Mary Poppins is a positive characteristic, which is valued by others. In the first interview, Rachel endorses Claire's telling of this story, but she is not present at the time when Claire returns to this

story with me in the second interview, suggesting potential influence of context on the telling. Each time that Claire tells the story of someone being like Mary Poppins, she identifies with the enchanting, fictional character, thereby crafting continuity in sense of self. Through this citation, Claire re-presents a separate occurrence of the story as not quite what it was before.

The Mary Poppins citation marks out Claire's sense of self in a manner which others may more easily comprehend and relate to, and value on its own, while challenging a deficit narrative that has marked her as 'a person with brain injury', 'with dysphasia'. Through reiterative telling and re-telling this story, Claire has been able to infuse herself with some magic and mystery, when positioned by others as someone who has 'changed' following her injury. Others' accounts of Claire as 'changed' had begun without her conscious response "when she woke up from a coma" (line 37).

Claire persists in advancing her sense of self throughout, by initially problematising the positioning she reports on from others, as someone who is "so negative" (line 6), only "talk[ing] about brain injury" and "speaking all this gobble-de-gook" (line 37), by finding a way of re-signifying the reported change as a valued aspect of herself. Through positioning herself actively, as the one who has always been "very califragilistic" (line 41), she undertakes a project of selfhood in the face of some opposition, advancing her "desire to persist in [her] own social being" (Butler, 2005, p. 44).

Andy was admitted to the trauma centre after a stranger assaulted him in the street. Like Claire, he was discharged home directly from the surgical ward, without rehabilitation in an inpatient unit. However, he seemed reluctant to take up community-based rehabilitation services following discharge. Andy and his partner, Danielle, were expecting their first child at the time of his assault and their son, Leo, had been born shortly before my visit to their home for the first interview. Andy and Danielle talk about follow-up arrangements made after his discharge from the trauma centre:

- 57 **Andy:** The hospital tried, sorted stuff out with [the brain injury day centre] and stuff. I
58 was up for it, but I just want to forget everything that happened to me now. I just want to
59 crack on with my life and with my kid and that. They arranged for me to come, I got a
60 letter this morning from [the brain injury day centre]. I am going to give them a call and
61 I'm not going to bother with it, to be honest.
62 It would be sessions with other people with the same injury as me. It could help me, it

63 might help me. But I don't really think that's me, in a group. It might have helped me
64 earlier, but not now. I feel like I'm a private person and I keep myself to myself. Being
65 around a lot of people I don't know, I don't want to be rude to people, but I want to keep
66 to myself. I don't want to engage with everyone, talking, like.

Andy resists the service offered by the brain injury centre, initially highlighting that it would mean "sessions with other people with the same injury as me" (line 62). He suggests this is a category he does not wish to identify with, while also conceding a possibility that the service "could help me, it might help me" (lines 62-62). He goes on to position himself differently from "other people with the same injury as me" by instead prioritising expertise in his own sense of self: "I don't really think that's me" and "I'm a private person" (lines 63-64). His partner, Danielle, does not comment on Andy's reluctance to attend these sessions at this point but, at the subsequent interview, she reopens the story, highlighting his independence and doggedness.

Six months later...

67 **Danielle:** We spoke last time about [the brain injury centre]. He didn't go ahead with it,
68 he didn't want to be reminded of it all the time.

69 **Andy:** I decided I just wanted to crack on with my life and not think about what happened
70 to me.

71 **Danielle:** You can't force him into anything, just does what he wants to do.

72 **Andy:** One of my mates works for the council, he said it is old people there. Not that I got
73 anything against old people, but I wanted to just get confident with myself.

74 Even when I was referred to fatigue clinic, I didn't go to it. I just feel I like to be in my own
75 environment, my home, and do normal life stuff, like a bit of shopping. I feel I just want
76 to get my life back and not get involved with stuff like that.

Here, Andy agrees with Danielle's portrayal of his reluctance to attend the brain injury sessions, nuancing his own refusal of the injury as "[I] didn't want to be reminded of it" (line 68). He goes on to introduce a further justification for distancing himself from "other people with the same injury as me" (line 62), highlighting that a difference in age, between himself and participants in the rehabilitation sessions, meant he would have even less in common with participants (line 72). This service feature has been pointed out to him by a valued peer, "one of my mates" (line 72). His conflicted positioning between "it might help me" (line 63) and wishing to "do normal stuff" (line 75) perhaps demonstrates frustration between an assumed passive role conferred by a health service making arrangements on

his behalf and his own desire for an agentive role to “do normal stuff”. Andy further demonstrates his reluctance to engage with such arrangements when he adds, “even when I was referred to fatigue clinic, I didn’t go to it” (line 74). Here, his earlier rationalisations of group format and age categories of service users do not necessarily apply and, instead, he re-asserts his desire to independently “get my life back” (line 76). For Andy, getting back on track is at odds with the position to which he is repeatedly hailed, as someone attending brain injury services. He determines to “not get involved with stuff like that” (line 76).

Though resisting the hail to ‘a person with brain injury’ by these services, Andy anticipates a normative clinical expectation of ‘compliance’ with their offerings (Dingwall, 2016). During our interactions, my sense was that Andy put forward rationalisations from a subject position ‘as a non-compliant patient’; as if speaking to a clinician. A ‘double-bind’ seems to operate in the communication from services, informing Andy of what has been arranged for him (Bateson et al, 1963; Gibney, 2006), thereby implying healthcare services know what is best for the “person with brain injury”. However, these arrangements require Andy to move away from his desired sense of self and instead “think about what happened” (line 66). Andy’s agenda instead is to integrate his activities within his own environment and “get confident with myself” (line 73). As a self-perpetuating medical convention, failure to comply with professional expectations in turn can be interpreted as ‘lack of insight’ and therefore ‘evidence’ of his identity being steeped in brain injury, in a further frustration to Andy’s desire to “crack on” with his desired sense of self (lines 59 and 69).

At other times, Andy more explicitly hails me ‘as a clinician’ in our interactions, when putting forward particular ‘medical’ questions. During these discussions, I occupy positions as a researcher/a clinician/both, but also neither: as a guest in Andy and Danielle’s home and aware of my possible intrusion, at a delicate time soon after the birth of their son. When Andy asks, “Now that I have got this titanium plate, is that just as strong as the other side of the skull?” he demonstrates an openness to consider his injury, alongside his earlier reluctance to do so when talking about the brain injury centre and the fatigue clinic. He initiates this question on his own terms, not in response to a clinician’s expectation that he will think about it. In responding, my various subject positions carry ethical obligations, including the position I resist during the interviews, ‘as a clinician’, from which I responded ‘clinically’ to his question. Andy achieves a fluidity in the ways we can now interact with each other, demonstrating his navigation in these moments of “getting confident with myself...in my own environment, my home” (line 75).

Andy goes on, in the second interview, to convey further significance of his own valued ways of being, in comparison with his avoidance of healthcare services' priorities. Talking about home visits from an occupational therapist (OT), he re-signifies the interpellation to a subject position as 'a patient' and 'a person with brain injury' who would engage with such a service, instead constructing his own achievement of "doing normal life stuff" (line 75) within the visits:

77 **Danielle:** An OT came round

78 **Andy:** Yeah, she come round and done a few little tests on my memory, little puzzles and
79 stuff like that. She gave me a task to cook food and stuff. Like, I baked a cake. This was
80 just to build my confidence and to do stuff myself in the kitchen, 'cos I weren't doing
81 nothing. It was all right. She came weekly and the night before, I got an urge to bake a
82 cake. She come round and er, yeah, I chose to do the cake.

83 **Danielle:** One thing that ain't changed with him is the cooking. He was only out a couple
84 of weeks and he was cooking.

85 **Andy:** I've always cooked, yeah.

86 **Danielle:** The only thing that might stop him now is tiredness.

87 **Andy:** From being indoors for a long time, that was my main highlight of the day, was to
88 cook something. I tried to like, put a bit of passion into my cooking. I didn't have nothing
89 else to do.

Andy appears to quickly dismiss the OT's "few little tests on my memory, little puzzles and stuff" (line 78), instead sharing a story where he positions himself agentively in deciding to bake a cake. He bolsters this active role by portraying the assigned "task to cook food and stuff" (line 79) as almost incidental. He emphasises: "I got an urge to bake a cake" and "I chose to do the cake" (lines 81-82), foregrounding his mastery in baking the cake on his own. Danielle brings additional attention to the significance of this story being about more than Andy's cake baking, instead bringing a sense of continuity for Andy and for their way of being together as "the thing that ain't changed" (line 83). Danielle extends this continuity back to an earlier stage of recovery after his injury, on which he is unable to report himself: "He was only out a couple of weeks and he was cooking" (line 83-84). Cooking is a skill Andy and Danielle value, which they relate to as "always" present (line 85), yet not as a mundane "task". He connects his "passion" through cooking (line 88) to a familiar practice in which he can "get confident" with himself.

Andy's story gives a sense of reconnection with "the energy of life" (Bamberg, 2010, p. 12), contrasting with his earlier talk about the fatigue clinic in which there was a sense of being weighed down; not wanting to "get involved with stuff like that" (line 79). Following brain injury, fatigue is commonly considered to be "one of the sequelae that pose the greatest challenge to self-efficacy and limit social participation" (Dumont et al, 2004, p.431). For Andy, reiterative actions through which he claims some degree of power over this immediate situation, illustrated here by cooking, achieves a continuity for Andy that has linearity to before the injury, becoming particularly meaningful for his identity at a time when he "didn't have nothing else to do" (line 88). He reflects on the steps (achieved without the clinic's intervention), saying: "I used to avoid going places, but now I am just getting up and doing it. The only way to conquer something is to get up and face it."

Ruby found her husband, Walter, unconscious at the bottom of the stairs, following a fall. He was admitted to the trauma centre and, after a prolonged hospital admission, he returned home. Ruby took early retirement to be at home to assist Walter. They have support from their daughters and their daughters' partners, who live nearby. Ruby and Walter talk about a group run by a local brain injury charity that they have been attending together:

- 90 **Ruby:** Another thing Walter enjoys, he doesn't remember these things, I have to remind
 91 him, but we are still in touch with the brain injury group and he does like going to those
 92 get-togethers. He is in his element and he can talk for as long as he likes. They are all, you
 93 know. Used to be every month, and everybody knows everybody.
- 94 **Walter:** They have got people [*at the centre where the group meet*], I was going to say they
 95 have got people with my complaint, but, er, it is not my complaint, it is my, um, exotic
 96 thing. You know, they talk and you can tell, when they talk, how they get on with people.
 97 And if you can get on with people like me, it's good. For them, and for me. I don't talk
 98 much about problems, I don't like to talk to people about problems because, er, I don't
 99 like to admit I have got any problems. But, er, it is nice to know what they are doing and
 100 sometimes you hear about some hobby they have got, and you have never met anyone
 101 with that hobby before. And it is interesting, what you can study and can enjoy yourself.

Throughout our discussions, Ruby reiteratively uses language of foreclosure that constitutes Walter as a subject "through a certain kind of pre-emptive loss" (Butler, 1997, p. 23). For example, she points out to me, "they are all, you know..." with reference to "the brain injury group" (line 92-93). To accept a subject position means recognition of

language as self-description, as if to respond “Here I am” (Foth, 2013, p. 121). However, Walter repeatedly resists Ruby’s hail as a ‘person with brain injury’, instead naming the injury his “exotic thing” (line 95). He brings valued aspects to the fore, such as finding personal interest in talking with others at the group. Walter and Ruby’s meaning-making of him as a person with ‘an exotic thing’ or ‘a person with brain injury’ differ, yet they co-construct continuity through reference to Walter’s characteristic of getting on with people. In the second interview, Walter and Ruby go on to discuss their differing approaches to interactions with others:

Six months later...

- 102 **Walter:** When I meet people, I don’t worry about them getting the wrong attitude or the
 103 wrong view, because you can talk to anyone and for some reason or other they get this
 104 wrong view, and don’t treat you the right way. But, you know, you can put up with it
 105 because you think to yourself, ‘Well, some people are like that, I’ll have to put up with
 106 them and, you know, make allowances for them’.
- 107 **Ruby:** I don’t want people to think any wrong of him. I want them to realise that, and
 108 I’m at great pains to explain to people as well, that he does understand what you’re saying
 109 and if he uses the wrong words, because sometimes when people don’t know and he uses
 110 the wrong words, they start laughing. And I’ll say he’s got this, because of the brain injury,
 111 he’s got this problem where he tends to use the wrong words. So, he knows what he wants,
 112 he knows what he’s saying and he does understand it, so I go to great pains to explain this
 113 to people.
- 114 The children are different. Joy does a lot more with him, and she won’t... She’ll just let
 115 him and she says whatever happens, happens. Or however they take him, that’s it. Because
 116 Joy is very much of the same sort of ilk as her Dad, so it doesn’t matter to her what people
 117 think, you know.

In contrast to Walter’s description of his injury, saying “it’s not my complaint” (line 95), Ruby points out, twice, that she feels at “great pains” (lines 108 and 112) to explain to others “his problem”, “because of the brain injury” (line 110-111). Ruby goes on to position herself differently from her daughter, in being more concerned about the injury and perceptions of others. She aligns her daughter instead with Walter, acknowledging that, for them both, it “doesn’t matter what people think” (line 116). Walter acknowledges that Ruby’s view of his interactional abilities differs from his own, and he is the one who then goes on to resolve potential trouble arising from their different views. Instead, he reworks the tensions to account for them as a consequence of social conventions and constraints:

118 **Walter:** I don't think I have problems, except I'm not allowed to do things I am fit to do.
119 But people who treat me like that cannot be blamed, because of regulations they are
120 looking at. And they don't want to spoil things or do things wrong way, so they treat me
121 what they think is nicely, even though I think I am fitter and should be able to ignore it. I
122 just say to myself, 'That is how it is, I don't think I can change things, it can create problems
123 and difficulties'. I don't want that, don't want difficulties and problems.

Walter demonstrates that when he goes along with restrictions, he allows "people" - indirectly referring to Ruby - not to feel she will "spoil things" according to the "regulations" that frame her support for him (line 119-120). He suggests that to confront or "blame" people [Ruby] for not allowing him to do things could open up unknown "problems and difficulties" (line 122), which lie outside their familiar ways of being together. Walter's positions himself actively, even when presenting his submission to "not being allowed to do things" (line 118), as he avoids potential disruption in their daily life.

Navigating an invisible position

Claire (introduced earlier, with her sister Rachel) is anxious that her brain injury might be apparent, saying that she is "always worried [others are] going to immediately know from me that I have had a brain injury" (line 45). She navigates the invisibility, or hidden identity, of being 'a person with brain injury' and yet wonders how she might be perceived by others, if they "notice the scars" (line 44). Claire and Rachel go on to discuss contradictory expectations from others:

124 **Rachel:** People will say, "Claire is okay, she looks brilliant"
125 **Claire:** "She looks fantastic"
126 **Rachel:** And we will say, "Yes, she may look okay, but she is not"
127 **Claire:** She is not, she is still really in a lot of recovery
128 **Rachel:** And why don't they take the time? I would never say that to anyone, and how can
129 people be so shallow? But they are.
130 **Claire:** I think that is general
131 **Rachel:** Yeah, 'cos I am 41, I am not married, just to give an example, and it's all things
132 like, "Why aren't you married, why haven't you got kids?" Well, I haven't. And what I'm
133 saying is, that is just a judgement. But people feel free to make the judgement. Nobody

134 knows what is actually going on, maybe you were divorced, maybe you can't have children,
135 but as a person, I would never say that to anyone. People need to be careful what they say
136 to you.

137 **Claire:** And that is the thing, with a blind disability, that people do make assumptions.
138 People do make the assumptions.

139 **Rachel:** Sometimes, it's society, "Oh, this is what you..."

140 **Claire:** That is different though, that is just about life

141 **Rachel:** No, it's because Claire looks well and they see that she, well, they think they see
142 that she does the things she used to do. And they think she is better, but she is not.

Claire speaks about herself in third person, positioning herself alongside her family in how they might explain her situation to others, and perhaps demonstrating to Rachel how to do it: "She is still really in a lot of recovery" (line 127). Rachel then attempts to extrapolate Claire's dilemma of others assuming they know what is going on, when "shallow" people cannot see below the surface (133). Interestingly, Claire refers to a "blind disability" here (line 137), when talking about others' inability to appreciate her situation (she is later corrected to say "*hidden* disability" by Rachel).

Rachel shares her own example of others' assumptions in relation to their normative expectations of marriage, which she apparently finds confronting (line 132). However, Claire resists Rachel's implication that this comparison shares similarity to her own situation, saying "that is different though" (line 140). She suggests her own experience cannot be understood through Rachel's observations, which she dismisses as "just about life" (line 144). For Claire, Rachel's story does not resonate with the unresolved liminality for her of "the fact that I nearly died" (line 9).

Talking about reactions of her work colleagues, Claire continues to talk about ways that others' responses can be confronting. Here, she distances herself from the character in her telling:

143 **Claire:** You are going to bump into people in the office who come out with strange things,
144 saying things like, "Have you still got a brain?"

145 **Rachel:** They did actually say that to her, and "Have you got a memory?"

146 **Claire:** Yeah, "Have you got a memory?" and all of that sort of stuff

147 **Rachel:** And these people are supposed to be educated

148 **Claire:** Well, that is the most outstanding thing, actually.

In Claire and Rachel's account, Claire's identity coherence is disputed by colleagues. Her private experience is rendered social, through a foreclosed identification that implies a loss of self-as-brain. This unliveable position, in an "exclusionary matrix" (Butler, 1993, p. 3), is created through the force of speech acts that bring expectation of an identity drastically spoiled: "Have you still got a brain?" (line 144).

Positive positioning, of a desirable self, preserves 'face' in situations of difficulty or potentially 'spoiled' identities (Goffman, 1967). Rachel's offering of her own example of "people need to be careful what they say to you" (line 135) perhaps demonstrates her desire to 'share' face with Claire, in the context of the interview. Resisting the attempt, "that is different" (line 140), Claire echoes her earlier assertion that she is dealing with "a real lack of understanding about the individual, of what the person is dealing with" (lines 16-17). Her description of "people in the office who come out with strange things" (line 143) further demonstrates more explicitly that, to give an account of herself, she requires others who are prepared to listen to her while developing some form of shared understanding of her private experience. She portrays this as clearly absent in her colleagues, dismissed through her comment "that it is the most outstanding thing", that they are "supposed to be educated" (line 147-148).

Claire's navigation of her position in isolation from work colleagues is also suggested in relation to her parents, her older brother, and Rachel. However, here she presents her sense of being marginalised and struggling to be heard in the family as a continuous experience over time, since childhood:

- 149 **Claire:** Being the youngest in the family anyway, I was never really listened to. Because I
150 was the youngest, I didn't know anything. So, then that as well, I think, has probably fed
151 into that there is no point me saying anything, because I probably won't be listened to,
152 really, and that is just family dynamics, or whatever it may be.

For Claire, overlapping positions of difference between herself and her family come from normative expectations of 'being the youngest in the family', and also of being 'the one with brain injury'. During the second interview, Claire describes conflict between her family's concerns and her own expectations for herself:

- 153 **Claire:** [My family] are compounding my anxiety because, (a), "What are you doing?

154 Where are you going? But you can't do that unless you go there now" and blah, blah, blah.
155 And it is just them trying to establish their own confidence, and lessen fear, but it is very
156 difficult then, 'cos it makes it twice as bad. I think there is also a factor of living at home
157 and being a 32-year-old adult, and not having my own independence. Um, because my
158 parents, on their own, are generally quite full on, if you want to say that. They always were.

Claire conveys a sense that she has always struggled to develop a sense of independent self as the youngest in the family and in the face of "full on" parents (line 158). She recreates a sense of continuity within the "family dynamics" (line 152) as it has always been, rather than as 'a person with brain injury'.

For Andy, who lives away from his parents with Danielle and his son (introduced earlier), his concern is to navigate an 'invisible position' while actively managing his parents' impression of him as someone who is coping just as he did before his injury:

159 **Andy:** I don't want my parents to worry about me, I don't want them to know. It's
160 probably, erm, I don't want them to think I am, I don't know, what is the word? I don't
161 want them to know, if I am going through anxiety.
162 **Petra:** You're aware of that, when you're talking to them?
163 **Andy:** Yeah

This moment brings emotional significance, marked out by a long silence (more than five seconds), in which I sense the tension that arises for Andy and Danielle as we discuss this topic. His negotiation of his sense of self, when interacting with his parents, is revealed in a way which, it seems, Danielle has not previously seen. After this pause, Danielle asks Andy:

164 **Danielle:** Do you do it to me?
165 **Andy:** [*Further pause*] No.
166 **Danielle:** How you are, you, you would tell me?
167 **Andy:** Yeh

Danielle is concerned that the facework portrayed in Andy's management of interaction with his parents as he says, "I don't want them to know...if I am going through anxiety" (line 161), is something that maybe he 'does to her' also (line 164). This is a moment potentially marking out distancing within their couplehood, now as parents themselves.

She goes on to comment, “I think, deep down, his parents do know, they know what he is going through”. Here, Danielle positions herself alongside his parents in their deep knowing of Andy. She does not disrupt his desired sense of self, or their shared way of being together, as she pulls off a complex navigation of their collective positioning. Danielle maintains their mutual interdependence, in a narrative move that also suggests its precariousness.

Reiterations of kinship practices

Monte was completing a postgraduate degree as an overseas student in Oxford, when a motorcyclist hit him on a pedestrian crossing. His family live in America and his younger sister, Florianne, was the one who flew to England to be with him, after they heard of his hospital admission. Monte and Florianne describe the early stages after his admission to the trauma centre:

- 168 **Monte:** It is funny as I still had some logic in me. I asked Florianne, “What are you doing
169 here, weren’t you in the States?”. And she said “Yes”, and I said, “So you came the entire
170 way here?”. She was like, “Yes”. And I’m like “Oh my god, I must be really fucked up, I
171 must be really in real bad shape”, you know? These were the small things that made me
172 realise that this is really serious.

Monte begins this telling with “It is funny” (line 168), marking this account out as a significant resource in making sense of “small things that made me realise that this is really serious” (line 171) soon after his injury, while still in hospital. Monte applies this story as a resource about a time that he cannot remember, for which he accepts the account he has been given by his sister, demonstrated as he says “I guess I realised that [Florianne had come over from the US] on the spot, for like fifteen minutes of realising it, but after that I don’t remember that interaction at all”.

In Monte’s accounts of later stages after his discharge, he constructs a sense of continuity in self, through the family’s natural way of being together, and contrasts this with the autonomous, distanced life he sought to return to:

- 173 **Monte:** While I am here [in Oxford], I’ve got to deliver, constantly delivering something,
174 or fighting for something, for my place, fighting for my art, fighting for my name. When I
175 go there [home, in America], I think that’s also about the idea of disconnecting, you just

176 drop your gloves, you eat well, eat better, just get the love. And to know that you are going
177 back, it gives you energy, you know.

Monte presents the comfort of his home life through reiterations of kinship in which embodied practices cultivate an idea of family; he can “just get the love” (line 176). By contrast, the life to which he seeks to return presents constraints of a position where he is “constantly delivering something” (line 173). Monte constructs a sense of self performatively, as he and his family repeatedly act in ways they perceive to be ‘natural’ for them in being together.

178 **Monte:** I would always go to my grandmother first, because everybody, we were all dealing
179 with that, it wasn’t just me, when she died two months ago. So, we were all supporting
180 each other, in that sense. And I am, er, a stone, for a lot of people in my family. So,
181 regardless of my tiredness, I still had to be, to be there.

182 **Petra:** You were saying it took a while before you re-found your voice in your roles here
183 [in England]. How about your voice at home, did that seem different?

184 **Monte:** Yes, yes, yes, yes. Definitely, I think that’s why, um, going home was important,
185 or having a place where you don’t have, or you don’t need, that warrior voice, you know,
186 because it has to rest also, you know. This voice of, like, “You’re gonna make it!”, this voice
187 also needs to rest. When you go home, well, you get that rest, because you don’t need to
188 fight for nothing.

Monte portrays acceptance of his need for family in a life where he otherwise “fought” for autonomy. Back at home, where “you don’t have, or you don’t need, that warrior voice” (line 185), Monte moulds a sense of self that is intimately connected to performative dimensions of belonging and residence. The sense of mutual constancy this provides is conveyed by his metaphor of being “a stone for a lot of people in my family” (line 180). In bringing to the fore his sense of reliability within family ways of being, effects of the injury become almost irrelevant: “regardless of my tiredness, I still had to be, to be there” (line 181). Monte negotiates this subjectivity not only in, but through, his sense of home (Brown and Knopp, 2003). His stories of everyday life back at home with family allow him to convey an identity that also allows disconnection from expectations of the lone self: “You’re gonna make it!” (line 186).

Andy (introduced in earlier sections with his partner, Danielle) demonstrated his desire to “get confident with [him]self” in his familiar routines within his home environment,

which appears to be key for Andy in claiming a confident sense of self (line 76). In the weeks after his discharge from the trauma centre, he awaited surgery for the repair of his skull defect (resulting from emergency neurosurgery at the time of his initial admission with TBI). He had been advised to wear a protective helmet when going outdoors, until the surgery to place the titanium plate had taken place. His partner, Danielle, highlights the impact this had for both of them:

189 **Danielle:** At first it was really hard, he had to wear a helmet. Like your whole life, you
190 find you're just indoors all the time, you can't really go out as much, obviously because of
191 his confidence and the way people were looking and him explaining all the time, what had
192 happened.

The potential for impact on Andy's confidence from "the way people were looking" (line 185), identifies the helmet as a 'social object' that is defined by norms of social phenomena and regulates interactions (Mead, 1967). Danielle presents the helmet as an out-of-place object that needs "explaining all the time" (line 191), suggestive of contravening a public norm in which the "normal' healthy body is a moral obligation" (Oakley, 2007, p. 117). The helmet, as a co-constitutive agent, produces a certain type of 'not normal' subject. Through a mutual relationality with the helmet, Andy loses the 'invisibility' of TBI that he has when not wearing it inside the home and, Danielle suggests, he loses confidence (line 191).

Andy's goes on to suggest further meaning that is endowed in the helmet, through its production of previously unimagined subjectivities, when positioning Danielle as intimate carer for Andy:

193 **Andy:** Danielle had to help me in the bath and stuff, because I was weak and I couldn't
194 afford to fall over. I had the helmet and stuff, but I took it off before I got in the bath.

Here, Andy tells a story in which he is vulnerable: "I was weak" (line 193), even "reduced to the object of body work" (Twigg et al., 2011, p. 215) in requiring his Danielle's help bathing. He foregrounds the helmet, whose materiality seems to exert a performative force, producing "the effect of boundary, fixity" (Butler, 1993, p. 9) between vulnerable Andy and his stronger, more confident self. Danielle continues her account of their home life in these months between Andy's initial discharge from the trauma centre and his later re-admission for the cranioplasty (surgical repair of his skull defect with the titanium plate):

195 **Danielle:** That is another thing we haven't mentioned: Titan [their dog]. If it weren't for
196 him, you said he was...
197 **Andy:** I had two rocks, him and my partner, to keep me going. I didn't walk him for about
198 four months. My partner used to take him, 'cos I didn't have the strength in me. He is
199 quite a strong dog, he pulls. And I was worried, 'cos I had my helmet on, I was worried he
200 would pull, and I would fall. After that, I started to do it again. Bit of fitness for me, to walk
201 him twice a day.

Andy highlights everyday embodiment (habits of the body) between himself and Titan - disrupted during the four months while Andy had to wear the helmet when going outdoors, and then reinstated when Andy reclaims a desired sense of self that is no longer bounded by the helmet. The story about Titan is marked out as an important shared resource by Danielle, as she introduces it saying, "That is another thing we haven't mentioned" (line 195). Andy positions Titan as "a strong dog" (line 199) in contrast with the vulnerability of himself as a character in telling of the months when he had the helmet, a time when "I didn't have the strength in me" (line 198). Instead of the dog, Andy positions himself as the dependant one. However, these valued stories - concerning shifts between Andy, Titan and Danielle - constitute the reiterations of kinship that keep him going (line 197), even when shared daily practices are disrupted by the need to wear a helmet.

Versions of the self

Chloe was holidaying with her friends from sixth form when she fell from a lakeside jetty, banging her head on a rock. Her admission to intensive care was followed by treatment on a neurosurgical ward, before her transfer to an inpatient neurorehabilitation unit. By the time of the first interview, she was living back at home with her parents and returning to her studies in Arts and Drama. Chloe, her father Aaron and her mother Maria describe family life since Chloe's discharge:

202 **Aaron:** Having been through the hospital, I think you came out with less inhibitions about
203 yourself, and you were quite relaxed about yourself
204 **Maria:** That's true
205 **Aaron:** And you almost had a strong self-confidence. It was almost like there was nothing
206 much more that was going to phase you, really
207 **Chloe:** It definitely puts, it shifts perspective, I guess, and um, yeah, I kind of feel like I
208 came out with that as well. And it does, when you go through something that, er, shocking,

209 or, there are little things that seem like such a big deal, especially in sixth form, you know,
 210 there is lots going on between friendship groups. And I think that sort of lost its
 211 importance in my head, once I had sort of gone through that. I definitely viewed people
 212 more, not viewed people more critically, but felt I could have more understanding, of why
 213 people acted the way they did, or, I don't know
 214 **Petra:** A different perspective?
 215 **Chloe:** Yeah, definitely had a different perspective. Not necessarily one that shifted who I
 216 was friends with, or what I did, but it just gave me a different insight into, just life really
 217 **Maria:** So, when did you, um, the other thing you talked about is that you've started to
 218 feel more under pressure, in a way that you hadn't before?
 219 **Chloe:** Yeah, I think that I noticed it more this year, in terms of the work that we had to
 220 do, and it was, you know, I was definitely more aware of it, but I definitely had, my
 221 confidence had been more knocked in terms of my work than it ever had been straight
 222 after my accident. Because then, there was that confidence thing.

Aaron positions Chloe in an active position, saying she “had a strong self-confidence” following the accident (line 205). This acts against a dominant healthcare narrative during her admission, in which the family were informed of “a bleak outlook”. Chloe was at a stage of transition from sixth form to university, and from living with her parents to living independently, at the time of her injury; a phase of young adulthood commonly seen as a time of change, associated with expectations that “disruption to a sense of self and life-context that is already somewhat fragile may be all the more devastating” (Saunders, 2017, p. 12). By contrast, Chloe elaborates that she has identified an ability to form different insights to those of her peers (line 211), presenting a positive component of coping with change while maintaining a sense of consistency, for example “not changing who I was friends with” (line 216).

Chloe's mother, Maria, alters the course of the discussion between Aaron and Chloe (line 217). Maria again brings Chloe's self-confidence to the fore, but now inserts a question that opens up considerations of potentially negative impacts on her confidence (line 217). Throughout our discussions, Maria frequently positions herself as ‘interviewer’, asking Chloe questions or prompting areas she might expand on, illustrated as she uses the narrative scaffold: “the other thing you talked about is...” (line 217). In addition, this opening, created by Maria, exposes the conditionality of my ‘researcher’ role, shifting the dynamics of our relational positions. Here, I became an observer to shifting family “narrative environment” (Hydén, 2017, p. 116), in which Maria appears to nuance an

established family narrative that positions Chloe as someone who is “confident” and “relaxed”. Instead, Maria tentatively questions the limits of this shared narrative, introducing the prompt that Chloe has been feeling “more under pressure” (line 218). Avoiding a direct contradiction with a narrative that Chloe is someone who has started to appear less confident, she attempts to frame this assertion collaboratively. This allows Chloe to reflect herself that, indeed, her high level of “confidence had been more knocked” (lines 221). In such moments, subtle shifts – rather than rupture – iteratively occur in the family narrative, through which Maria seeks insights into sources of trouble arising, which have not been explicitly shared in our discussion. These shifts perhaps accommodate her own uncertainties ‘as a parent’, as suggested by her later comment, “We were given quite specific advice from the Neuropsychologist...about Chloe not going back to sixth form when she did. I felt irresponsible as a parent”.

During the second interview, Chloe talks openly about her feelings of anxiety, for example, saying “I kept looping back to, ‘Have I permanently damaged my brain [by returning to study too soon]?’”. She describes steps she is taking to manage her anxiety and her return to study. She continues her earlier storyline of seeing her situation differently from typical worries of her peers and goes on to describe a critical opening in how she views her situation, when supporting her friend Lola in her struggles with anxiety:

Six months later...

223 **Chloe:** I think in terms of anxiety or depression or mental health, it’s about being able to,
224 in the way that me and Lola have been giving each other advice, and knowing that we
225 should give it to ourselves.

Chloe expands this line of thinking by talking about ways that acting (in plays) enables her to gain “different insights” (line 15), echoing her earlier positioning of difference from peers, in appreciating broader perspectives about sixth form troubles that are “just life, really” (line 15).

226 **Chloe:** I think it is, you know, that benefit of stepping outside yourself for a bit and seeing
227 it from someone else’s perspective or being someone else. Um, I think it can be just really
228 useful and at the same time, in building confidence, and um, at the same time just having
229 fun as well, making it seem less, er, you know, medicated, or less sort of, I don’t know.

Her narrative line of looking at her situation through a different lens from her peers is a useful device for Chloe in “building confidence” (line 228) and also suggests her desire to distance herself from a dominant clinical and “medicated” (line 229) framing of her emotions. Instead, she stories the building of her confidence through ways she is able to “step outside herself”, in relation to peers’ struggles and not be “left behind” in the social world a young adult (Harries et al., 2019, p. 10). She resets the family’s version of Chloe as someone who will be “confident” - even in the face of the family’s uncertainty. She incorporates the fragility exposed by Maria (line 216) while positioning herself as someone who is still able to “just have fun as well.” (line 217).

Brenda and Derek had moved to warden-controlled accommodation eight years before Brenda’s injury. They had been managing everyday activities without external help, though each had been experiencing mobility difficulties due to arthritis. They were both still driving, but Derek had sold his own car some years previously, following his retirement. Brenda had been driving them both in her car for short trips locally, until Brenda fell while they were at the shopping centre, banging her head on the concrete floor. She was admitted to the trauma centre and then transferred for inpatient rehabilitation in a specialist unit. At the time of the first interview, Brenda’s car was still parked outside their ground floor flat, visible from her armchair through the window in the living room. By the time of my second visit, eight months later, Brenda’s car had been sold, following medical advice that she should not return to driving after her injury. Over the course of our two discussions, Brenda and Derek return to talk about their cars and about driving.

230 **Derek:** Her biggest sorrow, though, is losing her car

231 **Brenda:** Well, I think I’m going to lose it but it’s not definite yet

232 **Derek:** It’s stuck out there. We can’t move it, because the battery is flat. I can drive but I
233 haven’t got a car now, we didn’t want two. We got rid of the big one and we kept the little
234 one, just to run about in. But now this has happened, we can’t do that.

Eight months later...

235 **Petra:** So, you were saying the car has gone now?

236 **Brenda:** Yes, isn’t that terrible? I didn’t expect really, not to drive. I thought once I got
237 better, I would drive. But even looking out there, I always see the car standing there. Even
238 now, when I open the blinds in the mornings, my first instinct is the car. And of course, it
239 has gone. Then I think, “Oh, you silly woman!”

240 **Petra:** You’re so used to seeing it there

241 **Derek:** The thing is, Tetra [*sic*], it was like protection to her, when she saw her car there,
 242 that was it. Now she can see an open gate and anyone can come in straight to our door
 243 and break in. That's what she is thinking.
 244 **Petra:** Oh, you think it's...
 245 **Derek:** Yes, it's so open now. It wasn't with our car standing there
 246 **Brenda:** I do miss it
 247 **Derek:** 'Cos mine used to stand there as well, and I had a big merc, didn't I
 248 **Brenda:** Mmm
 249 **Derek:** So, that used to stand there and give her a little satisfaction. Mine went first,
 250 because I worked abroad for a few years and it was just standing there, wasting away. And
 251 it was a lovely car, beautiful car.

[Derek leaves the room to make tea; Brenda continues]

252 **Brenda:** I miss that car more than I realised, now it has gone. Still, never mind, what can
 253 you do? Things alter, don't they?
 254 **Petra:** You had a lot of good times with that car?
 255 **Brenda:** Yeah, it was wonderful. I just used to jump in and drive, clear off to the coast or
 256 clear off somewhere else. All that has gone. Perhaps it would have gone anyway, 'cos I am
 257 getting older.

Derek positions Brenda as passive and vulnerable, in his portrayal of her car as a physical barrier, "like protection to her" (line 241). Brenda appears to adhere to his narrative scaffold, initially deploying a co-construction strategy of compliance by simply saying "I do miss it" (line 246). However, she subsequently shifts to a more agentic position when he leaves the room, exposing apparently suppressed resistance to his account. With Derek gone, her pleasure erupts as she tells me of her thrill in driving for its own sake, as she recollects, "I just used to jump in and drive" (line 255). In place of the subordinate passenger, Brenda takes pleasure in telling her story of her liberty to "clear off to the coast" (line 255). She brings forward a subversive challenge to the masculine notion of driving and Derek's framing of the car as static protection, a physical blockade. Instead, she uses driving to symbolise independence and choice (Charmaz, 1983). Her shift, with Derek out of earshot, suggests at least ambiguity about the shared construction of their relationship with (and through) cars.

In the second interview, Derek introduces a story suggestive of further shifts in their shared lifestyle as a couple:

258 **Derek:** She has conveniently forgotten a woman's job in life, laundry and washing-up,
 259 which has done her a favour actually, because now it is up to me to do washing and cooking
 260 **Brenda:** Well, I think I have taken on a, a part of me just doesn't work the same way as it
 261 did [*laughs*]
 262 **Derek:** Well, certainly not
 263 **Brenda:** Still, never mind. I'm better than I was.
 264 **Petra:** So, with the washing and things...
 265 **Brenda:** Oh, Derek does that. I'll wash a top myself if I want it for a couple of days' time,
 266 but I can't seem to take on anything big. I can immediately feel myself sort of withdrawing.
 267 **Petra:** Why do you think that is?
 268 **Brenda:** I don't know. I've never had it explained to me. Because, I always did all the
 269 laundry, and all the ironing, ironed all his shirts and everything.
 270 **Derek:** [*Talking at same time, inaudible*]
 271 **Brenda:** I never iron a shirt now
 272 **Derek:** I hate ironing. Do you like ironing?
 273 **Petra:** I hate ironing [*laughs*]
 274 **Derek:** Oh, 'cos I've got a couple of shirts [*laughs*]. I'm trying to pass it on!
 275 **Brenda:** Well, we do get by, sometimes it is a bit muddly. I was sort of so efficient, even if
 276 I say it myself, when I did all that. And I went to work as well, didn't I.

Derek explicitly presents gendered norms in remarking on “a woman's job in life, laundry and washing-up” (line 258), explaining that he now does this this gendered work and framing this as a convenience for Brenda (line 259). He positions himself as someone who ‘knows what is really going on’ in his interpretation of Brenda's withdrawal from tasks, which now comprise his work of caregiving, yet are “intimately bound with female identity” (Ribeiro et al., 2007, p. 303). When Derek asks me, “Do you like ironing?” (line 270), he again invokes the idea of “a woman's job in life”, further exerting symbolic violence, where “the other is dehumanised or rendered deferential” (Brady and Schirato, 2010, p. 141). His words exert a power that disrupts the research interview by exposing taken-for-granted identity distinctions. ‘Saving face’ - my credibility as a researcher and guest in their home - I find myself colluding with rather than challenging this narrative trajectory, in my apparently compliant echoing of Derek's words: “I hate ironing” (lines 272 and 273).

There were other times during my visits that I felt aware of Derek's intrusive control. He sought to choreograph the interview situation in alignment with his dominant (gendered) scaffolding of narration. He insisted on taking my bag away to another room, organising our seating arrangements and, after pausing for a tea break, suggesting I move from the couch, next to Brenda, to a seat closer to his armchair. These interventions disrupted the practicalities that enabled Brenda and myself to speak together. Additionally, he opened up a line of personal questioning of me; for example, questions about marital status. In my accompanying field notes from this visit, however, I noted that "Derek was having trouble getting up from his low armchair". This embodied reality contrasted with his attempts to narratively – and literally – position himself as having the power in the interview triangle. Morrison and Macleod similarly observed "certain gendered behaviours...for instance, men's tendency to challenge a female interviewer in various ways like asking her personal questions...These strategies served to shift the balance of power towards the male participant" (Morrison and Macleod, 2014, p. 705).

Brenda challenges Derek's assertions with the closing line that she "went to work as well" (line 276). She reveals this shift that had occurred many years before, away from Derek's expectation of "a woman's job in life" (line 258); that is, that a woman stays at home (Wetherell et al., 2001). Derek's portrayal of gendered roles, told through stories of driving and housework, are in the context of his own physical decline and multiple shifts in his idealised self where his wife had been going out to work, though he downplays this in his talk of a woman's job in the home. Derek avoids a positioning of self as 'the other' who is getting older, becoming physically frail, and struggling to stand from his chair. He is 'trying out' new draft versions of self, now navigating unfamiliar identity as Brenda's carer; himself doing "a woman's job". He sustains a masculine identity, and power over the relationship, while renegotiating "what it means to be an old man in a 'woman's domain'" of caregiving (Ribeiro et al., 2007, p. 311). In turn, complying through a submissive positioning may offer Brenda legitimisation of (a degree) of dependency on Derek-as-carer (Jolanki, 2009).

After Derek leaves the flat to attend a General Practitioner appointment, Brenda returns to talk about the positioning by Derek that she no longer fulfils a woman's job in life:

- 277 **Brenda:** Going back to when you said about how did we manage and that. Well, with food,
 278 you did know we have a restaurant upstairs, do you?
 279 **Petra:** No, I didn't know about that

280 **Brenda:** Well, it's on the floor that you come in, the third floor. You can get a meal there
 281 every day. You get a menu so you can choose, if there is something that you don't like. If I
 282 don't like it, then I'll have an omelette. And we've started doing that more often than we
 283 did before. When I first came back [from hospital], we tried to still stay in our own place
 284 here to eat, but it got very tiring. Every time I had a bad patch, he'd get, well not irritated,
 285 but he'd want to sort of take over. And if you're a woman and you've always run a house,
 286 um, well it's ever so hard to drop back

287 **Petra:** So, are there things you're doing differently now?

288 **Brenda:** Well, I like going up to lunch or dinner now. We see different people, sometimes
 289 sit with the same couple, sometimes other people who that haven't seen before, and then
 290 you get to know somebody else

291 **Petra:** It sounds like you enjoy that?

292 **Brenda:** Oh yeah. I like people. I like to hear their life stories, things like that. Once they
 293 said to me, "How did you get to know that lady, Brenda?" And I said, well I saw her sitting
 294 all alone in the lounge, so I went in and started talking to her. And we went off from there.
 295 And I said, "Yes, she's a very pleasant lady, I'm sure she will fit in nicely". And sure enough,
 296 she has. But yes, I like speaking to people.

Brenda demonstrates recognition of norms that structure Derek's accounts, saying "if you're a woman and you've always run a house" (line 285), while positioning herself as the one who has been in control of the house. In response to Derek's actions to "take over" (line 285) in cooking their meals, Brenda describes a shift to using the restaurant in their sheltered accommodation more frequently. Being with others who live in the neighbouring flats, hearing "their life stories" (line 292) and "speaking to people" (line 296) bring advantages for Brenda, through which she presents her social skills. She shares a story of her approach to a newcomer and, "sure enough", she was correct in her assessment that this lady "will fit in nicely" with their friendship group (line 295-296).

Narrative co-construction between Derek and Brenda presents a "complexity which is not easily named" (Butler, 1997, p. 35). In parts of their shared storytelling Brenda complies with his presentation of problems, where she will "drop back" and "feel myself sort of withdrawing" (line 266). At other times, she conveys that it is "ever so hard to drop back" (line 286) and appears to resist positioning as a passive character in their shared stories. My own emotional response to being within this narrative environment involved a feeling of identification with the Brenda that Derek overlooked. I desired to enter the interactional space where she narrated the things she values; recollects humorous

interactions with her former colleagues; and elaborates on stories such as her thrill in driving down fast roads and country lanes to “clear off to the coast”. In this space, Brenda brings to the fore a continuity in her sense of self, such as when making friends, or through her close relationship with her sister. She demonstrates iterations in kinship bonds maintained through narratives that are constructed away from Derek, while continuing to comply with the norms of expectation in their life project of the last forty years together – collaborative scaffolds of meaning-making that precede Brenda’s injury and Derek’s increasing physical fragility.

Although Walter (introduced earlier, line 90) had retired from teaching at the time of his fall down stairs, he continued to work on a part time basis. Ruby described Walter to be “the head of the family who did everything”, saying “I didn’t get involved in hardly anything”. Talking of their daily life together since Walter’s return home from hospital, Ruby shares a story of Walter’s allotment:

297 **Ruby:** When Walter says he’s got nothing to do almost every day, I try and make time to
298 take him up the allotment, but he will tell me he doesn’t want to go. And then in the next
299 breath, because that happened on Wednesday when I took him to the doctor; the day
300 before I said to him, ‘Right, get your stuff together I’ll take you up the allotment’. ‘No, I
301 don’t want to go’. I pleaded with him but, ‘No, I don’t want to go’. Then, the next morning
302 he went to the doctor and said, ‘I never get up there’.

Ruby infantilises Walter as someone for whom decisions must be made, and as an object of others’ actions: “get your stuff together and I’ll take you” (line 300). Ruby’s positioning of Walter apparently reduces his prospects of being viewed as having an agentive role, where he is entitled to make decisions for himself. Ruby goes on to convey expectations of Walter’s appearance, sharing a story of negotiations with Walter and his formal carer about taking him (as if a child) to have a haircut:

303 **Ruby:** He would get to the stage where his hair so needs cutting and he would just refuse
304 to have it cut. But Jenny [*the carer*] would say, ‘Leave it with me’, and they would go out.
305 And I’d come back and he would have had a haircut [*laughs*]. I mean, it is silly little things
306 like that, she is just so good with him.

By the second interview, Walter had longer hair and had grown a beard and a moustache. Ruby and Walter talk about these personal grooming choices:

Six months later...

- 307 **Walter:** Well, I also haven't shaved off my top lip...
- 308 **Ruby:** [*interjects*] Moustache
- 309 **Walter:** ...properly, because I want to grow that, see whether I can have it sticking over
- 310 the side. It's not that I'm untidy and couldn't care less. It's taking care with it.
- 311 **Petra:** You're working on the length?
- 312 **Walter:** Yes
- 313 **Ruby:** Dear me
- 314 **Walter:** I'm hoping my dreams come true!
- 315 **Ruby:** And it doesn't matter how I feel? Doesn't matter how I feel, at all. I said to him, if
- 316 when I met him he looked like that, I would never have touched him with a barge pole. I
- 317 can't stand it.
- 318 **Walter:** But how would I think, if you had a beard?
- 319 **Ruby:** I won't grow a beard though, so there's nothing to compare there
- 320 **Petra:** What is it about it, that you like?
- 321 **Walter:** Well, it just, it's a natural thing. Because shaving off a beard and a moustache is
- 322 the way of getting rid of it day, by day, by day, by day, by day, by day. And it goes on your
- 323 lifetime. So, it's far better to let it grow, which is the natural thing to do
- 324 **Interviewer:** Okay, so that makes more sense to you
- 325 **Walter:** Well, if it made sense to you, go home and tell your husband!

In sharing stories about Walter's appearance, the emotionality underpinning Ruby and Walter's account is close to the surface. Ruby expressed her exasperation with Walter, and appeared visibly upset at times. Walter would suggest that he would go upstairs to "allow her to continue". In Walter's account of his decision to grow a beard and moustache, he asserts the importance to him of "taking care with it" (line 310). Walter displaces acts that have comprised their married life together, represented by his telling of shaving "day, by day, by day, by day, by day, by day" (line 323), in fulfilment of performative expectations in his marriage and employment. Walter reconfigures an agentive positioning, instead of that of a child where he feels that he is "not allowed to do things I am fit to do" (line 118). However, while an expression of agency, the act of not shaving jars with Ruby's performative expectations of their life together. So much so, she goes on to state: "I don't recognise him".

Walter resolutely foregrounds his embodied adulthood, defying infantilisation and the “dichotomy between dependence and independence” that underpins it (Weicht, 2010, p. 212). Further, Walter resignifies the ‘researcher-participant’ relationship, which I have ‘fixed’ as the researcher bringing an unquestioned right to question the participant who is constrained in response (Law, 2016). Instead, Walter’s hail to me involves inviting me to consider the merits of – and potentially act upon – his world view: “If it made sense to you, go home and tell your husband!” (line 325).

Relational scaffolding

Mike owns a construction company. He fell from a height while at work and was admitted to the trauma centre before having rehabilitation in a specialist inpatient unit and, after discharge, through the community rehabilitation team. Mike and Donna discuss their adaptations in running the company since his fall, and implications for each other while Mike is not permitted to drive:

326 **Donna:** It’s quite tiring, doing driving as well as all the bits I would normally be doing. He
327 said we need to meet a new customer on Saturday, and I said ‘I don’t work on Saturdays’
328 [*laughs*]. But it is tiring and I think for myself, and Mike, it will be nice, nothing I am
329 waiting for more, than to see him get in the car and get his independence back, as that is
330 really important. For me, it is nearly normal for me, but the driving is the thing that is not
331 normal, so it will be nice to just wave him off in the morning. I could still drive him if he
332 wanted, to start, but I would like the licence to not take too long. I don’t mind driving ‘cos
333 it is just what we do now, you know, I do the driving, and I drive him around but it would
334 be nice not to have to so much, some time. I think we are ready to move onto next phase
335 now, aren’t we?

336 **Mike:** I think Petra can see who gets stressed out at work now!

337 **Donna:** Who is that?

338 **Mike:** You!

339 **Donna:** No, it is just that it is not the norm, is it? But I don’t mind, I accept that, but the
340 day you get your licence back I will have a big smile, ‘cos I know it is what you want. You
341 are desperate for it. We will celebrate that day.

342 **Mike:** I am not stressing. I have seen people in a worse state than me getting their licence
343 back. Someday, I will get my licence back.

In telling the story of ‘swapping roles’ as the driver (Stepney et al., 2018), Donna portrays this to be the thing that is “not the norm” (line 339). However, this narrative moves beyond

the activity of driving, instead demonstrating Donna's positioning of Mike in his valued work identity, to which she could "wave him off in the morning" (line 332). Donna appears to joke about the notion that this is her work as well now as she says, laughing, "I don't work on Saturdays" (line 327). She diminishes the significance of "all the bits I would normally be doing" (line 326). However, Mike then hails Donna as 'co-worker' when he says, "I think Petra can see who gets stressed out at work now!" (line 336). Donna appears surprised (line 337) by Mike's reference to her being "at work", in a shift from the expectations of their marriage that she considers to be "the norm". In describing Mike's return home from hospital, Donna navigates further shifts in their marital norms:

344 **Donna:** Obviously, I was a bit worried. I was watching him like a hawk all the time. A little
345 bit like, "Don't fall, don't". Probably, I worry too much anyway, all the time. But no, it was,
346 yes, you coped really well. For me, as I say, obviously I was just watching everything that
347 he was doing and making sure everything was all right. Fussing, probably [*laughs*]. Fussing
348 too much.

349 **Mike:** Good word, fussing.

350 **Donna:** Fussing too much because yes, I mean I was worried, because he's been in hospital
351 with all these therapists, and nurses, and carers, and everyone sort of protecting him, sort
352 of looking after him. Then all of a sudden, it's me. So, yes, I was fussing, probably a bit too
353 much.

354 But as I said before, we are, we just, head up, shoulders back and we get on with it, don't
355 we? That's how we are really, all of us, you know. One day at a time and you just have to
356 deal with what's put in front of you. We coped really well, didn't we?

357 **Mike:** I think so, yes. I do.

358 **Donna:** We don't look at the past. As I say, the past is the past. There's nothing you can
359 do or say that will change what's happened. Mike had his accident. We got over that, didn't
360 we, because at the end of the day it happened, there's no point keep going over it, we can't
361 change it, so then we just literally get on with today and tomorrow, don't we?

362 **Mike:** Yes, absolutely.

Tension arises for Donna as she shares concern that "all of a sudden, it's me" (line 352), and "watching him like a hawk" (line 344) may seem like fussing, in Mike's view. Mike navigates his agreement while avoiding also criticism, saying, "Good word, fussing" (line 349). Describing how she was watching everything he was doing, Donna risks positioning Mike as someone who needs to be looked after, potentially challenging normative expectations of husband and wife. Donna instead moves to a shared understanding of their

established ways of coping, replacing her positioning as the one who worries “too much”. Instead, she brings forward a sense of collective family contribution, saying that together they “just get on with it” (line 361), in cohesion with their three children here also, “that’s how we are really, all of us” (line 355). In the second interview, Mike tells a story that appears to be a resource for him in scaffolding this family narrative environment of coping:

- 363 **Mike:** I remember Father John, our priest, when we had had a couple of deaths in the
 364 family. Within four months, four people. And I asked him, ‘Is this normal?’, and he went,
 365 ‘Mike, this only happens to the strongest people, life is just a test, you are just being tested
 366 at the moment’. I thought, ‘Well, this is interesting’, and I have always thought of it like
 367 that. And now, a few years later, or six years later, we got tested again, didn’t we?
 368 **Donna:** Mmm-hmmm
 369 **Mike:** And that is honestly how I see it.

Mike marks this out as a significant story-telling moment, which he commences with “I remember” (line 363). He positions himself as an actor from the perspective of his priest, as one of “the strongest people” (line 365). He makes relevant his ability, as assessed by a valued other, to manage in conditions that are beyond “normal” for most people. He brings off a positioning of strength when “being tested” and emphasises “that is honestly how I see it” (line 369). The story demonstrates the struggle for shared meaning-making in circumstances where normative expectations have been disrupted, where they each find a way to re-instate the gendered order. Donna reiteratively employs this shared meaning-making, at times when she may be “fussing too much” (line 347), instead reverting to a positioning she seeks to share with Mike, with “head up, shoulders back” (line 354): a move in which she can “express and communicate belonging and identity as a family” (Hydén, 2017, p. 116).

Raminta moved from Latvia to England with her two sons. She was found unconscious after falling down stairs. She underwent emergency neurosurgery and required prolonged care on the intensive care unit. In the first interview, Raminta and her partner, Martin, talk about clinical reviews following her discharge from hospital:

- 370 **Raminta:** I went back to [*the trauma centre*], all the staff, my surgeon, and those who were
 371 working with me in hospital, they asked me if I suicidal. I said ‘I haven’t got time to die’
 372 [*laughs*]. ‘I have no time’. It was mostly psychological stuff, about my moods, ‘How is

373 mood?'. They are making more sure you are in the right position, that it is okay and you
 374 are not going to die soon.
 375 **Petra:** And how did you think your mood was?
 376 **Raminta:** When I left the hospital, or when I got out of the coma, I had wires everywhere.
 377 So, you know, one by one they start taking it away, so I can turn on my side. Then, when
 378 I started thinking about it, I started to appreciate my life more

Raminta returns to the story about being asked if she felt suicidal, during the second interview:

Six months later...

379 **Raminta:** After surgery and discharge, they looked at me every month, three months and
 380 six and the thing they would ask was about my suicide [*laughs*], which I have no time to
 381 die here [*laughs*].
 382 **Petra:** They asked if you had thought about that?
 383 **Raminta:** Yeh, makes me feel I have no time to die
 384 **Martin:** You was more surprised than anything, weren't you?
 385 **Raminta:** Maybe some other people when they have some nick off the brain, maybe they
 386 go funny or mad, I don't know, but I have no time for dying, too busy really.

In each telling, Raminta contrasts the clinicians' questions about suicidal thoughts, with a portrayal of the fullness of her life: "I have no time to die" (lines 371, 381, 383, 386). She brings to the fore how much she has to do, while positioning at other times 'as a mother' of two sons (who are soon to move out of the home), 'as a partner' to Martin (who lives separately from her), and 'as an accountant' (who has been unable to work in this role since moving to England). Martin endorses that a wish to die was out of the question for Raminta, saying "You was more surprised than anything" (line 384). Through her story about clinicians' questions about suicide, Raminta brings off a sense of stability in the fragile life that she "started to appreciate...more" (line 378). Raminta also resignifies the clinician's hail to 'a person with brain injury', 'who may wish to die', limiting the brain-as-self discourse by instead using minimising talking of "some nick off the brain" (line 385).

Raminta positions herself in a similar way in each telling of the "no time to die" story, but when telling of her return to the hospital ward where she was treated, she uses the resource of the story in contrasting ways each time; firstly when Andy is not in the room and, the second time, when he is. In the first interview, Raminta describes:

387 **Raminta:** I know they called me a miracle that I survived. Even when I came for the check-
 388 ups later, the nurses in the ward all ignored me, don't remember me. I remember their
 389 faces, but they say, 'Hello?' [*laughs*]
 390 **Petra:** How was it, to hear that?
 391 **Raminta:** Well, my cousin's wife said, 'Go and buy a lottery ticket!' [*laughs*]

Six months later...

392 **Martin:** Everything went fine in her care, care was fantastic. Great hospital that is, no
 393 complaints whatsoever
 394 **Raminta:** We went to see the team and still the nurses recognised me on the corridor,
 395 even though I don't recognise them. I forgot a lot of things. The people in the room would
 396 remind me that Andy was coming every day, 'cos I couldn't remember
 397 **Martin:** Yeh, but all your memory is coming back now, isn't it
 398 **Raminta:** Yeah, but my son said, "Well you forgot my name, why didn't you forget to stop
 399 smoking?!"
 400 **Martin:** Well, she couldn't remember anything

Raminta tells the story about returning to the ward, firstly bringing to the fore that she remembered the nurses but they did not recognise her (line 388). During the second telling, she reverses the plot as she is the one who could not remember, and here the nurses did recognise her (line 395). Concerns about the 'real' events, who was recognised by whom, whether or not this was the same occasion, whether memory impairment is behind the discrepancies, may ensnare her stories if told in a clinical interaction that has hailed 'a person with brain injury'. Instead, the story becomes part of a relational activity for Raminta, in which the 'actual events' or 'reliability' of her memory are beside the point. She has become a character in her own story, in the former case exceeding expectations of recovery to the extent that the nurses "called me a miracle" (line 387). In her later telling, when Andy is present, she does not recognise the nurses and brings an additional storying element about "Andy coming everyday" (line 396) while she was in hospital, though stresses that she had needing reminding of this by others on the ward. Talk of her memory loss is then supported by Andy's positive response about it "all coming back now" (line 397). Raminta closes by jokingly sharing a comment from her son about her memory and her smoking (line 399). She demonstrates interpersonal significance of this story as a resource that positions Raminta as one who is valued in her relationships: this is no time to die.

Talking of clinical follow-up appointments, Claire (introduced earlier, with her sister Rachel), describes her sense of interactions with professionals in a way that suggests she is offering advice for their development, beyond their interaction with her:

401 **Claire:** Some discussions with health care professionals are all about the medical
402 terminology and it is not about the individual sat in front of you, who may not know the
403 medical terminology you are using, may just be agreeing with the diagnosis and symptoms
404 and whatever. Just get them to have an opportunity to have, I guess, a personal platform
405 with you. It doesn't mean saying you will sit there and listen all day, but "Is there anything
406 you want to discuss, or me to explain? Anything, rather than it be solely medical, 'You've
407 got that, that is going to be like that, you are going to get these drugs, and it can have
408 these side effects, but that will be all right'.
409 It makes you feel like they lack understanding or they lack empathy. Particularly because
410 it is a brain injury, you don't know what their experience is, you can't know, so do give the
411 opportunity to say what they have come across. In turn, that will help those people be
412 more educated, or have more knowledge.

Claire portrays a sense of distancing by healthcare professionals, who fail to connect with "the person sat in front of [them]" (line 402). She asserts her preference for an interaction with more opportunity to talk, to establish a "personal platform" (line 404). She indicates that this would, in turn, help professionals to "be more educated or have more knowledge" (line 412), highlighting a missing component in professionals' education and knowledge. The "voice of medicine" (Mishler, 1984, p. 95) instead scaffolds these clinical interactions: a script for professionals that is marked out by diagnoses, symptoms, terminology, medication, side effects, "and whatever" (line 404).

Claire's and Raminta's accounts each suggest lack of opportunity for establishing connection, sharing understandings or co-constructing narrative scaffolds in interactions with healthcare professionals. In stories of such interactions since his injury, Toby conveys active disruption to sense of self. Toby was a passenger in a car that was hit by another vehicle. Following discharge from the trauma centre, he returned to live in his parents' home for a year and then attempted a return to university, studying Chemistry as an undergraduate. During the first interview, Toby perceives standardised assessments administered by healthcare professionals as unhelpful, in delineating change that

rendered him ‘different’ to his peer group, conflicting with the continuity of self that he strove to maintain (Mäkelä, 2017). Ten months later, he reflects:

413 **Toby:** The best way to see if I am capable is trying. If I can’t do it, I can’t do it. So, the
414 cognitive tests, they do frustrate me, I don’t like going through them. Well, I don’t think I
415 would be too fussed now, but when I first came out of hospital, they were really irritating
416 me. They were coming round here every week or so and giving me these tests, I wouldn’t
417 get any benefit from them, and I was in a lot of pain and discomfort and these people were
418 telling me to remember these random words, and that was frustrating.

His mother, Susan, presents situations in each interview in which a sense of continuity has been supported for Toby in interaction, such as a story about their General Practitioner who “remember[ed] Toby from before, and he remembered Toby was at uni and he, he didn’t remember what science, but he knew he was doing a science, and he talked to Toby as a person”. In the second interview, Susan returns to a story about an assessment by a healthcare professional, who stood out from others:

419 **Susan:** She explained to me, I remember I said to Toby afterwards, she was just talking
420 about Chemistry, and she was pulling off him what he learned in first year, and to me it
421 was gobble-de-gook.
422 And he said, ‘What was that about? That was nothing’.
423 And I said, ‘She was finding out what you knew before and how much you remembered’.
424 He was like ‘Well, that was a waste of time, useless’. You have got no memory of that, have
425 you?
426 **Toby:** No, well, a lot of things are useless in hospital.

Toby continues his positioning of healthcare professionals as “frustrating” and “useless”, in contrast to his own preference to get on and try for himself those tasks he finds relevant and meaningful (line 414). For Susan, the different interactional approach from this particular healthcare professional - more suggestive of building a “personal platform” (as described by Claire, line 404) - appears to be more significant for Susan and a resource that she returns to in talk of Toby’s recovery: “I remember I said to Toby afterwards...” (line 419).

Susan repeatedly positions Toby as someone who has always been academically capable, “a very clever boy”. Her story of this atypical clinical assessment suggests she found

reassurance through an approach that aligned with her own scaffolding of interactions with Toby through promotion of his capabilities, and she carefully contrasts this, in his presence, with the “really irritating” (line 415) standardised assessments that repeatedly distressed Toby and from which he felt he “wouldn’t get any benefit” (line 417).

Ewa moved to England from Romania and has a four-year-old daughter. Her brother shares the house, though she described that doesn’t spend a lot of time there. She was admitted to the trauma centre after being hit by a bus. Here she talks about trouble arising from her interactions with healthcare professionals: during follow-up reviews.

427 **Ewa:** I was seen by a doctor and, er, yeah, he gave me kind of like a test. And he decided
428 that I don’t need any help. I was feeling kind of, also slightly angry, when I saw the test,
429 because it was a few pictures, like it was a kind of test like you would give to a child
430 [*laughs*]. You were supposed to name the animals. Maybe if you gave me that test the next
431 day after I left the hospital, I wouldn’t be able to do that, but well not now, it was about
432 six months after the accident.

433 **Petra:** That made you feel angry?

434 **Ewa:** Yes, I was so ridiculously angry, kind of. But you know, I understand. It was his test,
435 and he asked me a few questions, and that was it. Aha, maybe some physical activity, walk
436 in a straight line, do something, er, yeah, [*proceeding very quietly*] and on the basis of what
437 he saw, he thought that, that I didn’t need anything [*shrugging*], didn’t need any other
438 help.

Beyond a missed opportunity for a personal platform, and beyond disruption to sense of self, Ewa’s talk of these assessments was accompanied by an embodied emotional response. I sensed her feeling insulted, patronised and undervalued in this telling of “a kind of test like you would give to a child” (line 429). She portrayed the gravity of her relational situation, a single-mother in a country that was not her own and with family support inaccessible to her, to be disregarded. The assessment pictures Ewa refers to (“you were supposed to name the animals”; line 430), frequently used in cognitive communication assessment tools, persist as a standardised practice that follows clinical norms (Wongvatunyu and Porter, 2008). They demonstrate a form of “institutional interaction, which differs in systematic ways from everyday conversations” (Myrberg et al., 2018, p. 471). In Ewa’s narration, these assessments have come to exclude any possibility of scaffolding a helpful relationship with clinicians. Instead, they exert a kind of erasure of

her personhood that made her feel personally cast aside and “so ridiculously angry” (line 434).

Ewa’s response is a refusal to the hail ‘to a patient’, which has become, for her, one “that you would give to a child” (line 429). Her subsequent disengagement from healthcare services states, “I will not dignify this with a response” (Butler, 2005, p. 12). The story of oneself is given in response to a “you” who has asked for an account (Butler, 2005, p. 11); Ewa’s silence then questions the legitimacy of the “you” who asks the question, and rejects the clinician-patient relationship. For Ewa, I sensed that I may have been representative of the symbolic violence of healthcare services that she conveys. She became uncontactable after our first interview, for reasons that I was not able to explore with her. However, her act seemed consistent with her silence as the “one queried refus[ing] the one who queries” (Butler, 2005, p. 12). I felt concern over our mutual positioning in this research interview, where ultimately I too was offering nothing other than “a few questions, and that was it” (line 435).

Donna (introduced earlier with her husband, Mike), describes interactions with community neurorehabilitation clinicians, after Mike’s return home. She portrays their requests for the family’s reports of changes in Mike since his injury:

439 **Donna:** We had forms to fill in. A questionnaire thing, like a multiple choice thing, and
440 my daughter had to fill one in and I had to fill one in, and we had to be honest. It was quite
441 hard really, because being honest is not being un-loyal to you. She done it in one room
442 and I done it in another and a couple of our answers were different. I said, “We’ve got to
443 be honest. If we’re not honest, they can’t help Dad”. And I felt like I was sort of being too
444 hard on him. But then, you know, as I say, I had to be honest and I did fill out the
445 questionnaires and that. And that obviously gave the girls [*rehabilitation team therapists*]
446 something to work on, because we were the people to know you more than anybody.

Donna indicates a sense of confrontation from healthcare professionals’ expectations, “we had to be honest” (line 440) in questionnaires seeking ‘standardised’ components of change. Donna alternates between explaining to me, and also reassuring Mike (and herself), that “being honest is not being un-loyal to you” (line 441). She again brings forward the collective family identity, saying, “We were the people to know you more than anybody” (line 446). Donna goes on to develop description of her dilemma further:

447 **Donna:** It's quite hard, because you don't want to highlight some of the changes that we've
 448 noticed in Mike. Yet, if you didn't highlight them, you thought, "Well, then no one can
 449 help him with them", you know. Sometimes I felt bad because I thought, I don't, I feel like
 450 I'm going against him, do you know what I mean? For Mike, he didn't really recognise the
 451 changes, unless we highlighted them and obviously sometimes if he was speaking too
 452 loudly and that I'd be like, shall I tell him? I didn't know whether to highlight it with him
 453 or just let him, it was quite difficult. He's quite accepting of when we highlight things to
 454 you but then, because I didn't want to worry him. Didn't want him to overthink, you know,
 455 so yes. No, it's all gone good hasn't it, really?

456 **Mike:** I think so, yes. I'm glad to be sitting here, telling you about it. I know I'm lucky.

Donna negotiates this telling in Mike's presence, presenting the difficulties she and her daughter had faced in an act that separated them from each other and from Mike (line 442). Her reporting of changes in Mike might help him, but also "feel like I'm going against him" (line 450). In addition, she negotiates whether letting him know of changes, to "highlight it with him", would be the best thing to do, as he "didn't really recognise the changes" himself (line 450-451). Mike does not contribute a specific view to this episode of telling, yet he resolves the tension that circles through Donna's presentation of these dilemmas. He moves her concerns aside as he says, "I'm glad to be sitting here, telling you about it" (line 456).

By the second interview, there is a shift in their shared narrative about changes in Mike's communication:

Six months later...

457 **Donna:** They [*therapists*] were trying to get Mike to maybe talk a bit more quietly, 'cos
 458 you do tend sometimes to talk a bit louder. But then, as I say, he used to do that before,
 459 so whether that is because it has been highlighted now, we are more aware of it

460 **Mike:** Yeah, the turn-taking and talking too much, the girls [*therapists*] turned round and
 461 said, "We don't want to change the way you are". So, they was quite happy with it, weren't
 462 they?

463 **Donna:** Yeah, like I say

464 **Mike:** So, don't take it personally if I butt in today [*laughs*]

Donna now positions her own view separately from the professionals, who brought forward the focus of change. Mike co-constructs the story this time, integrating the

potential discrepancy between clinicians' assessment of changes in his speech, and a narrative that normalises his "louder" speech with Donna's observation that "he used to do that before" (line 458). A shift has occurred from Donna's talk about needing to report on changes she notices in Mike, as otherwise "no one can help him with them" (line 448), to instead an attribution of noticing it as change "because it has been highlighted" by the neurorehabilitation team (line 459). Mike resolves this tension and resignifies the narrative, invoking therapists' endorsement to him in saying, "We don't want to change the way you are" and "They was quite happy with it" (line 461).

Here, change and consistency are working together (Bamberg and Demuth, 2016). This co-construction permits the family to talk, without the dilemma of whether to "highlight" that he is speaking in a way that would be suggestive of change from his pre-TBI self. Donna enacts a form of "*procedural commitment...in the way that joint activities progress*" (Hydén, 2017, p. 121)(italics in original). If Mike had trouble hearing, Donna might be talking more loudly. Instead, with "the turn-taking and talking too much" (line 460), Donna makes an analogous adjustment. She fulfils her procedural commitment to their shared intention, where neither wants to "change" him. Mike reinforces this shift in meaning-making about his speech, by using humour to pre-empt any occurrences of him "butting in" during our discussion (line 464). He includes me in their experience of change as part of the "new normal" (Hydén, 2017, p. 123).

Chloe (introduced earlier, with her parents) talks about assessments and tasks given by community neurorehabilitation clinicians, which "felt like homework and were not enjoyable". Talking about her interests more broadly in the second interview, she shares her recent learning about theatre "that has moved away from traditional text":

465 **Chloe:** The audience technically become part of the performance, because there's no
 466 longer this separation of having a traditional stage and a world that is so separate from the
 467 world the audience are in. There's now sort of like, because the texts have been broken
 468 down and the characters have been broken down, so sometimes the performers aren't even
 469 necessarily named characters, they're just bodies on stage. I think that creates less
 470 separation between performers and the audience because everyone seems to be in
 471 technically the same space and the same world, so it is that interesting thing. Where I
 472 think it is now, it is very much like a tennis match kind of thing where, a performance
 473 obviously is all, predominantly, what is happening on stage, but I do think what makes it
 474 maybe different is how the audience and performers respond to each other.

Chloe's analysis perhaps offers a dramaturgical metaphor for a shift in healthcare (or qualitative interviewing) normative scaffolds of interaction. Instead of 'performers' (clinicians) and 'audience' (patients), Chloe's metaphor reframes us all as "just bodies on stage" (line 469). Here, equality in positioning removes the epistemic privilege that is rehearsed in the 'back region' by performers (clinicians) if there is a shift to a shared normative script in the 'front region' (Goffman, 1959; Joseph, 1990).

In our discussions in the second interview, Chloe's own analysis further disrupts my own 'researcher' performativity by moving us into "technically the same space" (line 471) in thinking with Butler:

- 475 **Chloe:** I've definitely always struggled with distinct differences between, you know,
476 gender norms because I haven't, since I was younger, I was never like a traditionally
477 female-female, if that makes sense. So, I could never quite understand why boys would
478 get certain toys and girls would get...For me, things like that, I just didn't quite get it. Then
479 reading into, it was Judith Butler and theory, queer theory. And it was all about this idea,
480 we make these performative utterances. So, when a baby's born we say it's a boy or it's a
481 girl, and just naturally through their upbringing, we are constantly giving them signs of
482 how we think they should behave, based on how we've been brought up thinking we
483 should behave. I think in terms of how we present ourselves, or how we think of what we
484 should do, or how we interact, is very much like social conditioning, I think.
- 485 **Petra:** So it's this expectation from others about how you're going to behave, and what
486 the interaction will be?
- 487 **Chloe:** Definitely, I think in a sense you can look at any area and say there's a pre-existing
488 expectations of how, what sort of person you should be.

In this moment, Chloe undoes my assumptions about our interaction through her own introduction of Butler's theorising. My "pre-existing expectations" shift and a new scaffold of shared meaning-making becomes visible to me in our intersubjective space: an unpredictable "personal platform".

CHAPTER 7: Discussion

Introduction

My intention in this thesis has been to explore the ways people living with TBI and their significant others construct stories about managing in everyday life, after discharge from hospital. The analysis in Chapter 6 demonstrates negotiations of sense of self within interactions across time points, where people are 'hailed' to identities marked out as 'you are a person with brain injury'. The focus on fleeting moments of interaction has demonstrated how talk about events is used as a resource in navigation of the self 'now' but also 'then', as a character in the telling. Positioning of the self, and by others, recreates versions of the self that resist the hail 'person with brain injury' and resignify meanings that diminish the self 'now' in comparison with 'before'. Navigation of the everyday occurs through reiterations of kinship interactional practices, and versions of the self that are brought to the fore according to constraints (or affordances) of the situation. Finally, talk about encounters with healthcare professionals demonstrates how norms and expectations further position the self as 'changed'. These encounters themselves become storytelling resources, in recrafting a desired sense of self.

Building on these findings, my intention in this chapter is to set out an overarching model, seeking to conceptualise the navigation of sense of self following TBI as a co-constructed achievement. I illustrate the model by drawing on examples from participants' talk, shared in Chapter 6. I contextualise these findings within the literature on biographical disruption (Bury, 1982), loss of self (Charmaz, 1983; Nochi, 1998), and narrative reconstruction (Gareth Williams, 1984) that I introduced in Chapter 2. I then consider the potential applicability of this model for thinking about clinical interactions that intend support for self-management for people following TBI. Further, I argue that the model holds potential for application in thinking about support for self-management for people living with long term conditions more broadly, thereby challenging the "seemingly unanimous discourses and practices" of the dominant, biomedical focus of supported self-management, introduced in Chapter 2 (Taguchi and Palmer, 2013, p. 672). I consider how the normative scaffolding of clinical interaction may itself be co-constitutive in a sense of *disrupted* self,

and explore how the model presented in this chapter may inform alternative constructions.

Toward a conceptual model

In this section, I consider how participants are dealing with experiences following TBI through their everyday processes of talk-in-interaction. I bring together theoretical insights from the analytic framework I described in Chapter 5: (1) Bamberg's positioning, as outlined in Table 4 (Bamberg, 1997); and (2) the constructs of normativity, citationality (introducing something different through repetition), and signification, from Butler's work on performativity (Butler, 1999). I consider a series of shifts in version-making of the self, through an application of the concept of scaffolding in interaction between conversation participants (Hydén, 2017, 2011).

When used in developmental psychology, scaffolding describes mechanisms through which 'experts' support 'novices' to perform actions on their own to "achieve a goal which would be beyond [their] unassisted efforts" (Wood et al., 1976, p. 90). Similarly, the term social scaffolding has been applied to the practicalities of social support (e.g., from family, friends) after TBI: "like scaffolding around them, propping them up" (Snell et al., 2017, p. 21). When applied to storytelling, the metaphor of scaffolding moves away from this original context of instruction - one person supporting another - and instead conveys a sense of productive "*mutual support*" (Hydén, 2017, p. 125) (*italics in original*). For example, when considering interaction between couples where one partner is living with dementia, the concept of scaffolding becomes a mutually dependent practice of collaboration in the creation of shared meaning and in sustaining storytelling as a shared activity between the couple (Hydén, 2017).

The understanding of narrative scaffolding as a mutual activity suggests that coherence is not an objective feature of storytelling, but instead is something that is jointly produced in the interaction. The implication, then, is that such narrative scaffolding may act to enhance or challenge coherence (Hyvärinen, 2010). The collaboration may encompass many practices that perhaps intend support, and yet intentions and experiences of such support do not necessarily coincide. For example, assistance may become undesirable for someone who perceives that they have capabilities to remain independent without this assistance, which then instead becomes interference. Alternatively, narratives of independence might be reframed within (or despite) the assistance that is received from

others.

The conceptual model I present below derives from talk-in-interaction with people living with TBI and their significant others (presented in Chapter 6), analysed through the theoretical constructs that I outlined in Chapter 5. My intention is to derive a broader understanding of processes of self-crafting, where the self is “that which keeps on telling and retelling, putting the pieces together in slightly different patterns and occasionally generating what seems like a new pattern” (Frank, 2018, p. 115). I build a model of self-crafting in talk-in-interaction, underpinned by the concept of narrative scaffolding as a mutual activity (Hydén, 2017, 2011).

In my application of the narrative scaffolding concept, my focus is not on a “renegotiation of the division of interactional work”, as conceived when a person without cognitive impairment assumes more responsibility for organising the interaction (for example, setting up narrative tasks such that a person with cognitive impairment can take part) (Hydén, 2017, p. 125). Instead, I consider the negotiation of mutual positions through scaffolds of meaning-making. Bamberg’s domains of positioning analysis (2004a, 1997) (Table 4, Chapter 5) provide an expansion of types of challenge to sense of self, through narratives of difference between the self and the other, change in the self across time, and the self as an active agent in relation to the world or passive recipient. I am interested in exploring ways that stories are mutually ‘scaffolded’ despite tensions between versions of oneself, interacting with versions of others, and being positioned *as the other*.

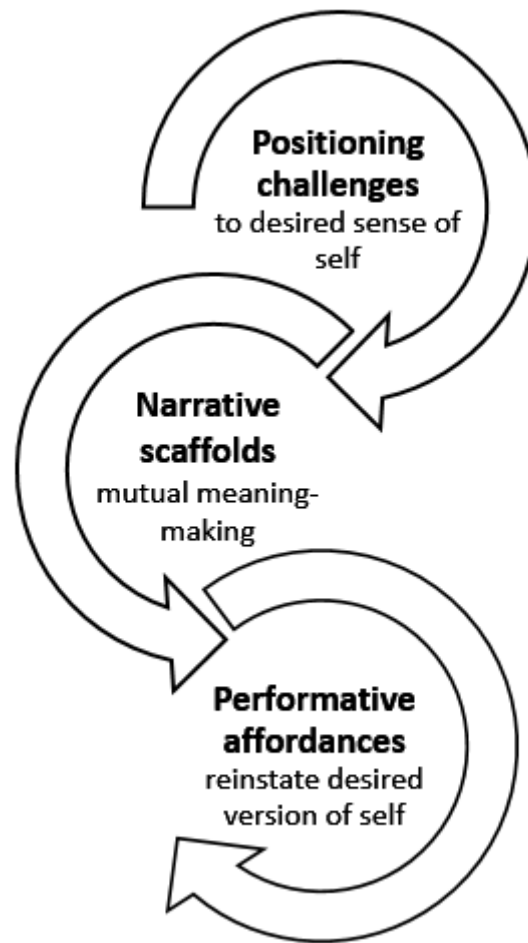
The project of selfhood - “the desire to persist in one’s own social being” (Butler, 2005, p. 44) - becomes challenged by conventions, when normative expectations become visible and “silence the question of who counts as a ‘who’” (Butler, 2009, p. 163). Forms of performative affordances that constitute the self can variably overcome - or further embed - the varied challenges to positioning of the desired self. As identification with normative limits is not fixed (Butler, 1990), performative affordances can be derived from “revisable criteria of intelligibility” (Butler, 1993, p. 14). In this understanding, conditions arise for agency at times when our lives are constrained.

In this study, constraint arises in the interpellation ‘a person with brain injury’; and, I argue, also in other interpellations to subject positions, including the hail to ‘a clinician’. Norms are consolidated or change through reiterations (Butler, 1999). If norms are consolidated in interaction, then scaffolds have served to re-affirm or reproduce prevailing

norms. However, Butler proposes that version-making of the self occurs through “a series of shifts” within fragile norms that are transformable (Butler, 2009, p. 169). My intention is to apply this concept within the model of narrative scaffolding, enabling versions of self-crafting when presented with challenges of positioning by others (for example, when change is implied by families or within healthcare encounters).

I propose narrative scaffolding that is (re)constructed as positioning of the self (that is constraining or enabling) interacts with performativity (expectations of constancy or space for change), thereby modulating agency to reinstate a desired sense of self. I demonstrate these key interacting components in Figure 4.

Figure 4 - Narrative scaffolding of positioning challenges & performative affordances



Source: Author

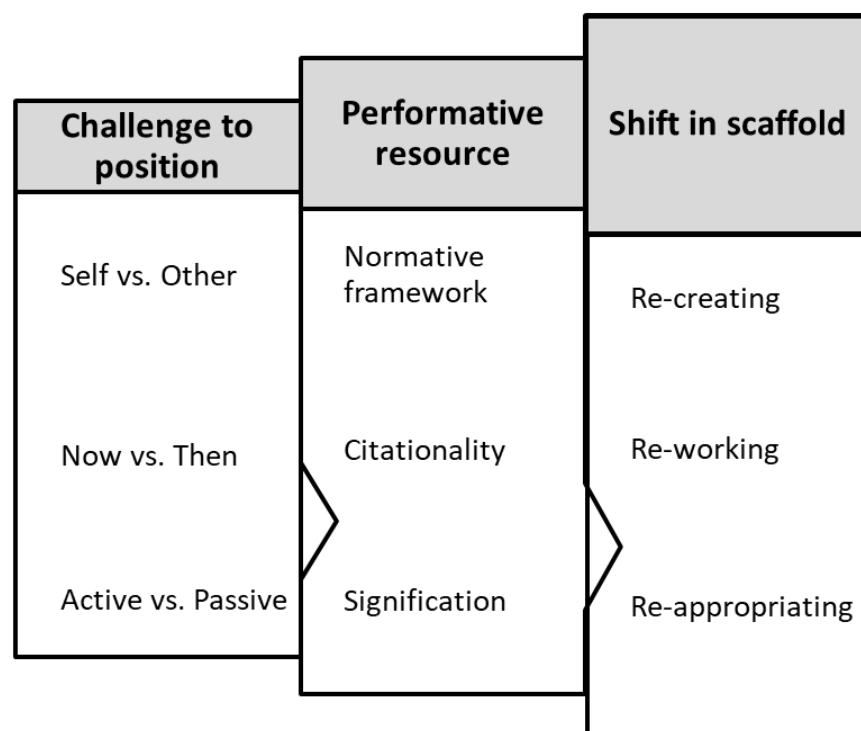
A typology of narrative scaffolds

To further consider the relationship between positioning challenges and performative affordances, through narrative scaffolding (Figure 4, above), I proceed by considering a typology that is generated through application of the respective theoretical constructs, shown in Figure 5 (below). I present these types as a way of thinking with the interlinked concepts and longitudinal data, but my intention is not to propose that these types are rigid and discrete.

Positioning challenges to sense of self may arise at the level of difference between the self and others, according to others' normative expectations. A scaffold might shift meaning

making through *re-creating* a normative expectation, which then aligns with a desired sense of self. Secondly, a positioning challenge may arise at the level of difference in the self over time (for example when positioning diminishes the self ‘now’ compared with ‘then’, through the hail to ‘a person with brain injury’ who has ‘changed’). Here, re-iterations of what has gone before - citations that are not exactly the same each time - allow narrative scaffolding that *re-works* the meaning of talk that contains the implied change over time. Finally, the desired self may be challenged through positioning as passive in relation to the world (Bamberg, 2004a). This positioning relies upon the significance, or signification, of talk that renders a character into the position of ‘victim’. Narrative scaffolds that *re-appropriate* the significance of meanings (take ownership of them) allow a re-alignment to prioritised values for the desired self, enabling a claim for a significance as an active agent in the story. The narrative scaffolds that are represented within this model are always provisional, situated, and achieved through the co-construction of meaning within talk-in-interaction.

Figure 5 - Narrative scaffolds of meaning-making and self-crafting



Source: Author

This typology of shifting narrative scaffolds (re-creating, re-working, re-appropriating) is defined further, in Table 5 below. Although presented as discrete elements, these narrative shifts are, of course, overlapping and inter-linked within talk-in-interaction. I suggest this conceptualisation to offer orientations for thinking that is connected to particular problems (without which it lacks meaning). In presenting this conceptualisation, I respond to my initial research objectives: exploring changes in narratives of TBI over time, seeking understanding of co-construction of narratives of challenges and tensions following TBI, and providing a nuanced account of sense of self and agency following TBI to understand potential approaches in supporting self-management. I argue that the connection of the typology of narrative scaffolds, with the problems outlined in these objectives, potentially enables new lines of thought (Deleuze and Guattari, 1994; Mazzei, 2017).

In the following section, I illustrate an application of this typology of narrative scaffolds by drawing on extracts from interviews shared in Chapter 6. I seek to bring attention to an understanding of agency that might be relevant when considering clinicians' approaches to support for self-management for people living with TBI.

Table 5 - Typology of narrative scaffolds that achieve shifts in shared meaning-making

Type of shift	Description
Re-creating	Introducing a new expectation, which becomes routine in interaction
Re-working	Adapting taken-for-granted notions by reconfiguring meanings in talk-in-interaction
Re-appropriating	Claiming active ownership of a position by foregrounding desired or valued aspects in talk

Before applying the model to examples of challenges to the positioning of the self after TBI, I briefly reconsider the construct of citationality within Butler's theory of performativity (Butler, 1999; Nakassis, 2013). Citationality is central to my integrated model (Figure 5 above), particularly when considering the question of constancy or change in the self over time, which is important when situating this analysis in the established literature on biographical disruption (Bury, 1982) and the notion of loss of self after TBI (Medved and Brockmeier, 2008; Nochi, 1998, 1997).

Sense of self may seem to derive from our own unique mental creations and yet, following Butler, it is instead seen to arise through conditions that have gone before us. Butler asserts that:

"speaking is always in some ways the speaking of a stranger through and as oneself, the melancholic reiteration of a language that one never chose, that one does not find as an instrument to be used, but that one is, as it were, used by, expropriated in, as the unstable and continuing condition of the "one" and the "we", the ambivalent condition of the power that binds"

(Butler, 1993, p. 242).

In the proposed typology of shifts in narrative scaffolds (Table 5), I emphasise the prefix 're-' each time (*re-creating, re-working, re-appropriating*), thereby recognising reiterations (citations) of what has gone before. A fictional example, from Daphne du Maurier's novel *Rebecca* (1938), might be useful to illustrate this point further:

"...the nameless narrator shocks her husband by turning up at a party in an identical dress to that worn by his dead wife [Rebecca] on a similar occasion. In preparation for the party, the narrator, assisted by the malign Mrs. Danvers, believes that she is choosing her costume and thereby creating herself, whereas it turns out that Mrs. Danvers is in fact recreating the narrator as Rebecca."

(Salih, 2002, p. 56)

du Maurier's story provides an example of the way that identities, rather than being chosen or created by an individual agent, instead precede and constitute those subjects, "just as Rebecca literally precedes the narrator" (Salih, 2002, p. 56). However, through small shifts across time and context, repeated reiterations then allow "a play of sameness and difference, identity and alterity [that] can open up new horizons of possibility, signification, and performative power" (Nakassis, 2013, p. 51). Importantly, the

signification of these shifts "harbors within itself what the epistemological discourse refers to as 'agency'" (Butler, 1999, p. 185). Small scale reorganisations can encourage new ways of doing identity, through formations that are not fully constrained in advance, producing "agency as resignification" (Butler, 1995, p.135). I proceed to illustrate how agency may arise through the types of narrative scaffold described above. I draw on interview extracts presented in Chapter 6.

Re-appropriating

When Brenda and I comply with Derek's talk of gendered expectations (lines 278; 308) we re-affirm his normative narrative scaffold. I apparently become complicit with his interventions, as he structures our interaction quite explicitly through re-arranging seating, and more implicitly in talk about normative expectations of "a woman's job in life" (line 290). In my compliance, I "enact[ed] what cannot be narrated" (Butler, 2005, p. 54), complying with the expectation Derek set out, perhaps in solidarity with Brenda's way of being within this interactional space. However, at other times when Derek is not present, Brenda reveals her alternative narrative scaffolds that seemingly operate alongside her compliance with Derek's dominant normative scaffolding in their shared "narrative environment" (Hydén, 2017, p. 116). Through my facilitation - by offering encouragement for Brenda's telling of her asides - I come to recognise and share her sense of vigour when telling them, for example her telling of when she would "clear off to the coast or clear off somewhere else" (lines 287-288). Brenda reveals to me a secret scaffolding of a more thrilling life that is independent of Derek, in which objects (her car) and relations (with fellow residents in the sheltered accommodation) take on an alternate signification.

When Brenda and Derek talk together about mealtimes, Derek brings to the fore his active role in undertaking the cooking tasks which he considers Brenda is no longer able to complete, positioning her in a passive role that contrasts with her own sense of always having been the one in control of household responsibilities. However, when Brenda talks with me, aside from Derek, she *re-appropriates* the significance of activities through which Derek has rendered her passive or incapable. When Derek is not present in the interaction, she re-appropriates mealtimes as a space for her social mastery, in which she becomes an active and skilled contributor as a member of the friendship group (in their sheltered accommodation): the one who approaches newcomers and is a trusted judge of character. She counters the challenge of passive positioning by Derek and re-appropriates the focus of the story, which no longer centring on her (in)capabilities in fulfilling "a woman's job in life". Instead, she foregrounds her desired self by reinforcing her thrills from driving, as

a symbol of choice and independence, and her achievements in making new friends in the restaurant.

I do not aim to reveal Brenda's 'real' identity here, but I propose that we are hailed to different subjectivities when telling and listening in conjunction with Derek and when he is not present. These subjectivities are enabled through mutual scaffolds that re-appropriate meanings. They are co-constructed and situated in our particular interaction.

By way of a further example - Andy talked of his reluctance to attend the brain injury centre and fatigue clinic but agreed to have occupational therapy (OT) visits to his home. In telling a story of a cooking task set for him as 'the patient' by 'the expert' (the OT), a scaffold of re-appropriation enables him to claim an agentive sense of self: he tells of his own choice, his *urge*, to bake a cake. Andy now 'owns' what was otherwise a therapy task that positioned him in a passive role as someone in need of brain injury rehabilitation therapy. Instead, he foregrounds baking as his lifelong passion, a talent endorsed and valued by his partner.

Re-creating

If the subject is re-iteratively constituted across time through the continuing action of norms in a social context, then the possibility for change derives from a shift in norms of expectation. Subjects formed within a system of norms that are recognisable by the other ('a person with brain injury', 'with dysphasia') risk foreclosure in sense of self. However, space remains for norms of expectation to be redefined (Butler, 1993). Scaffolds that *re-create* meaning involve the undoing and re-forming of norms.

Walter, positioned in interaction with Ruby as a child whose actions she controls and contains, confronts her expectation that he will always be clean-shaven. This is a norm that he has consistently complied with throughout their married life: Ruby's normative expectation that he must "enact—and must perpetually re-enact" (Frank, 2018, p. 114) the daily task of shaving. When Walter tells of his care with his newly grown beard and moustache (second interview), his talk of shaving now presents it as an act that is not "natural". This re-creating of a norm of expectation is also a citation of his younger, bachelor self. He opens the possibility of self-crafting while extending a sense of continuity, as he tells of his bearded self that pre-existed his marriage, saying "I had [a beard] years ago". This performative affordance then counters the position of infantilisation by Ruby, through re-creation of a narrative scaffold in which he *re-creates*

the expectation of shaving and, in his talk of his beard and moustache, he clearly distinguishes himself as 'adult' not 'child'. Walter recreates himself as person – an adult – beyond the more controlled parts of his life with Ruby, which he cannot recreate.

The scaffold of re-creation becomes routine and spreads among others in the interactive network, if the modification is to become collectively accepted. Walter seeks to demonstrate scope for [masculine] ratification beyond Ruby and beyond me, as he commends me to “go home and tell your husband!”.

Re-working

Through reiterative talk about their cars, Brenda and Derek's narrative co-constructions demonstrate performative gender, where Derek talks of his car as “the big one”, in contrast to Brenda's “little one, just to run about in”, thereby invoking a “gendering of the car” (Lumsden, 2010, p. 13). By adopting 'compliant' routines such as deferring to Derek, using a low amplitude voice, and suggesting that she withdraws when Derek takes charge, Brenda complies with normative expectations (enforced by Derek) of the submissive woman. The performative routines “index womanliness” (Meyerhoff, 2015). Normatively gendered language routines between them are affordances that appear to reaffirm the structure of their “joint life project or ‘couplehood’” as a shared commitment to their relationship (Hydén, 2017, p. 121).

Derek seeks positioning of strength and power aligned with masculinity (Stepney et al., 2018; Wetherell and Edley, 1999) in an interaction where this might be somewhat challenged by the stories that convey him as changed, and passive – he no longer has a car, and Brenda has been the one driving them, until her injury, in her car. The normative scaffolding, demonstrated through his talk of cars and driving, has been threatened as part of a larger story of changes in his life. Though he had previously surrendered some of his own independence in these ways he *reworks* the story of driving – firstly by emphasising that he did not like driving Brenda's “little” car, and then proceeding to narratively rework their current life without cars as a consequence of Brenda's brain injury. Through this re-working, Derek's words “exercise a certain power” (Butler, 2002a, p. 63). He reworks the story to draw on a performative positioning in the face of his own increasing fragilities that pre-exist Brenda's injury (his physical frailty as well as the loss of his own car, and earlier reliance on Brenda as driver). Derek reworking of the narrative foregrounds importance of the car as an object that provided physical protection for [vulnerable] Brenda.

Claire avoids positioning of change from her pre-injury self that is suggested by healthcare professionals and her family, during stories about her speech. Instead, she attributes her particular style of using language to a unique and valued sense of self: that she has always been “like Mary Poppins, making up my own, like I had swallowed a dictionary, and making up own phrases, and words and stuff”. She *re-works* this scaffold of meaning that she and her sister previously used in describing a friend’s admired characteristics. Reworking the Mary Poppins story generates a sense of consistency for Claire when she has been positioned as ‘changed’, and by using the magical characteristic of being “califragilistic” she illustrates how:

“the very possibility of linguistic agency is derived from the situation in which one finds oneself addressed by a language one never chose”

(Butler, 2005, p. 53)

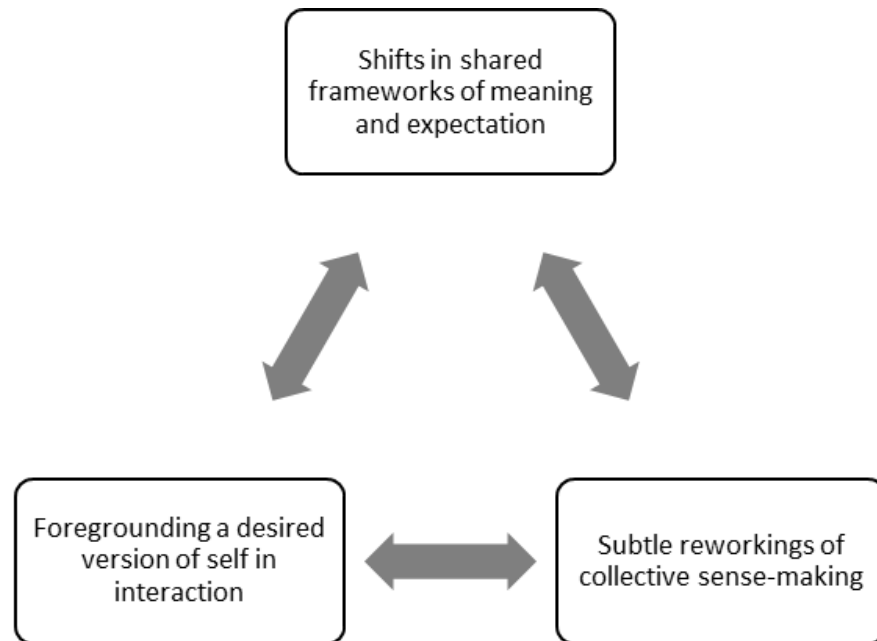
Telling of the same story or extract can be a way to represent important aspects of the self (Hydén, 2018). The considerations above demonstrate how re-tellings can become part of fleeting self-craftings according to the norms of a situation. I have proposed that meaning-making occurs through the telling and re-telling within interactions, rather than through the content, or ‘facts’, of the story shared. By contrast, the dominant approach in a clinical interaction points out and categorises inconsistencies in talk. In the example above, a clinician might suggest that Claire’s ‘alternative story’ about her speech demonstrates a ‘lack of insight’ into cognitive and communicative impairments (Le et al., 2014; Prigatano and Schacter, 1991). Focusing exclusively on deficits after TBI disregards “the more ‘positive, adaptive’ or ‘productive’ aspects of the meaning” (Örülkv and Hydén, 2006, p. 649).

Summary

Narrative scaffolds provide a platform for a sense of self that is “always journeying” (Latham and Faulkner, 2019, p. n/p) and requires navigation. As conventions are reinstated time and time again, bonds and constraints are created, and recreated (Butler, 2002a). Our project of selfhood seeks to uphold a desired sense of who we are, who we have been, who we hope to be (Medved and Brockmeier, 2008). Here, co-narration fulfils an interpersonal purpose where issues such as memory impairment are beside the point, in contrast with assertions that memory and narrative are “identity's twin supporting structures” (Eakin, 2004, p. 121) and the Western insistence that selfhood depends on cognition (Kontos, 2004). I propose that agency is demonstrated through *re-creating, re-appropriating and re-working* of narrative scaffolds to actively extend and maintain a desired sense of self in the face of constraint - not only from functional consequences of TBI, but from attendant challenges of being positioned ‘as a person with brain injury’ within a social interaction.

The scaffolding of these stories demonstrates the negotiation of “epistemic primacy” (Meschitti, 2018, p.17) in kinship relations. For Claire, failure to co-construct a “personal platform” in a clinical encounter loses an opportunity for each party to extend their epistemic possibilities through co-construction. Although derived from my qualitative data relating to people living with TBI, I argue that this analysis becomes applicable when conceptualising support for self-management in long term conditions more broadly (as I discuss further in Chapter 8). Narrative scaffolding becomes the mediator between challenges to a desired (hoped for) self and affordances in generating an agentive response: a co-construction that has the capacity to change all involved in the interaction. Figure 6 provides an overview of the integration of the concepts I have discussed above.

Figure 6 - Integrating core concepts



When outlining the typology of scaffolding and the conceptual model, I am aware that “...one person’s operationalisation is another’s subversion of a complex phenomenon” (Scambler, 2009, p. 447). However, I seek to use this operationalisation in the context of the literature introduced in Chapter 2, as I reconsider conceptualisations of biographical disruption (Bury, 1982) and loss of self after TBI (Charmaz, 1983; Medved and Brockmeier, 2008; Nochi, 1998, 1997) in light of the discussion above. I then continue with analytic reflections and outline some possible strengths and limitations of this research.

Reconsidering ‘biographical disruption’

The analysis brings into focus co-constructed narration with people following brain injury who are dealing with “a culture emphasising the view that ‘you *are* your brain’ rather than ‘you *have* a brain’”, and expectations that damage to the brain will damage personhood (Krahn, 2015, p. 1515) (emphasis mine). The analysis demonstrates often precarious negotiations of sense of self within normative expectations and when future outcomes, once taken for granted, are opened to doubt.

Bury’s concept of biographical disruption takes a central role in ‘big story’ (‘life story’) research where the implication is of a need for narrative reconstruction following a disruptive event (Bury, 1982; Gareth Williams, 1984; Williams, 2000). TBI has been conceived as a disruptive event that severs “the continuity of who the person is” and encompasses a sense of transition through “mourning” of the past identity and “construction” of the new self (Moldover et al., 2004, p. 151). The injured person who is in this transitional phase is conceived to be living with two images of the self: “who I am now” and “who I was before” (Cantor et al., 2005, p. 531). The concept of liminality (Turner, 1975, 1967) has been applied to this space: “in limbo” between the former and future states (Muenchberger et al., 2008, p. 990). The challenge to sense of self within this space of liminal uncertainty has been described by Langellier as “a site of negotiation and struggle” (1999, p. 138), and has been considered intrinsic within a dynamic construction of identity (Piazza, 2019).

In dominant neurorehabilitation discourse, a finite conceptualisation of liminality can be inferred as clinicians routinely convey expectations about recovery periods following TBI - for example, “following mild TBI, most people are back to normal by 6 months” (Canterbury District Health Board, 2012, p. 4). These prognostications are accompanied by various scales and models intended to “reliably predict recovery” (Rizoli et al., 2016, p. 2). Normative expectations then anticipate a chronologically linear trajectory of recovery following TBI that can be understood through the “application of reason, and the exercise of science and of ‘expert’ knowledge” (Fisher and Goodley, 2007, p. 66). These clinical processes suggest that there will be a particular period of time after which recovery from TBI will have taken place, implicitly define a period of ‘biographical disruption’ meanwhile, that is characterised by its temporariness – its finite liminality.

As discussed in Chapter 2, this state of liminality after TBI has further been described as a “void” in understanding of the self after TBI, which potentially threatens one’s “sense of agency” (Nochi, 1997, p. 533). An individual’s ‘void’ in past memories is seen to act as a barrier to self-understanding, or even to present a “‘tragedy’ that one’s former self is gone” (Weicht, 2010, p. 211). The interpellation ‘person with brain injury’ further provides the possibility for an identity to become signified through narratives of neuroscience that “increasingly entrap all aspects of human experience within a single gaze” (Cohn, 2010, p. 70), and the creation of “kinds of people that did not exist before” (Hacking, 2007, p. 293). The creation of a new reality through narratives of neuroscience is illustrated by Claire, who talks of neurorehabilitation interventions that deliver education about brain injury which is then “all that is going to be in your head”.

Previous research has also suggested that, for people living with TBI “without clear recollection of events, [they] were less able to “own” their experience, constructing a position of disempowerment”(Cloute et al., 2008, p. 664) (p. 664), and that others can become keepers of an injured person’s identity at times when the person is unable to fully express it themselves (Whiffin et al., 2017, p. 6; Williams, 2000). These implications raise the question posed by Charmaz: “What happens then when images of self, reflected to ill persons by others, are inconsistent with their core self-concepts?” (1983, p.170). The integrated model outlined in the section above, informed through by concepts of scaffolding, positioning and performativity, suggests a fluidity that opposes the notion of a ‘tragic’, ‘diminished’ or ‘lost’ self which are inconsistent with people’s desired sense of self. The interpellated subject (‘person with brain injury’) is incomplete, with an agentive gap to do something differently within normative constraints of the situation and expectations: possibilities to reaffirm a desired sense of self when positioned as ‘changed’.

When exploring narrative structures used by family members to understand change after TBI, authors suggest that concepts of biographical disruption, biographical continuity and biographical reconstruction underpin their understandings of change (e.g. Whiffin et al., 2017). I propose that the analysis of talk-in-interaction co-constructed with people living with TBI in this study extends these conceptualisations beyond the biographical disruption and finite liminality paradigm to include consistency and change that continue to work together. In the navigation of a sense of sameness, changes are taking place on a fleeting, ‘micro’ level - not generally changes of the major ‘biographical’ kind where “we have changed from one person to another” (Bamberg and Demuth, 2016, p. 14).

Analytic reflections

Much of what is said in an interview may appear to be nothing new, as researchers' and participants' positions are produced within the discursive practices that render what is said possible (Mäkelä, 2017). Further, the analytic dogma of coding practices (Mazzei, 2014) risks predictable interpretation, which may appear to add 'nothing new' or to equate to 'common sense'. By way of example, in a recent qualitative study on the experiences of significant others whose relatives were admitted to a brain injury rehabilitation unit, the authors' inductive thematic analysis identified: "*trauma; grief and loss; journey; and uncertainty*", and concluded that "the whole experience for the significant other is traumatic as they try to understand changes to both their loved ones and their own roles"; also that the significant other may need time to talk about their experiences with health professionals (Checklin et al., 2018, n/p). When considering application of this thematic analysis to conceptualise experience, or to inform practice, it could be argued that such findings replicate the existing framework of normative understanding and do not necessarily move us forward in determining, for example, how talking with health professional staff may, or may not, be helpful within people's experiences.

By using theoretical insights, I have instead sought to see these issues in alternative ways, "to produce different knowledge and produce knowledge differently" (St Pierre and Pillow, 2002, p. 27). Despite the awkwardness in applying performativity to issues of identity and agency after TBI, it has enabled me to explore how taken-for-granted identities (for example, 'patient', 'clinician', 'person with TBI') could be destabilised. I started with brief extracts of talk-in-interaction and used positioning analysis with Butler's performativity as sensitising devices. Through the use of multiple theoretical insights within the development of my interpretations, I sought to "move qualitative analysis away from habitual normative readings" (Mazzei, 2014, p. 742). I did not seek definite accounts but instead I have suggested one interpretation among many plausible ones. My intention was to seek entry points for a relational understanding of supporting self-management. By interviewing pairs of participants instead of individuals, the context was already relational.

Instead of a view of narratives as a performance, where "the entire bodily presence and identity of the narrator are staged" (Hydén and Brockmeier, 2008, p. 10), I have considered how performativity shapes its intersubjective co-construction. The potential for change is realised through narrative scaffolds that subtly rework, re-appropriate and recreate meanings and norms of expectation. In particular, I have explored ways that the content

of stories may be adapted according to the context and co-narrators in the telling. This process is a joint accomplishment within the interaction, forming and reforming a sense of who we are as a continuous process.

I proceed to consider aspects of reflexivity as a process between my approach to interviews and my analysis, particularly seeking to explore the “emotional, embodied, and performed dimensions” (Ezzy, 2010, p. 163). I commence by reflecting on my approach to interview contexts before considering the analytic significance of ‘emotional overlaps’ (Feldman and Mandache, 2019) with participants during interviews.

Reflexivity

Approach to interviews

When meeting with people for research interviews, my intention was to talk about what they wanted to say, instead of pursuing preconceived assumptions about what might be important to include. However, “all interpretations are provisional; they are made by positioned subjects who are prepared to know certain things and not others” (Rosaldo, 1993, p. 8). Reflecting on my approach, I consider my spoken and unspoken framings of the interviews, and potential consequences. I explore ‘interruptions’ to these framings, illustrating with examples from one interview.

Although I attempted to encourage participants’ own narration and avoid directive questioning (Jones, 2003), my initial open question, “How have things been since you were in hospital?” has normative expectations attached to it. The question assumes that the response will be orientated to particular aspects of experience, like improvement or lack thereof (Ryan, 2018). Thus, this opening question risked potential restriction of subjectivities within the space of our interaction: the ‘hail’ to a subject position which itself requires navigation. Through iterative processes of data generation and analysis, I became increasingly aware of the identity categories implied by my opening question (positioning participants as ‘a patient discharged from hospital’, ‘a person with brain injury’), which could potentially complicate the subjective (in)coherence that I sought to explore.

Moments of interruption in interviews can unsettle the ‘researcher-participant’ framing of the relationship (Ryan and Ziebland, 2015). For example, Walter (introduced with his wife Ruby on p. 113) ‘undid’ my organisation of the research interview, as he nimbly and repeatedly attempted to position me as other than a researcher within our interactions. Instead, he attempted to produce a ‘host-guest’ relationship. In accepting his invitations

to show me his treasured belongings, we moved to other parts of his home or garden, disrupting the typically seated and stationary arrangement of a research interview. Walter offered to show me his book collection in the study upstairs (his “library”), then brought our attention to certain books, and ultimately insisted that I have two of these books as gifts to take home. These ‘interruptions’ challenged my assumptions and expectations; for instance, that I would contain our interaction, and maintain my identity as researcher. In walking and talking together around his home, he revised the narrative of his experiences “since being in hospital”, which I had framed in my opening question. Further, he created a new dyad, as he freed us from moments of tension and potential constraint in interaction that included his wife Ruby, who remained downstairs. Importantly, during these ‘interruptions’, he created a context that brought to the fore our less formal homebody and entertaining sense of selves, which were not readily available in my (unspoken) formal ‘rules’ of interviewing practice.

This reflection has raised an area of interest for me around ‘mobile methods’ – for example, the use of walking as a method for doing social research (O’Neill, 2018). I am curious about the relational aspects that happen when walking with someone and talking, disrupting researcher-participant constraints that generally characterise the normative ‘fixing’ of interactional spaces in research interviews.

Emotional overlaps

The conventions of research practice require that we, ‘as researchers’, should exclude our emotional responses, through conscious denial or being subsumed as part of habitual practice (Law, 2016). Researchers reflecting on emotional entanglement when undertaking qualitative interviews have pointed to the significance of the central values of their previous professional training. For example, the teacher-researcher entanglement was considered to bring a pedagogical approach towards interviewees, leading the authors to reflect that personal subjectivity and biography should be an integrated component within analysis (Holtan et al., 2014). This ‘professional background conscious’ approach to analysis is also evident from the suggested need for clinicians to “turn the lantern of inquiry to oneself...if we cannot see ourselves in our explanations, perhaps we should pause before proffering these explanations to the [medical] profession” (Hendricks, 2008, p. 113).

Undertaking this research from a professional background ‘as a clinician’, with people whom I have hailed (for participation in this research) ‘as patients with brain injury’

invokes specific ethical considerations. I negotiated various identities during the fieldwork, which did not completely displace each other, as I shifted between the “pre-established discourse” of my professional clinical background (Magnus, 2006, p. 99) and my qualitative researcher role. These dual positions presented ethical considerations, such as my sense of exploiting people’s experiences for the purposes of the research rather than offering personal ‘help’ for the challenging circumstances confronting them. I consider this in further detail relating to a particular example, below.

In considering the emotion in my selection of data for detailed analysis, my emphasis has been on small moments of interaction - not overtly emotionally charged words or exchanges. I have highlighted small scale, fleeting emotions that may allow a reimagining of “a person’s relation to his or her vocational activity” (Rosiek and Snyder, 2018, p. 8). Moments of emotion that start as a vague feeling (for example, discomfort, connection, intimacy, irritation or concern), occur in both clinical and research interactions. Bringing attention to these fleeting moments might contribute to critical opening within the interaction, through exploration of my “emotional overlap” with participants (p. 227), as discussed in Chapter 5. This epistemological reflection offers a shift in the potential distancing that is normatively maintained through power asymmetry in clinical and research encounters. I consider three examples from moments of interaction shared in Chapter 6.

Firstly, I experienced ‘symbolic violence’ as a feeling of being controlled, in the interactions with Derek (Brenda’s partner), which appeared to be reproduced in everyday interactions with Brenda and had come to appear ‘natural’ in their narrative environment (Thapar-Björkert et al., 2016). I was aware of my reluctant compliance with his gendered narrative scaffolding. Perhaps I mirrored Brenda’s compliance, in the version of self that she co-constructed with Derek, which was dependent on these normative expectations. However, reflecting on my emotions that were triggered by the sense of being controlled in these interactions with Derek (frustration and at times even anger), I ultimately became more aware of the fragility of our mutual subject positions. Derek, the main support person for Brenda since her injury, was struggling to maintain a position as the powerful agent, in control, at the same time as visibly struggling to stand from his chair in his home. Becoming complicit with his gendered normative expectations in interaction, I perhaps contributed to possibilities for a recreation of his desired position of strength. The potential power of my own positioning, ‘as a researcher’, ‘as a clinician’, was subsumed by his asserted positioning of me (and Brenda) ‘as a woman’, which we each

complied with. In doing so, and processing these moments of interaction subsequently, I began to appreciate the emotionally-driven complexities that scaffold Brenda and Derek's narrative activities of the everyday.

A further example of moments of emotional overlap during interviews related to feelings of emotional tension sensed between Andy and Danielle, which I shared, and feared I may have brought to the surface. Danielle questioned whether Andy had been attempting to hide his anxieties from her in the way he suggested he has been doing with his parents. In several moments of silence that we shared during this part of the interaction, it seemed as if a new, generative space for collaborative reflection and fluidity had opened up between the three of us, a depth of connection that had not been present until these shared silences, and an emotional awareness I had infrequently experienced in structured interactions from my distanced subject position 'as a clinician'. Yet, in the intersubjective space of clinical encounter, subjective experiences are central to experience of care and ultimately to outcomes (Wong et al., 2018).

As I discussed in Chapter 5, the traditional expectation for professionals is the performance of a dispassionate, distanced, and 'objective' manner for professionals, where 'professionalism' becomes the "discursive and rhetorical practical compass for navigating interpersonal complexity" (Wong et al., 2018, p. 2) and is integral to Menzies-Lyth's notion of a social defence against anxiety (1970). A focus on the emotions of patients, rather than those relationally generated *between* clinician and patient, means they can be separated as 'clinical products' that then require professional assessment and intervention, or *fixing*, in a largely technical exchange that negates the critical intersubjectivity of these encounters. (Wong et al., 2018). For the clinician, emotions are to be managed within a performance of professional competency that includes affective control as well as technical competence. This stance is reflected through the medico-normative framework of *do's and don'ts* that operate within the "hidden curriculum" of medicine, where the workspace is defined by "professionalism" and yet "no one talks about [this constraint] much" (Coulehan and Williams, 2001, p. 7). However, it includes the avoidance of expression or acknowledgement of own emotions, despite the complex intersubjective experiences that invariably constitute 'the workspace'.

Ewa was the only participant with whom I did not meet for a second interview, and is the interaction that feels most emotionally complex to explain, from this series of longitudinally organised research encounters. I was confronted by the sorts of difficulties

that perhaps maintain the suppression of emotional reflection in clinical and research practice - a sense of failure of intersubjective connection with Ewa, where I perhaps perpetuated the positioning portrayed in her stories about clinical interactions where she had felt disregarded, and as if she was not worthy of more considered and tailored attention. For Ewa, I sensed that the research interview may have recreated this, raising a question of whether I failed in an ethical obligation to her. After all, in this research interview, I too was offering nothing other than “a few questions, and that was it” (line 470) as she had told of in the healthcare encounters where she felt dismissed. However, as noted by Twigg, “power relations are not unilateral” (2011, p. 175). Ewa exercised her (perhaps unacknowledged) power, as the “one queried refus[ed] the one who queries” (Butler, 2005, p. 12): she had disengaged from clinical follow-ups, and I was unable to contact her again regarding the follow-up research interview. Although these observations may be explained in alternative ways (for example, Ewa may have returned to her family overseas meanwhile), I suggest the significance of this reflection lies in the intersubjective processing of what went on here, in contrast to the norms of a clinical encounter in which the next step would generally call for application of a ‘depression questionnaire’ (NICE, 2018). In Ewa’s situation, lack of a sense of intersubjective connection could further risk heightening her sense of being disregarded, which made her “so ridiculously angry” (line 469).

Strengths and limitations

A distinctive feature of this study has been inclusion of people who have experienced cognitive and communication consequences of TBI and might be excluded from a biographical narrative inquiry approach that anticipates a particular type of telling ‘big stories’. Further, the longitudinal approach to interview and analysis was possible due to a high ‘retention’ of participants in the study, achieving follow-up interviewing over the course of a year for each of nine out of the total of ten dyads. The dyadic approach to interviewing with family members and partners allowed the inclusion of family interaction as a unique source of understanding for how people position themselves in the adjustments following the experience of brain injury (Medved, 2014).

Although I consider that dyadic research is a strength of this study, I acknowledge some critiques of this method. It is frequently suggested that people may feel inhibited from sharing their individual experience in the presence of a family member partner (Taylor

and De Vocht, 2011), or participants may comply with what they think is acceptable to their partner, or aligns with their partner's assumed position (Zipp and Toth, 2002). However, my analysis explored joint negotiations and constructions of brief extracts of narrative, rather than seeking to "tease out the individual experiences" (Taylor and De Vocht, 2011, p. 1577). I did not assume that there would be a single truth - one that is 'correct' - which participants would openly talk about in the interview and I would then extract from the transcript, or that it would emerge from the data (Heidegger, 1998). In contrast to seeking the participants' 'true' experiences or individual perspectives, my analysis instead acknowledges the "experience in the telling and its reception" (Frank, 1997, p. 22) and attends to issues of negotiation in joint telling, particularly its fluidity across time, within my methodological approach of dyadic, longitudinal interviewing.

Although follow-up interviews introduced a temporal component to the analysis, the practicalities of undertaking the project limited these to one additional time point over the course of a year after the first interview with each dyad. Further, the current study was restricted to people within the first few years following TBI. Looking at a longer time period could expand understanding of shifts in narrative scaffolds. To analyse co-constructions further, additional interviews may have allowed strengthening of the conceptual model developed from the theoretically guided analysis of empirical findings (Figures 5 and 6). However, participants introduce nuanced temporal connections within each interview, and so my analysis in relation to time has not strictly depended upon interviewing at different time-points. Instead, my focus has been on the use of time within meaning-making in narration, for example through bringing attention to participants' (and my own) positioning of the self in the 'there and then' of the story or the 'here and now' of the telling. By focusing on the brief moments of interaction, I consider navigation of sense of self as an ongoing process that is constantly taking place in mundane situations of the everyday, including the past, the present, and imagined futures. Bamberg argues:

"if we take the notion of 'life as a continuous process' seriously, we may have to rethink qualitative methods, and narratives methods in particular, in terms of how they capture and do justice to the constant changes that take place"

(Bamberg, 2008, p. check).

A further consideration is that these interviews should be viewed as triadic instead of dyadic, in view of my own contribution to their co-construction, thereby maintaining awareness of positioning 'as a researcher' with its associated power asymmetries that may influence the trajectory of conversations. The analysis of positioning, using Bamberg's

domains (Table 5), in combination with Butler's theoretical constructs from performativity, enabled an opening up of my understandings of 'agency' and issues of power within narrative co-construction, by attending to how people position themselves, are positioned by others, and navigate between normative expectations, in maintaining a desired sense of self. Approaching sense of self as a "performative struggle over the meanings of experience" (Langellier et al., 2001, p. 3) allows analytic possibilities that may be overlooked through static conceptions that assume unity of a singular, inner self tied to a particular position, such as that 'as a researcher'.

By invoking the dichotomy of 'brain injury / no brain injury' in my purposive sampling for this research study (i.e., inviting people on the basis of a diagnosis of TBI), I have inevitably reproduced the discourse that I critique: the totalising identity of 'a person with brain injury'. The alternative view of the subject, which I have attempted to develop through the analysis, highlights relational and embedded understandings of the self, and which, I propose, transcends this dichotomy. Further, the demographics of those included in the interviews represent subjects whom Henrich et al (2010) refer to as WEIRD: Western, Educated, Industrialised, Rich, and Democratic. Despite this, I argue that the analysis sheds light on co-construction of interactions that might be of relevance beyond these demographics, and beyond the geographical location of study (in the south of England). As I discussed in Chapter 5, my sampling intentions evolved from this type of fixed identity attribution, instead attending to a fluid, storied approach to sampling that attended to complex, changing social circumstances. Claims about idealised sampling, derived from assumptions based upon configurations of identity from demographic labels, risks an oversimplification of complex human spaces, potentially making invisible more subtle forms of human self-presentation (Horton and Horton, 2018).

Although the extracts in Chapter 6 were not co-constructed in a clinical context, participants' talk about clinical interactions demonstrated their meaning-making about professionals' interventions and approaches to interaction that intended support after TBI. In Chapter 8, I contextualise these findings within my research objectives by exploring implications for approaches to support for self-management. I consider interviews with professionals to be beyond the scope of the current study.

A common caveat in theoretically-guided analysis is that "every theory provides both a way of seeing and a way of *not* seeing" (Ray, 1996, p. 674) (*italics in original*). Through these narrative analytic methods, I do not intend to generate research generalisability -

that is, I do not propose that these experiences apply to all those after TBI, whose meaning-making is situated in local social contexts. I have presented a conceptual model derived from theoretically-guided analysis of empirical data. Moving forward, this will require further research to elaborate and explore its potential for contribution to understandings of approaches in supporting for self-management after TBI, and for people living with long term conditions more broadly. I discuss these applications further in Chapter 8.

Summary

The stories told and re-told across two time points, presented in Chapter 6, demonstrate tensions between constancy and change for people living with TBI and significant others. Through analysis of these stories, I sought insights into self-management after TBI as a “construction process in situ” (Bamberg and Demuth, 2016, p. 18). In this chapter, I have returned to the concept of narrative scaffolding where meaning-making is a shared achievement, underpinned by “activities and interpretations of other persons” (Hydén, 2017, p. 107). I also elaborated on negotiation of the interpellative hail that operates as an implicit binary (for example, participant-researcher, patient-clinician, dependent-independent) and produces a labelling that has power to break up subjectivity – through an “alienation” from one’s own subjective life (Kitwood, 1997, p. 10).

As we display a sense of who we are, we are affirmed or confronted, and we react. We turn these interactional practices into “rituals of identity work, that become metaphorically speaking ‘us’” (Bamberg and Demuth, 2016, p. 21). I have considered not only how narrative is co-constructed, but how it can be productive of new possible realities. Narrative scaffolding mediates between subject positions that are claimed, accepted, exploited or resisted, through reiterative shifts that maintain a platform for agency under conditions of constraint.

CHAPTER 8: Conclusions

Introduction

In this thesis, I have sought insights into the construct of supported self-management, a core component of patient-centred care in the NHS in England (de Silva, 2011a; NHS England, 2019). To date, supported self-management has infrequently been considered as an intervention framework for people living with traumatic brain injury (Mäkelä et al., 2019; Muenchberger et al., 2011). I argue that exploration of narratives of TBI after hospital discharge can contribute to a broader conceptualisation of self-management, constituted by social relations that are characterised by norms and (potentially) diverging agendas or expectations. In proposing a relational understanding of support for self-management, my framework contrasts with dominant approaches where the focus is typically on individual concerns, like biomedical constructions of health, as well as patients' confidence with carrying out health-related tasks (Entwistle et al., 2018; Morgan et al., 2017; Owens et al., 2017).

Normative and individualised expectations of support for self-management are evident within documents that highlight, for example, “a patient-oriented guide to educate patients about various aspects of self-management and to help them monitor their self-management activities” (Schulman-Green et al., 2012, p. 144). Technologies such as standardised tools may intend to deliver patient-centred care, yet they also focus professional attention on a particular type of interaction, embedded within health systems' expectations of proof that what clinicians do ‘works’, and works quickly, and can be measured (Turner-Stokes et al., 2005). These kinds of nudges, toward a neoliberal construct of the self, obfuscate aspirations for a shift in power relations between healthcare professionals, patients and significant others, which could be facilitated through a new kind of self-management paradigm (Brahim, 2019; Carel and Kidd, 2014; Kennedy et al., 2013).

I argue that dominant approaches to supported self-management (1) neglect the deeply complex and social nature of the relational support required, including the central role of the ‘patient-practitioner’ interaction itself; and (2) comprise underdeveloped notions of

self and identity, that rarely extend to intersubjective understandings. In this study, my focus on narratives of TBI and self-management is situated within a ‘disrupted identity’ approach (Bury, 1982; Corbin and Strauss, 1988; Krahn, 2015) and the accompanying expectation that support will help to ‘fix’ this disruption. Through analysis of co-constructed stories with people living with TBI and a family member or partner, across two time points, I highlight a “crisis of positioning” (Horton and Horton, 2018, p. 1) for the person whose life is assumed to have been disrupted. In this research, stories of the hail to ‘a person with brain injury’ positioned people as diminished (for example, through clinical assessments), thereby challenging a desired sense of self. Clinicians’ power, constructed through an ability to deeply ‘know’ about the nature of the disruption, paradoxically risks “*violation to patients’ sense of self*” (Kocman et al., 2019, p. 13) (*italics mine*).

I argue that, if clinical interactions are to form the central ‘*how*’ of healthcare professionals’ support for self-management (Sheridan et al., 2018), then a nuanced understanding of meaning-making through talk-in-interaction is required. Support for self-management, as a mutual achievement through reiterations of shared meaning-making, calls for attention to the norms and expectations that surround the interaction asking what is left out, and what else might usefully be accommodated.

In this chapter, I consider my analysis in relation to healthcare policy in the NHS in England. I then explore potential implications for healthcare interactions that intend to support self-management in clinical practice. I briefly describe a practice model for supported self-management in which stories told by people living with TBI form a central resource in shifting norms of professionals’ interactions, developed in a separate project through collaboration with [Bridges Self-Management](#) social enterprise (Makela et al., 2015; Mäkelä et al., 2019). Finally, I consider implications of my findings in relation to existing research and I discuss ideas for extending it.

Policy

Contemporary healthcare policy creates:

“a difference between those needing help and those providing it... The provision of care has always been viewed as something done by one part of the population for another part... This allows for an emotional distancing, and a self-protective response that treats anyone in need of any sort of help as automatically ‘other’ and ‘different’”.

(Unwin, 2018, p. 14)

When considering how the findings in this study might relate to healthcare policy, I consider its relevance at the level of understanding the context of supported self-management, and its potential for contribution to the development of models for practice (Shaxson et al., 2012). Policy intentions for self-management support typically centre on the provision of education for patients to gain skills, with the aim of somehow empowering them (Wyatt et al., 2010). Here, patients are positioned as initially deficient, the ‘other’, and are assumed to be in need of help from the professional. As I discussed in Chapter 2, a traditional individualistic view of autonomy - that anticipates that the patient will be independent, rational and self-governing - dominates self-management-related policy, neglecting emotional and social contexts and arguably reinforcing inequities, within a neoliberal framing (Brahim, 2019; Vassilev et al., 2017). A policy agenda that structures support for self-management according to biomedical priorities fails to recognise the kinds of harm that can be caused when pursuing exclusively biomedical goals, with insufficient attention to people’s values and (socially shaped) capabilities (Entwistle et al., 2016). If self-management policies fail to recognise tensions that people experience as they navigate consequences of a condition within their social roles and identities, then support will lack meaning and relevance. Professional and patient behaviours may then constitute no more than transactional practices (Henwood et al., 2003; Horton and Horton, 2018), and remain bounded by distinct positions where a distanced professional stance deflects attention to the “pathological other”, legitimising the “expert” role within the interaction (Flick, 2019, p. 85).

When considering policy aspirations of putting people at the centre of their care, ‘personhood’, ‘selfhood’ and ‘identity’ are key concepts, and yet remain poorly conceptualised in this context (Horton and Horton, 2018). I propose that understandings of self and identity can be re-framed within co-constructed interactions. ‘Patient’ and ‘professional’ subject positions are then considered relational within the ‘here and now’ of the clinical encounter and yet extend beyond it, thereby acknowledging social embeddedness and complexities of the everyday, where the health condition is only one factor. I proceed to consider implications of my findings in relation to current clinical practice (as introduced in Chapter 2), before introducing a practice model for supported self-management after TBI, developed in a separate project (Mäkelä et al., 2019).

Practice

“Tread softly because you tread on my dreams”

(Yeats, 1899)

Although support for self-management in clinical practice is typically presumed to involve “collaborative activity between patient and healthcare practitioner” (Rijken et al., 2008, p. 117), substantial shortfalls have been identified in studies of its implementation internationally (Elissen et al., 2013, p. 6). Understanding of what comprises a collaborative interaction, or how it might be achieved, remains limited (Franklin et al., 2019; Jones et al., 2013; Morgan et al., 2017; Thille et al., 2014). Further, the self-management paradigm typically focusses on patient-related behaviours and (dis)engagement, (Potter et al., 2018), without attention to professionals’ approaches to interactions and how they might influence the intended collaboration (Bright et al., 2017). Recommendations for professionals’ practice suggest they should “support the active role of a patient” in the interaction (Alanko et al., 2019, p. 2280) and yet do not offer understandings or conceptualisations of how to achieve this type of support through the interaction.

Big stories of ‘real’ events shape the healthcare language of interventions for people with long term conditions, including TBI. The “biographical gaze” expects the person to have a coherent biography and a life plan (Flick, 2019, p. 87). For example, clinical guidance recommends the inclusion of a summary of the patient’s “life story” in care plan documentation for older people as an attempt to deliver person-centred care (NICE, 2015, p. 6). When conducted as formal task by professionals, the implication is that a fixed, coherent and temporally ordered story can be identified and documented by the clinician and will be meaningful for the person. Further, life story resources and formats recommended for this purpose by professionals have:

“the potential to be reduced to a rigid clinical encounter if the individual delivering the activity feels they must fill in each box in a prescribed order...the difference between performing a clinical test and facilitating life story work...may lie solely in the communication skills of the worker.”

(Kindell et al., 2014, p. 7).

In a further example, interactions such as goal-setting in self-management support may remain fixated on the represented contents of a biography, to conclude how the teller reflects on the self, disregarding relational constructedness of interaction (Meschitti,

2018). These practices turn peoples' stories into a standalone product that can be acted upon by the professionals - the 'experts' (Brockmeier and Meretoja, 2014, p. 20). Studies have shown that goal-setting interactions for people who have experienced brain injury are likely professionally-determined: healthcare professionals name the things that will be attended to in the interaction, and frame the context in which professionals will attend to them with patients (Jones et al., 2016b).

When considering self-management following TBI, issues of self, identity and relational support are brought to the fore differently to other long term conditions, for example self-management for diabetes mellitus (Hinder and Greenhalgh, 2012), where clinical surveillance and monitoring against biomedical targets predominate, rather than social and emotional aspects (Entwistle et al., 2018). Neurorehabilitation professionals attend to an assumed altered sense of self after TBI, which is typically attributed to cognitive and communicative impairments and situated within broader cultural understandings that 'you are your brain' (Eagleman, 2015; Krahn, 2015). In addition, a focus on supported self-management for people who are living with TBI disrupts expectations of "an 'ideal patient' who operates in 'activated' and 'motivated' ways" to self-manage (Franklin et al., 2019, p. 4).

Conditions of constraint are typically attributed to neuropathological consequences of TBI. On the other hand, I propose that the notion of constraint also applies to healthcare professional/patient subjectivities, within increasingly target-driven healthcare cultures. Normative frames - "assumptions, values, and beliefs, by which individuals and organizations provide meaning to their daily activity, organize time and space, and reproduce their lives and experiences" (Thornton et al., 2012, p. 2) - regulate the subject positions of 'patient' and 'clinician'. Although these tensions are not widely spoken of among practitioners (Entwistle et al., 2018; Jones et al., 2013; Morgan et al., 2017; Sheridan et al., 2018), research into professionals' experiences of supporting self-management do allude to them through discourses such as :

"working hard to change their communication style to one that allowed or encouraged the patient the opportunity to talk and express how they felt, in order to avoid making assumptions about the feelings, needs and preferences of patients."

(Mudge et al., 2015, p. 8)

Charon advocates a form of deep listening in which healthcare professionals "will, between the lines of listening, recognize what the teller is revealing about the self" (Charon, 2008,

p. 66). I propose that, instead of simply *listening* to recognise what patients are “revealing” about the self, healthcare professionals and patients (and family members or others) instead could become more aware of the mutual co-construction of feelings and social realities, through scaffolds of interaction that constrain or generate what is possible to know. By problematising ‘individual voice’ as the unit of focus in supported self-management interactions, I propose a relational understanding of supporting self-management and a focus at the ‘micro’ level of interactions where healthcare staff potentially miss, suppress or inspire patients through the positions they take up in their interactions. The practice model introduced below illustrates one way of moving toward such interactional co-construction.

In the current study, participants frequently identified a ‘professional stance’ where clinicians had interacted with them as if in “a field of objects from which one remains strangely distanced and toward which one acts instrumentally” (Butler, 2008, p. 98). For example, Claire describes the medical discourse that overshadows her own priorities in encounters with professionals intending to support her recovery. She identifies this failed collaboration as potentially detrimental not only to her progress, but also for those positioned ‘as a clinician’ in interaction with her as a person living with TBI. Claire explains her metaphor of a “personal platform” in clinical interactions, in contrast to a focus that is “solely medical, ‘You’ve got that, that is going to be like that, you are going to get these drugs, and it can have these side effects, but that will be all right’”. She explains that a more reciprocal exchange could “in turn, help those people [clinicians] be more educated, or have more knowledge”. The creation of opportunities for “listening and understanding in new and often surprising ways” (Hydén, 2018, p. 49), brings attention to the intersubjective space and its generative potential, instead of a technical transaction or constrained ‘protocol’ for self-management support.

The notion of relationships as the core of service design and delivery is not well established in Western healthcare in general (Wise, 2019), though applications are described in mental health contexts. Literature on relational psychoanalysis has emphasised “the mutual construction of meaning in the analytic relationship” (DeYoung, 2014, p. 28), and advocates for a relational recovery approach to mental health (in contrast to an individualistic approach) propose that there is a need to “properly acknowledge the irreducibly relational nature of recovery” (Price-Robertson et al., 2017, p. 108). Models of ‘family recovery’ promote a perspective of processes that are distributed throughout a relational network, rather than being attributed entirely to an individual.

Challenges remain in how professionals might co-construct support within the established norms and cultures that structure their relationship with patients and families. Conceptualising self-management as mutual construction raises questions about the scaffolding that might be achievable between the 'patient-as-person' and the 'clinician-as-person'. The idea of 'doctor-as-person' was described almost two decades ago, when its integral place in patient-centred care was proposed (Mead and Bower, 2000), yet this idea remains underdeveloped in contemporary interpretations of patient-centeredness (Beach and Inui, 2006). The clinician-as-person idea calls for the capacity for self-awareness in relational interactions that challenges the positioning of 'clinician-as-expert'. I propose that consideration of the intersubjective – the interaction as a co-construction – can generate opportunities to relate not only to the person at the time of the interaction, but also by allowing renegotiation of selves, acknowledging “identities as contextual, and draft-like processes” (Bamberg, 1997, p. 7). This intersubjective space opens opportunities for sharing stories as a resource, where the telling may relate to recollections (whether 'real memories' or not) and to future imaginaries (which may be 'achievable' or not), and would otherwise be clinically closed down by categorisation as deficit ('lack of insight') by the clinician-as-expert. Instead, it requires an expansiveness beyond norms and expectations, "a risking of [selves], a moving out and a moving towards" (Kitwood, 1997, p. 4).

How supported self-management can be (co)produced through talk requires a radical shift from the dominant literature on supported self-management, which retains the expert position of the healthcare professional (Jones et al., 2013; Owens et al., 2017), whose training and professionalisation, in turn, instil a tacit expectation of taking control of patients' problems (Elissen et al., 2013). Shifts in norms are necessary “to weaken understandings, structures and practices that sustain established ways of working...[through] disrupting activities that encourage professionals to question and reflect on elements of their established way of working” (Huq and Woiceshyn, 2019, p. 2). These practices are formed within dominant discourses that continually evolve (Crowther, 2000). Thus, reiterations can bring to the fore possibilities of disruption, including possibilities for a re-working of the identity 'clinician-as-expert'.

There is much overlap between approaches to supporting self-management and for the implementation of shared decision-making in healthcare. In each model, professionals and patients are anticipated to achieve collaboration and shared goals in interaction.

‘Shared decision-making’ has become well recognised within person-centred care practices internationally, intending more positive interpersonal encounters in health care settings that might enhance agency and meaning-making (Carney, 2014; Knight et al., 2018). In the NHS in England, it is manifest in the rhetoric of ‘no decision about me without me’. However, many differences of opinion surround shared decision-making and knowledge is limited about the best strategies for its implementation, as it “does not happen with the ease implied by current models” (de Silva, 2012, p. 29). Behaviours and beliefs of healthcare professionals remain central to the realisation of reciprocal relationships in conversational activities underpinning supported self-management or shared decision making intentions. For example, professionals may hold normative beliefs that it is “not possible to respect a patient’s autonomy while still delivering high-quality evidence-based care” (de Silva, 2012, p. 29).

Healthcare professionals seeking to support self-management might reconsider their positioning in clinical interactions through reflexive abilities, acknowledging that “even if positioning is a joint process, participants in a conversation can consciously work on it” (Meschitti, 2018, p. 5). Others have proposed that healthcare professionals might “recognise and develop an awareness of the potential implications of the narratives/discourses we adapt in our dealings with others” (Burr, 1998, p. 147). In this way, the promotion of “positions in discourses which are less personally damaging” (p. 151) might start with an awareness of the potential impacts of the clinical interaction itself, including clinical predictions about recovery trajectories and outcomes (Kulnik et al., 2017). This shift toward prioritisation of interpersonal capabilities (instead of clinical, ‘rational’ ones) calls for:

“an epistemology of practice implicit in the artistic, intuitive processes which some practitioners do bring to situations of uncertainty, instability, uniqueness, and value conflict”

(Schön, 1983, p. 49).

To summarise, instead of seeing narrative as yet another therapeutic ‘tool’ to be applied by the clinician-as-expert in support of interaction, I instead bring to the fore the “intersubjective dynamics in relationship between teller and listener” (Hydén and Brockmeier, 2008, p. 7). A greater emphasis on the intersubjective space offers transformative potential that contrasts with normative, standardised practices that risk violation of “the mystery of the other...reducing his or her consciousness or freedom to passivity...or infancy” (Irigaray, 2001, p. 27), as described by participants in this study.

In the following section, I describe an example of a practice model that intends to shift norms of clinical interactions in supporting people living with TBI and their families, within a service improvement project using principles of coproduction, through a collaboration with 'Bridges Self-Management' social enterprise.

Practice model

Coproduction is considered to represent one mechanism through which power relations within healthcare services can be challenged (as discussed in Chapter 1). 'Coproduction' is an elastic term (Verscheure et al, 2012; Palumbo, 2016) but is underpinned by the principle that "you start from the people themselves and find out what they think works well, and what needs to be addressed" (SCIE, 2009, p. 4). This approach contests the traditional biomedical model of healthcare services and the maintenance of control by healthcare professionals (Palumbo, 2016). Coproduction may ultimately be compatible with broader interpretations and implementation of a relational understanding of self-management.

In conjunction with colleagues in the brain injury team at King's College Hospital NHS Foundation Trust, I collaborated with Bridges Self-Management in an empirical study that is closely related to (but distinct from) my research in this thesis. After securing funding for a service innovation project from the Health Foundation UK, we collaborated with people living with TBI, their families, and multidisciplinary professionals working in acute trauma and rehabilitation settings, to co-design a novel self-management support intervention. This was informed by Bridges' established model for people living with stroke (Jones et al., 2016a). A key component in the development of the intervention centred on stories told by people living with TBI and their family members and friends. These stories offer a rich resource for healthcare professionals that shift the interaction from professionals' priorities to people's own priorities and ways of talking about managing the everyday, for example, their stories about 'things that make me...me'. The stories are presented in people's own words within two complementary books, one for people with TBI and one for family and friends. Staff training introduces ways of implementing these resources within interactions and, importantly, emphasis is placed on the intervention not simply being "a book" to be "given out", without interactional support. We have reported elsewhere on these co-design activities, and the feasibility of implementation of this supported self-management approach (Mäkelä et al., 2019). This work offers a practice framework for supporting self-management after TBI: a map of what

can be done, a tangible, co-designed format that helps practitioners to make sense of collaborative principles in clinical interactions (Connolly, 2013).

Research

Contributions of this thesis include empirical insights into families' adjustments following an experience of TBI; theoretical application of combined concepts from performativity, positioning, and narrative scaffolding; and methodological extension through dyadic, longitudinal narrative interviewing, which has been infrequently used within neurorehabilitation research. Qualitative longitudinal research is "relatively unknown within the field of rehabilitation" yet ideal for research that aims to understand health-related challenges that unfold over time (Solomon et al., 2019, p. 1). Similarly, there has been little direct research seeking understandings of the role of storytelling within TBI rehabilitation (Weatherhead and Todd, 2013). However, in recent years, research interest in narratives as a therapeutic approach after TBI has increased, for example intending to address "how brain damage disrupts survivors' narratives about who they are, as well as their spontaneous efforts to cope with these changes via the generation of alternative narratives" (Salas and Prigatano, 2018, p.25). This research direction assumes that the narration will involve 'big stories' and does not elaborate on the central question of *how* this may or may not be helpful in co-creating collaboration in interactions between professionals and people living with TBI.

Through the current research, I have focused on understanding what might be accomplished through 'small', fleeting storytelling and re-tellings. Extending this work to consider its implications for research requires consideration of practices that are tied to specific subjectivities, arising unpredictably within clinical interactions and requiring the negotiation of power. I propose that understandings of subjective effects of labelling – the positions to which people are interpellated or 'hailed' – provides one way of raising awareness over "the labels which patients are given [that] may be detrimental in healthcare interactions"(Gershater and Forbes, 2013, p. 78). I have demonstrated the work of navigating sense of self when confronted by a hail to a position that challenges the desired self and expects "a particular patient voice" in the interaction (Gardner and Cribb, 2016, p. 1052).

The theory of performativity has been critiqued in terms of difficulties in its empirical application (Riach et al, 2016). In common with a wide variety of research endeavours (from exploring nursing home staff-resident-family interactions in England (Mäkelä, 2018)

to performative practices that produce donkeys' marginalised status in Botswana (Geiger and Hovorka, 2015)), I consider that concepts from Butler's performativity have helped me to open up new ways of thinking, for example, about ways that meanings are co-created, repeated and re-created. Critics have suggested that Butler's performativity creates a distancing from our everyday ways of thinking about the self (Fraser, 2013). By contrast, my application of constructs (particularly normativity, citationality and signification, as discussed in Chapter 7 (Butler, 2005; Nakassis, 2013), in conjunction with positioning analysis to consider challenges to sense of self (Bamberg, 2004a), has rendered certain things more visible and offered disruptive openings in my interpretations.

Although I have focused here on narrative construction with people living with TBI, the analytic approach and conceptual model may hold applicability to research on long term conditions more broadly, particularly those that involve positioning in "dominant power/knowledge hierarchies" (Bantjes and Swartz, 2019, p. 3) and where professionals may be "enabled in and constrained by mechanisms and institutions that they very much take for granted" (Gardner, 2001, p. 192). The framing of narratives as co-constructed, within inherently collaborative interactional processes, may be applicable for research particularly into conditions where people may be 'othered', or where there are associations to 'hidden' challenges to the sense of self (for example, narratives of people living with substance dependence, self-injury, depression, or people who are classified as 'frail'), rather than over-emphasising first-person 'life story' accounts.

Future research

In the course of undertaking this research, I have identified avenues of further inquiry that lie beyond the practical scope of this thesis. Beyond further elaboration of the positioning-performative analytic framework that I have applied, and the conceptual model outlined (Figure 6), I would particularly like to explore additional research openings that include: (1) metaphor in narration; (2) pets within narrative interviews, (3) emotion in research and clinical interaction; and (4) talk-in-interaction about supporting self-management, co-constructed with healthcare professionals. I consider each of these four areas briefly below and, in each case, I include a possible question as an initial prompt for further research.

Metaphor

Much social science research focuses upon the effect of recurring metaphors in framing the social world (Checkland et al., 2019). Metaphors represent an important narrative form, communicating complex concepts using analogy and inference that may indicate

underlying norms and expectations (Suddaby and Greenwood, 2005; Turner, 1975). Metaphors were often by the participants in this study, for example, Andy described his partner, Danielle, and their dog, Titan, as “my two rocks” (line 228), and Monte talked of going back to his family home as a place to “just drop my gloves” (line 209), and not need “my warrior voice” (line 218). Further, in giving my account of this study, I have relied on the metaphor of ‘scaffolding’ to represent an underpinning concept of mutual self-crafting, where I propose the tailoring of something that already exists. By contrast, metaphors of ‘loss’ of self or ‘void’ in the self after TBI (Nochi, 1998, 1997) invoke total devastation, as if “one’s old self has died” (Brown et al., 1997, p. 21); the need to start again.

Metaphor has generative potential to develop ideas in novel ways while also being embedded in the conventional language of daily life (Latham and Faulkner, 2019). In future research (or a secondary analysis of these data), a focus on metaphors could lead to additional insights in narrative analysis, or allow further consideration of their use within clinical interactions that intend to support self-management.

Question: *How is metaphor used to convey normative expectations or as a resource in shifting narrative scaffolds after TBI?*

Pets

I am interested in exploring literature on pets in qualitative research into long term conditions, for example, “how pets feature in people’s narrative accounts of their experiences” (Ryan and Ziebland, 2015, p. 67). I am particularly interested in analysis that brings attention to pets as characters in relation to self-crafting after TBI. Positioning of people in relation to pets was frequently apparent in these interviews, including participants’ talk about the pets’ views of subjects within narration. By way of brief example, I present two extracts where pets were brought into focus by participants introduced in Chapter 6. After Brenda had shared fond stories of their (now deceased) dog, of whom there were many photos around the home, Derek (her partner) went on to comment:

“He was Brenda’s dog, and he loved her dearly [laughs], and as soon as I came home, he didn’t want to know her [laughs]”

(Brenda’s partner Derek, Interview 1)

By contrast, when a dog and cat joined us in the room where Toby, his mother Susan and I were talking during the first interview at their home, Susan’s storytelling first positioned

the cat as a significant character for the family, by explaining that the cat was older than Toby, before going on to emphasise, in Toby's presence:

"The dog and cat get jealous for Toby's attention, him more than anyone else in the family"

(Toby's mother Susan, Interview 1)

In earlier chapters, I discussed Derek's reworking of narrative scaffolds in claiming a desired sense of self when facing physical fragility and altered 'male' positioning, and Susan's positioning of her son Toby as capable, in contrast with his stories of healthcare professionals' insistence on highlighting cognitive deficits. Further analysis of these interviews, attending to the many times that pets were present and physically contributed, or emotions and perspectives were attributed to them, or they were talked about as characters of strength in stories, would allow consideration of performative relationality with pets that is central in reiterations of kinship, home and everyday life for many, recognising the production and reproduction of selves "in specific contexts of human/non-human interaction" (Barad, 2007; Birke et al., 2004, p. 169).

Question: *How does relationality with pets constitute a performative affordance in storytelling, when facing challenges to self after TBI?*

Emotion

I am interested in further exploring emotion in the stories shared in these interviews, in two particular ways. Firstly, to analyse the power of emotion through the co-constructed story to which it is attached: "deep feelings are linked to a deep story" (Hochschild, 2019, p. 12), where a 'deep story' is one evoking a range of emotions. Here, deep storytelling may reaffirm kinship relationships and signal resolution of differences around inchoate emotional forces.

Secondly, attention to moments of heightened emotional awareness within my analysis has raised a question for me about the significance of contrasting moments: those where emotion seems to be absent or somehow does not register as emotion. Silent emotion - that is not explicitly expressed or attended to - may shape the interaction by becoming an entrée for "busywork", that is, technocratic and time-consuming distraction activities (Madden and Speed, 2017, p. 1). A seemingly non-emotive interaction may then take the place of a potentially emotion-laden exchange. Through reiterative practice, this may become the recurring norm or the taken-for-granted behaviour as "repeated practices that

cultivate certain emotions over others and certain ways of experiencing them over an array of options” (Cantó-Milà, 2016, p. 1).

I consider the ‘problematic of silence’ in qualitative research (Mazzei, 2007, 2003), and Morison and Macleod’s work on “taken-for-granted normative frameworks in veiled silences” (2014, p. 694), as potentially useful starting points in the development of this line of narrative inquiry. Here, ‘veiling’ refers to the *masking* of a speakers’ silence on a particular issue. Extending this concept, I am interested in what can be learned from moments where absence-of-emotion (instead of absence-of-voice) is masked within co-constructed narration. The masking may take the form of unemotive talk, or inauthenticity that marks out “absent present” emotion (Mazzei, 2017, p. 677). This type of analysis may identify otherwise *unrecognised* emotion that signals a positioning challenge to sense of self. For example, anxiety may have been the ‘absent-present’ emotion in Chloe’s father Aaron’s narration, for example when saying: “My advice is to ignore all advice and enjoy student life!” (Chloe’s father Aaron, Interview 1).

Question: *How can understandings of co-constructed emotion in narration inform interactions that intend to support self-management?*

Healthcare professionals

Extending this research, there is scope to explore how healthcare professionals navigate agency within conditions of constraint through the hail to a professional identity, and within the normative expectations of a healthcare institution. The analytic framework I have described (combining positioning, performativity and narrative scaffolding) could be explored and extended in analysis of healthcare professionals’ talk. One line of inquiry could explore talk that is situated within entanglements with elements that are “both material and discursive—objects, signs, physical acts, utterances, bodies” (Mazzei, 2017, p. 679), for example objects such as clinical ‘tools’ that are routinely used to structure interactions.

The conceptual model could be applied to analysis of interactions in which multidisciplinary rehabilitation professionals implement the co-designed supported self-management intervention for people living with TBI outlined above (Mäkelä et al., 2019). I would consider whether “normative restructuring” occurs – that is, changes to norms, rules and resources in professionals’ interactions with people living with TBI and families (May et al., 2016, p. 5) where “interactional asymmetry” may occur (Myrberg et al., 2018, p.

418) The co-designed resources, including stories from other people living with TBI, and their families, in managing everyday life and 'being me', might enable a shift in interactional norms of self-management support, opening up an intersubjective space.

Question: *How can norms of clinical interaction shift to create useful inter-subjectivities in supporting self-management, within constraints of 'professional' and 'patient' identities?*

Conclusion

“Good patient-professional communication” is identified as a central component of self-management support, to enable patients to feel “in control” (Pearce et al., 2015, p. 1). However, healthcare encounters may paradoxically constrain agency. In this thesis, I have explored the co-construction of stories about managing in everyday life with people living with TBI and their significant others. I have highlighted under-explored issues of how families sustain, or readjust, their narrative environments after TBI, and suggest implications that involve complex relationships of mutual interdependence and support. I have considered challenges of positioning, where new sources of adversity can arise not only through TBI impairments but through the dominant expectation: ‘you have changed’.

A focus on managing the everyday following TBI has brought to the fore issues of self, identity, and agency, within a culture where you *are* your brain (Krahn, 2015), and a dominant dichotomy of understanding the self as being defined ‘before’ and ‘after’ onset of a health condition (Power et al., 2018). Despite the centrality of ‘personhood’ and the ‘self’ within the contemporary health system constructs of person-centred care and self-management, these concepts remain poorly understood within clinicians’ approaches and interventions (Entwistle et al., 2018). The experience of TBI, and onset of long term conditions more generally, is viewed as biographically disruptive (Bury, 1982) or is alternatively conceptualised within narrative achievements of continuity in an inner self (Gelech et al., 2017) or as biographical flow (Faircloth et al., 2004). By contrast, the narratives in this study demonstrate navigation of consistency and change, aligning with emergent research suggesting that implications a person's narrative will be dominated by either disruption or flow are an over-simplification (Meijering et al., 2018).

The focus on brief moments of talk-in-interaction has allowed a different way of looking at illness narratives in this research, which I have interpreted through iterative applications of positioning analysis (Bamberg, 2004a) and performativity (Butler, 1993), brought together through an elaboration of the concept of narrative scaffolding (Hydén, 2011). I propose a need for attention to co-constructed narrative scaffolds as a collaborative activity in interaction, offering generative potential in recrafting sense of desired self in the face of positions of constraint. Potential for shifts in norms of clinical interaction require further exploration, to understand how a focus on the intersubjective interaction,

beyond the norms of the 'social script' of the patient-professional encounter, might become *constitutive* of support for self-management – a “personal platform”.

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Appendices

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1: Literature review resources

These literature review resources were initially developed in the DProf assignment FHSS804: 'A scoping review on self-management after traumatic brain injury'

Appendix 1a)

Sample MEDLINE Search Strategy:

- 1 exp Brain Injuries/ (52443)
- 2 "brain injury".ti,ab. (37988)
- 3 exp Craniocerebral Trauma/ (127017)
- 4 "head injury".ti,ab. (15068)
- 5 1 or 2 or 3 or 4 (145533)
- 6 exp Self Care/ (43160)
- 7 exp Self Efficacy/ (13190)
- 8 "expert patient".ti,ab. (95)
- 9 "self care".ti,ab. (11029)
- 10 "self management".ti,ab. (9258)
- 11 6 or 7 or 8 or 9 or 10 (65005)
- 12 5 and 11 (272)
- 13 limit 12 to English language (259)

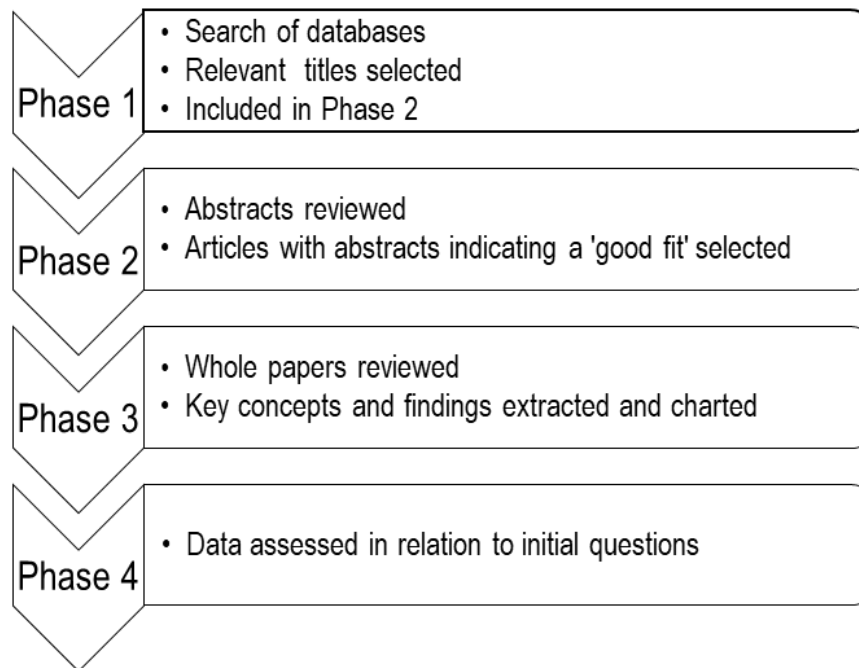
Appendix 1b)

Table: Inclusion and exclusion criteria applied to abstracts in literature review of self-management support after TBI

Inclusion criteria	Exclusion criteria
Relating to self-management following brain injury Diagnosis of acquired brain injury of any cause but traumatic brain injury represented in sample Healthcare professionals supporting self-management for people after brain injury Interventions to support self-management after brain injury Development of outcome measures for supported self-management after brain injury	Solely on pathophysiology, prevention, assessment, treatment or other unrelated aspects of clinical management No representation of traumatic brain injury within sample diagnoses Self-management in non-brain injury contexts Reported in a language other than English Focus on children aged under 18 years

Appendix 1c)

Figure - Flowchart of phases in literature review process



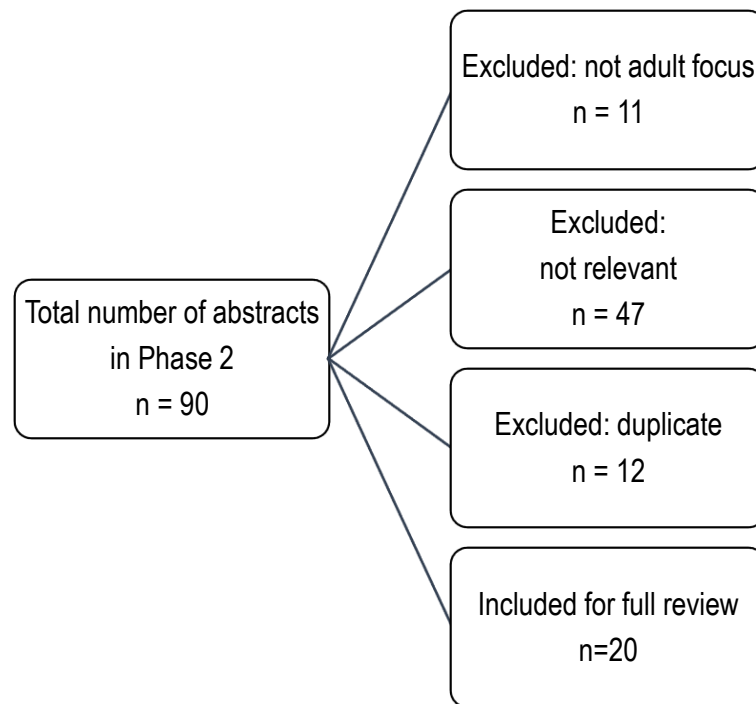
Appendix 1d)

Table: Breakdown of numbers of articles identified phases of literature search

	Phase 1	Phase 2	Phase 3
Medline	262	33	12
CINAHL	166	25	6
PsychINFO	55	15	2
EMBASE	45	4	0
AMED	34	5	0
Cochrane	17	4	0
ProQuest	11	4	0
Total	590	90	20

Appendix 1e)

Figure: Literature selection process



Appendix 1f)

Summary table of articles included in literature review (Chapter 2)

<i>Papers relating to self-management support interventions</i>					
	Ref	Title	Study type	Summary of purpose	Summary of main findings
1	(Kendrick et al., 2012)	Acquired brain injury self-management programme (SMP): a pilot study	Pilot study	Does a self-management coaching intervention improve daily function after acquired brain injury?	Canadian Occupational Performance Measure scores improved from baseline to discharge
2	(Muenchberger et al., 2011)	Living with brain injury in the community: Outcomes from a community-based self-management programme in Australia	Longitudinal study	Does a time-limited supportive group with collective activity goal improve self-management after acquired brain injury?	Trend for lower self-management and goal commitment with higher stress in females; stable for males across the assessment time period (no control group)
3	(Backhaus et al., 2010)	Brain injury coping skills group: a preventative intervention for patients with brain injury and caregivers	Randomised controlled pilot study	Does a Cognitive Behavioural Therapy (CBT) approach to a group programme improve perceived self-efficacy after brain injury?	Significantly improved perceived self-efficacy in treatment group as measured by the Brain Injury Coping Skills Questionnaire immediately after treatment
4	(Bergman et al., 2011)	Symptom Self-Management Measure for TBI	Adapting a measure and pilot	To develop a symptom self-management scale for people after TBI	Pilot testing of an adapted scale from HIV/AIDS context in sample of 14 with "mild TBI" and 14 healthy controls.
5	(Eghdam et al., 2012)	ICT to support self-management of patients with mild acquired	Systematic review	Do information technology tools used by healthcare professionals	7 articles met the inclusion criteria, (5 technologies were memory aids, and 6

		cognitive impairments: systematic review		assist people with acquired brain injury-related mild cognitive impairment to self-manage?	studies were mobile technologies). Concluded lack of information on tools suitable to support self-management after ABI
6	(Connolly et al., 2014)	An integrative review of self-efficacy and patient recovery post- acute injury	Integrative review	Is there a relationship between self-efficacy and recovery post-acute injury?	Interventions that increased self-efficacy included supervised educational interventions, coping strategies and/or cognitive behavioural training with feedback.
7	(Jones et al., 2015)	The efficacy of self-management programmes for increasing physical activity in community-dwelling adults with ABI: a systematic review	Systematic review protocol	Are self-management programmes for increasing physical activity effective?	Protocol only - for a systematic review.
8	(Wegener et al., 2014)	The Development and Validation of the Readiness to Engage in Self-Management After Acute Traumatic Injury Questionnaire	Questionnaire based study	To create an instrument to assess "readiness to engage in self-management programs" following acute traumatic injury	Suggested possible to measure "readiness to engage in self-management" following acute traumatic injury using the 'stages of change' model.
9	(Raina, 2018)	Effectiveness of a self-management intervention to teach individuals management of post-traumatic brain injury fatigue	Randomised, single-blind clinical trial	To test the efficacy of the maximizing energy (MAX) intervention ("education by using a problem solving therapy framework to teach individuals to self-manage their fatigue")	Modified Fatigue Impact Scale (mFIS) and PROM reported to show significant differences at intervention completion, 4 wk, 8 wk compared to baseline for the

				compared to a control for decreasing the impact of post-TBI fatigue	experimental group
<i>Papers relating to self-efficacy after brain injury</i>					
	Ref	Title	Study type	Summary of purpose	Summary of main findings
10	(Cicerone and Azulay, 2007)	Perceived self-efficacy and life satisfaction after TBI	Prospective cohort study; questionnaires	What is the contribution of perceived self-efficacy to global life satisfaction after traumatic brain injury?	Perceived self-efficacy for managing cognitive symptoms after brain injury accounted for 24% and 40% of variance predicting satisfaction with life and perceived quality of life.
11	(Dixon et al., 2007)	Perceptions of self-efficacy and rehabilitation among neurologically disabled adults	Qualitative study	Which constructs are relevant to self-efficacy in a neurological rehabilitation setting?	Eleven themes 'emerged' from the data, proposed to reflect self-efficacy beliefs.
12	(Tsaousides et al., 2009)	The relationship between employment-related self-efficacy and quality of life following traumatic brain injury	Correlational questionnaire based	How does employment-related and general self-efficacy contribute to perceptions of quality of life for individuals with traumatic brain injury?	Employment-related and general self-efficacy correlated positively with perceived quality of life and unmet important needs in 427 individuals with self-reported TBI under the age of 65.
13	(Trontel et al., 2013)	Impact of "diagnosis threat" on self-efficacy for academic tasks after mild traumatic brain injury	Prospective randomised; questionnaires and cognitive testing	Does external attribution of difficulties to a previous TBI affect own evaluation of academic self-efficacy?	Diagnosis threat group reported significantly lower academic self-efficacy than the control group, in 49 students with self-reported history of TBI.

14	(Ingrid Brands et al., 2014a)	Influence of self-efficacy and coping on quality of life and social participation after ABI: 1yr follow-up study	Prospective clinical cohort study; postal questionnaires	Does self-efficacy influence quality of life and social participation over one year following discharge with acquired brain injury?	High self-efficacy 'protective' against negative effects of 'emotion-orientated coping' in mixed sample of patients with variety of ABI diagnoses but less important for social participation, up to one year post injury
15	(Ingrid Brands et al., 2014b)	How flexible is coping after ABI? A 1-year prospective study investigating coping patterns and influence of self-efficacy, executive functioning and self-awareness	Prospective clinical cohort study; postal questionnaires	What is the influence of self-efficacy, executive functioning and self-awareness on patterns of coping over one year following discharge with acquired brain injury?	Found higher self-efficacy correlated with increased task-oriented and avoidance coping and decreased emotion-oriented coping in people with mixed ABI diagnoses up to one year after onset.
16	(Sherer et al., 2014)	Prognostic Importance of Self-Reported Traits /Problems/ Strengths and Environmental Barriers/Facilitators for Predicting Participation Outcomes in Persons With Traumatic Brain Injury: A Systematic Review	Systematic review	How do self-reported variables contribute to predicting participation outcomes after TBI?	Limited evidence identified regarding the prognostic importance of environmental barriers/ facilitators and patient self-reported traits/ problem/ strengths for participation outcomes, including employment, after TBI.
17	(Yehene et al., 2019)	Self-efficacy and acceptance of disability following mild traumatic brain injury	Prospective clinical cohort study; questionnaires and	What is the relationship between general self-efficacy, acceptance of	Authors suggested that their results indicated low levels of general self-efficacy

			'psychiatric ' clinical interview	disability and their impact on prolonged emotional outcome following TBI: depression, posttraumatic Stress Disorder and quality of life?	accentuate low acceptance of disability, leading to depression and poor general quality of life
<i>Selected papers using qualitative approach</i>					
	Ref	Title	Study type	Summary of purpose	Summary of main findings
18	(Price-Lackey and Cashman, 1996)	Jenny's story: Reinventing oneself through occupation and narrative configuration	Qualitative interview: one case at two time points; narrative analysis	How does narrative relating to adaptation to 'turnings' or major life events contribute to 'exceptional recovery' after TBI?	Narrative configuration had the theme "times of great change are times of great opportunity," used to contextualize events; also revealed engagement in self-devised occupations of increasing complexity.
19	(Schutz, 2007)	Models of exceptional adaptation in recovery after traumatic brain injury: a case series	Qualitative case series	Does adaptation explain 'exceptional recoveries' after post-acute treatment for TBI?	Nine "exceptional outcomes" (out of 204 follow-ups), as case series for phenomenological perspectives on "highly successful" recovery in relation to academic, vocational, and social achievements

20	(Soeker, 2012)	Development of the Model of Occupational Self Efficacy: An occupational therapy practice model to facilitate returning to work after a brain injury.	Qualitative: semi-structured individual interviews	What are the contributory factors to 'Occupational Self Efficacy' in returning to work after TBI?	10 participants (9 male) with "mild to moderate" TBI. Four themes emerged that reflected the lived experiences for people returning to work after a brain injury, which contributed to the central concept 'Occupational Self Efficacy'.
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Abbreviations: ABI – acquired brain injury; TBI – traumatic brain injury; SE – self-efficacy

2: Initial sampling frame

NB: sampling moved away from these initial categories as the research project progressed (sampling changes are described in Chapter 5)

	Younger age group (18 - 25)	Mid-range age group (25 - 65)	Older age group (>65)
Unemployed/not studying pre-TBI	X	X	X
Employed/studying pre-TBI	X	X	X
More severe TBI: requiring initial management in Intensive Care Unit	X	X	X
Less severe TBI: Not requiring initial management in Intensive Care Unit	X	X	X

- Participation sample size: 8 -12 people after TBI (If two age range categories used (<40 or >40) then sample size of 8. If the three categories above used, then sample size of 12)
- In addition, one relative or significant as identified by each individual after TBI invited to join dyadic interview
- The variable of requiring/not requiring initial management in the Intensive Care Unit intended sampling of a range of TBI severity of that could be clearly established at recruitment (Bulger et al, 2002), avoiding practical obstacles of inconsistent recording of clinical markers such as Glasgow Coma Score (GCS) and/or Post-Traumatic Amnesia (PTA).

3: Participant information sheets



Participant information sheet

A project to understand how people manage in their daily lives following a traumatic brain injury

Full title: A narrative inquiry into how people with traumatic brain injury 'self-manage' after discharge from hospital

What is the purpose of this project?

After traumatic brain injury (TBI), people often experience problems that may include a change in their mood, difficulties with memory or concentration, and challenges managing everyday activities. We know that some of the problems can persist after the initial brain injury and can have an impact on aspects of everyday life for the person with TBI and their family.

Many problems experienced by people after TBI are not fully acknowledged by all healthcare professionals or within society in general. At present, people may receive little support for getting on with their lives, and options for help are limited.

After discharge from hospital following TBI, people work out their own ways to manage challenges within their daily lives, often with support of family and friends. This project is intended to find out from people after TBI themselves, and family members or significant others, how they manage, what helps, and what would be important for healthcare professionals to know about in supporting other people to manage.

What will happen?

The researcher will discuss the project with you, either when you/ your family member or significant other is ready to leave the hospital, or when you have outpatient clinic follow-up.

You will be asked whether you would be willing for your General Practitioner to be informed that you are participating in the study, and for them to be provided with information, by the researcher, about what the study will involve.

You will be given a chance to ask questions and, if you agree to participate, you will be asked to sign a consent form.

The researcher will discuss with you when and where would be convenient to meet with you for an interview. This could be in your own home if you prefer, or at another location. It is important that the location is quiet and that interruptions will be minimised. Although 'interview' sounds very formal, it will be conducted as a relaxed conversation and you will be able to have breaks as you wish. The interview will last around one hour but this will depend on the individual and how much they would like to say. The interviews will be recorded with a digital recorder and will later be transcribed into a written version.

What if I change my mind?

You will be free to withdraw your consent to participate in the study at any time and without giving any reason. There will be no change in, or effects on, your (or your relative's) usual care.

Will my expenses be covered?

Yes. You will be reimbursed for your travel expenses and you will be given a grocery store voucher in recognition of your time and input.

What will happen after the project is finished?

The interviews will be analysed to find out what people have said about how they (or their relative) manage in their daily lives after TBI. This information will be used to increase understanding of what can help other people after TBI, and how healthcare professionals can best support them.

Who is carrying out the project?

The project is being undertaken by a Consultant in Rehabilitation Medicine based at King's College Hospital, who is undertaking this study as part of a professional doctorate degree that is academically supervised by the University of Westminster, London.

If you have any concerns:

If you are unhappy about anything to do with this research study and you wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) at King's College Hospital:
Email kch-tr.PALS@nhs.net or telephone: 020 32993601.

Further information and contact details:

For further information about this project please contact Petra Makela on:

Email: p.makela@nhs.net

Telephone: 07582494104

Thank you for taking the time to read this information sheet.

Information sheet for family member or 'significant other'

A project to understand how people manage in their daily lives following a traumatic brain injury

Full title: A narrative inquiry into how people with traumatic brain injury 'self-manage' after discharge from hospital

You are being invited to participate in a research study. This information sheet explains why the research is being done and what would happen if you agree to be involved. Please ask the researcher if you would like additional information or have any questions - contact details are available at the bottom of this sheet.

What is the purpose of this project?

After traumatic brain injury (TBI), people often experience problems that may include a change in their mood, difficulties with memory or concentration, and challenges managing everyday activities. We know that some of the problems can persist after the initial brain injury and can have an impact on aspects of everyday life for the person with TBI and their family.

Many problems of these experienced by people after TBI are not fully acknowledged by all healthcare professionals or within society in general. After discharge from hospital following TBI, people work out their own ways to manage challenges within their daily lives, often with support of family and friends.

This project is intended to find out from people after TBI themselves, and their family members or significant others, how they manage, what helps, and what would be important for healthcare professionals to know about in supporting other people to manage.

What will happen?

Each person with TBI who has agreed to take part in this study will be asked to identify one person who is close to them, to participate as well. This may be a family member or someone who is considered to be their 'significant other', in terms of support provided to them.

You will be given a chance to ask questions and, if you agree to participate, you will be asked to sign a consent form. The researcher will discuss with you when and where would be convenient to meet with you for an interview. This could be in your own home if you prefer, or at another location. It is important that the location is quiet and that

interruptions will be minimised.

Although 'interview' sounds very formal, it will be conducted as a relaxed conversation and you will be able to have breaks as you wish. The interview will last around one hour but this will depend on each person and how much they would like to say. The interviews will be recorded with a digital recorder and will later be transcribed into a written version.

You will be asked to participate in a similar, follow-on interview approximately six months later, again at a time and location convenient for you. Any information you provide will be anonymous. Information used in the research study will not include details that identify you personally.

Why have I been chosen?

You have been asked to participate as someone identified by a person who has experienced TBI from whom they receive support, as you may be able to share insights for others, about how you manage this.

What if I change my mind?

You will be free to withdraw your consent to participate in the study at any time and without giving any reason. There will be no change in, or effects on, your relative's usual care or any support that you would be offered as part of usual services.

Will my expenses be covered?

Yes. You will be reimbursed for any travel expenses incurred for the study, and you will be given a grocery store voucher in recognition of your time and input, for each of the two interviews.

What will happen after the project is finished?

All interviews will be analysed to find out what people have said about how they manage in their daily lives, after their or their relative's TBI. This information will be used to increase understanding of what can help other people after TBI, their families and significant others, and how healthcare professionals can best support them. Information will also be made available to health care professionals and other researchers, though articles published in medical journals.

Who is carrying out the project?

The study is being undertaken by a Consultant in Rehabilitation Medicine based at King's College Hospital, who is undertaking this study as part of a professional doctorate degree that is academically supervised by the University of Westminster, London.

If you have any concerns:

If you are unhappy about anything to do with this research study and you wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) at King's College Hospital:

Email kch-tr.PALS@nhs.net or telephone: 020 32993601.

Further information and contact details:

For further information about this project please contact Petra Makela on:

Email: p.makela@nhs.net

Telephone: 07582494104

Thank you for taking the time to read this information sheet.

Information sheet for General Practitioners

A project to understand how people manage in their daily lives following a traumatic brain injury

Full title: A narrative inquiry into how people with traumatic brain injury 'self-manage' after discharge from hospital

This sheet provides information about a research study in which a patient under your care has agreed to participate.

What is the purpose of this project?

After traumatic brain injury (TBI), people often experience problems that may include a change in their mood, difficulties with memory or concentration, and challenges managing everyday activities. We know that some of the problems can persist after the initial brain injury and can have an impact on aspects of everyday life for the person with TBI and their family.

After discharge from hospital following TBI, people often work out their own ways to manage challenges within their daily lives, with support of family and friends. This study is intended to find out from people after TBI themselves, and their family members or significant others, how they manage, what helps, and what would be important for healthcare professionals to know about, in supporting other people to manage.

Study design

This is a non-interventional, qualitative study, based upon interviews with people who have been discharged from hospital after TBI. In addition, each person with TBI who has agreed to take part in this study will be asked to identify one person who is close to them, to participate in interviews as well. This may be a family member or someone who is considered to be their 'significant other', in terms of support provided to them.

Interviews will be conducted by the researcher at a time and place identified as convenient by the participants. Each interview will last around one hour but this will depend on each person and how much they would like to say. The interviews will be recorded with a digital recorder and will later be transcribed into a written version. Participants will be asked to participate in a similar, follow-on interview approximately six months later. Information used in the research study will not include person-identifiable information.

Participants are free to withdraw consent to participate in the study at any time and without giving any reason.

There will be no change in, or effects on, usual care or support offered through services for people discharged from King's College Hospital after TBI.

What will happen after the project is finished?

All interviews will be analysed to find out what people have said about how they manage in their daily lives, after their or their relative's TBI. This information will be used to increase understanding of what can help other people after TBI, their families and significant others, and how healthcare professionals can best support them. Information will also be made available to health care professionals and other researchers, though articles published in medical journals.

Who is carrying out the project?

The study is being undertaken by a Consultant in Rehabilitation Medicine based at King's College Hospital, who is undertaking this study as part of a professional doctorate degree that is academically supervised by the University of Westminster, London.

Further information and contact details

For further information about this study, please contact the researcher:

Name: Petra Makela

Email: p.makela@nhs.net

Telephone: 07582494104

Thank you for taking the time to read this information sheet.

4: Consent forms

CONSENT FORM

A project to understand how people manage in their daily lives following a traumatic brain injury

Full title: A narrative inquiry into how people with traumatic brain injury 'self-manage' after discharge from hospital

Thank you for reading the Participant Information Sheet about this project. If you would like to take part, please read and sign this form.

Name: _____ Date of Birth: _____

1. I have read and understand the project information sheet in the Information Sheet dated April 2015, and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I agree that my General Practitioner be informed by the researcher that I am participating in this study.
4. I understand the interview session will be audio-recorded, and that it will be stored by the researcher for a period of 5 years from project completion.
5. I understand that the audio-recording will not be used for anything but the intended purpose of this project.

I agree to take part in the above project:

Name of person giving consent	Signature	Date
_____	_____	_____
Researcher	Signature	Date
_____	_____	_____

Department of Neurosciences
9th Floor Ruskin Wing
Denmark Hill
London
SE5 9RS

Email: p.makela@nhs.net

**CONSENT FORM
FOR FAMILY MEMBER OR SIGNIFICANT OTHER**

**A project to understand how people manage in their daily lives
following a traumatic brain injury**

Full title: A narrative inquiry into how people with traumatic brain injury 'self-manage' after discharge from hospital

Thank you for reading the 'Information Sheet for family member or significant other' about this research project. If you would like to take part, please read and sign this form.

Name: _____ **Date of birth:** _____

1. I have read and understand the Information Sheet dated April 2015, and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand the interview session will be audio-recorded, and that it will be stored by the researcher for a period of 5 years from project completion.
4. I understand that the audio-recording will not be used for anything but the intended purpose of this project.

I agree to my taking part in the above project:

Name of person giving consent Signature

Date

Researcher

Signature

Date

5: Ethical approval letters

1a) (Page 1 only)



Health Research Authority

NRES Committee London - City & East

Bristol Research Ethics Committee Centre

Whitefriars

Level 3, Block B

Lewins Mead

Bristol

BS1 2NT

Telephone: 01173421386

02 June 2015

Dr Petra M Makela
King's College Hospital NHS Foundation Trust
Denmark Hill
London
SE5 9RS

Dear Dr Makela

Study title:	A narrative inquiry into the experiences of people with traumatic brain injury and family members in 'self-managing' over the first two years following discharge from hospital.
REC reference:	15/LO/0525
Protocol number:	V1
IRAS project ID:	168036

Thank you for your letter of 26 May 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mr Rajat Khullar, nrescommittee.london-cityandeast@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

1b) (Page 1 only)

04/08/2015

Dr Petra M Makela
King's College Hospital
Department of Neurosciences
9th Floor Ruskin Wing
Denmark Hill
London
SE5 9RS

The Research & Development Office
Kings College Hospital NHS Foundation Trust
First Floor 161 Denmark Hill,
London, SE5 8EF

Direct tel: 020 3299 1980

www.kch.nhs.uk/research
kch-tr.research@nhs.net

Dear Dr Petra Makela,

Study Title: Self-management after traumatic brain injury: a narrative inquiry

Ethics ref: 15/LO/0525

Sponsor: King's College Hospital NHS Foundation Trust

Location: - Denmark Hill

Study end date as per SSI: 16/08/2018

Target Recruitment: 20

Protocol Version: V1.0 29/01/2015

On behalf of King's College Hospital NHS Foundation Trust, I am pleased to inform you that your project is approved and you may proceed.

The study has been registered as **KCH15-126**. Please quote this reference in any communications with the R&D Office regarding your project.

All approved documents are listed at the end of this letter. Please ensure that any amendments to the documents or changes to the study team are notified to the office.

Investigator Responsibilities:

You are expected to recruit to time and target. A condition of the approval is to notify the R&D Office of the date of first recruitment at the above email address.

The approval is conditional on the project being conducted as described within the application. The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures – especially those relating to research and data management.

You must notify the office of all changes to the project, such as extension of study activity time at site, amendment to protocol, changes in study team and site closure. For all KCH

V4 March 2015

1c)



PRIVATE AND CONFIDENTIAL

Petra Makela
and
Damien Ridge
15 July 2015

Dear Petra and Damien

App. No. External IRAS: 15/LO/0525
Name: Petra Makela
Faculty: Science and Technology
Mode: Doctoral Researcher (Professional Doctorate)
Supervisor: Damien Ridge

Project Title: A narrative inquiry into the experiences of people with traumatic brain injury and family members in 'self-managing' over the first two years following discharge from hospital

I am writing to inform you that the University Research Ethics Committee considered and noted the favourable opinion from NRES Committee London – City and East, REF Reference 15/LO.0525 and IRAS project ID 168036. The proposal was **approved**.

In the meantime if your proposal changes significantly, please contact the University Research Ethics Committee immediately in case of further consideration.

Yours sincerely

Huzma Kelly
Secretary, University Research Ethics Committee

cc. Chair, University Research Ethics Committee
Chair, Faculty Research Ethics Committee
Faculty Research Director
Supervisor
Graduate School Registry Manager

1d)



Health Research Authority

Dr Petra M Makela
King's College Hospital NHS Foundation Trust
Denmark Hill
London
SE5 9RS

Email: hra.approval@nhs.net

25 July 2016

Dear Dr Petra M Makela,

**Letter of HRA Approval for a study
processed through pre-HRA
Approval systems**

Study title: A narrative inquiry into the experiences of people with traumatic brain injury and family members in 'self-managing' over the first two years following discharge from hospital.
IRAS project ID: 168036
Sponsor: King's College Hospital NHS Foundation Trust

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given HRA Approval. This has been issued on the basis of an existing assessment of regulatory compliance, which has confirmed that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

1e)



Sent: 16 November 2016 15:07

To: MAKELA, Petra (KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST)

Subject: IRAS ID: 168036

Dear Dr Petra Makela

Study Title: A narrative inquiry into the experiences of people with traumatic brain injury and family members in “self-managing” over the first two years following discharge from hospital

DOCUMAS NO: 16HH3380

IRAS ID: 168036

I can confirm that Imperial College London/Imperial College Healthcare NHS Trust (ICHT) have the capacity and capability to host this research and confirm organisational readiness for this study

This means the project may now start at Imperial College/Imperial College Healthcare NHS Trust sites. Before you commence your research, please note that you must be aware of your obligations to comply with the minimum requirements for compliance with the Research Governance indicators 17 (Data Protection); 25 (Health and Safety) and 22 (Financial Probity). Details of the requirements to be met can be found in the Research Governance Framework available on www.dh.gov.uk

Under the Research Governance regulations, Serious Adverse Event Reports and amendments to the protocol or other supporting documents must be forwarded to the Joint Research Compliance Office.

In accordance with the Research Governance Framework, research projects carried out in the Trust will be randomly chosen by the Joint Research Compliance Office for auditing. Please see the attached checklist for documentation that will be required during the audit.

I wish you well in your research

Becky Ward, Research Governance Manager

Joint Research Compliance Office

Imperial College London and Imperial College Healthcare NHS Trust

Room 215, Level 2, Medical School Building

Norfolk Place

London, W2 1PG

Tel: 0207 594 9459 | E-mail: becky.ward@imperial.ac.uk

<http://www3.imperial.ac.uk/clinicalresearchgovernanceoffice>

6: Interview schedule

Overall approach

The researcher will follow the participants' narration and will generate questions in response to the participant's own flow of topics. The structure of the interview will be broadly guided by the 'aide memoir' below. This will be used flexibly, rather than as a pre-specified wording and ordering of questions (Zhang and Wildemuth, 2009).

Initial interview

Opening

- "Thank you for agreeing to take part in this study. I would like to find out how people cope after leaving hospital following a head injury".
- "Have you had a read of the information sheet? Would you like to discuss anything further, or ask any questions?"
- Talk through information regarding recording and transcribing of the interview and why this will be done.
- Explain about confidentiality and anonymity.
- Explain that an information sheet will be sent to General Practitioner (GP), to let the GP know about involvement in the study.
- Explain that participants are free to withdraw from the study at any stage if they wish, without any effect on their usual care or follow-up plans.
- Ask participants to read the consent form, give them opportunity to consider the content, ask them if they have any questions.
- After any additional issues have been addressed, ask participant if they are willing to sign to indicate their consent (respectively for each participant, if interviewing together as a dyad), then add researcher signature.
- Ask for mobile phones to be set to silent, ask if any interruptions are expected within the timeframe and, if so, discuss how these can be managed within the interview processes.
- Brief initial 'warm-up', rapport-building conversation not directly related to interview topic.

Body of interview

Can you tell me something about how things have been since your discharge from hospital?
[Follow-on questions*, according to participant's narrative]

**Examples of follow-on questions:*

Asking for more details:

- Can you tell me more about that?
- How do you do that?
- How did others respond to that?
- What did you do then?
- What felt helpful in doing that?

Exploring thoughts and feelings:

- Why did that matter to you?
- What felt important about that?
- What did that mean to you?

Clarifying questions

- Would you mind explaining that again? I'm not sure I understood correctly.

Closing

- Is there something else you would like to add?
- Would like to ask me anything else about this study?
- At interview 1: discuss what to expect for future plans regarding the follow-on interview, after an interval of around 6 -12 months
- Give store voucher as per protocol, in acknowledgement of time and contribution, and thank participants.
- Leave sheet with participants as described in 'sensitivity protocol'.

Follow-on interview

NB: The overall interview process will be developed iteratively, on the basis of reflection on successive interviews. This outline represents an early-stage guide.

Opening

- Reminder of intention of study: to explore how people cope after head injury, and that this 2nd interview is to find out about coping over a longer period of time since discharge from hospital.
- Review consent form signed prior to interview 1; give opportunity for questions, ask if participants are willing to proceed with next interview.
- Explain that participants are free to withdraw from the study at any stage if they wish, without any effect on their usual care or follow-up plans.
- Remind that the interview will be recorded and transcribed, and explain about confidentiality and anonymity.
- Ask for mobile phones to be put onto silent, check if any disruptions anticipated.

Body of interview

Can you tell me something about how things have been since the last interview (or since you left hospital, if unable to recall initial interview)

Follow-on questions as for initial interview

Any 'closed question' information (if not already gathered from clinical notes and/or at interview 1), for example information relating to each patient/significant other dyad; the nature of their relationship, whether they cohabit (before and since the discharge from hospital).

Closing

- Is there something else you would like to add?
- Would like to ask me anything else about this study?
- Give store voucher, in acknowledgement of time and contribution.
- Thank participants.
- Leave sheet with participants as described in 'sensitivity protocol'.

7: Honorary research contract

(page 1 only)

Honorary Appointment

Name	Dr Petra Marie Makela	
Address	20 Arthur Place Reading Berkshire RG1 3JP	
Substantive Employer	King's College Hospital NHS Foundation Trust	
Date issued	1 st March 2016	
Issued By (HR)	V Dyer	
Valid From	1 st March 2016	
End date	1 st February 2019	
Signed by (HR)	V Dyer	Date 1 st March 2016
Signed by Honorary		Date

1. Scope of Honorary Appointment:

1.1 The terms of the honorary appointment allow you to carry out certain duties at King's College Hospital NHS Foundation Trust (King's). The appointment is subject to the terms and conditions of service of Medical and Dental Staff insofar as they apply to honorary staff, and are further conditional upon your continued Registration and where appropriate licence to practice, with the relevant professional body.

1.2 You are appointed in an honorary unpaid capacity as a Research Fellow in the Networked Services Department at Denmark Hill with effect from 1st March 2016

1.3 We will confirm to you your duties of your honorary appointment prior to its commencement. By accepting such duties at King's you will be accepting the terms of the honorary appointment.

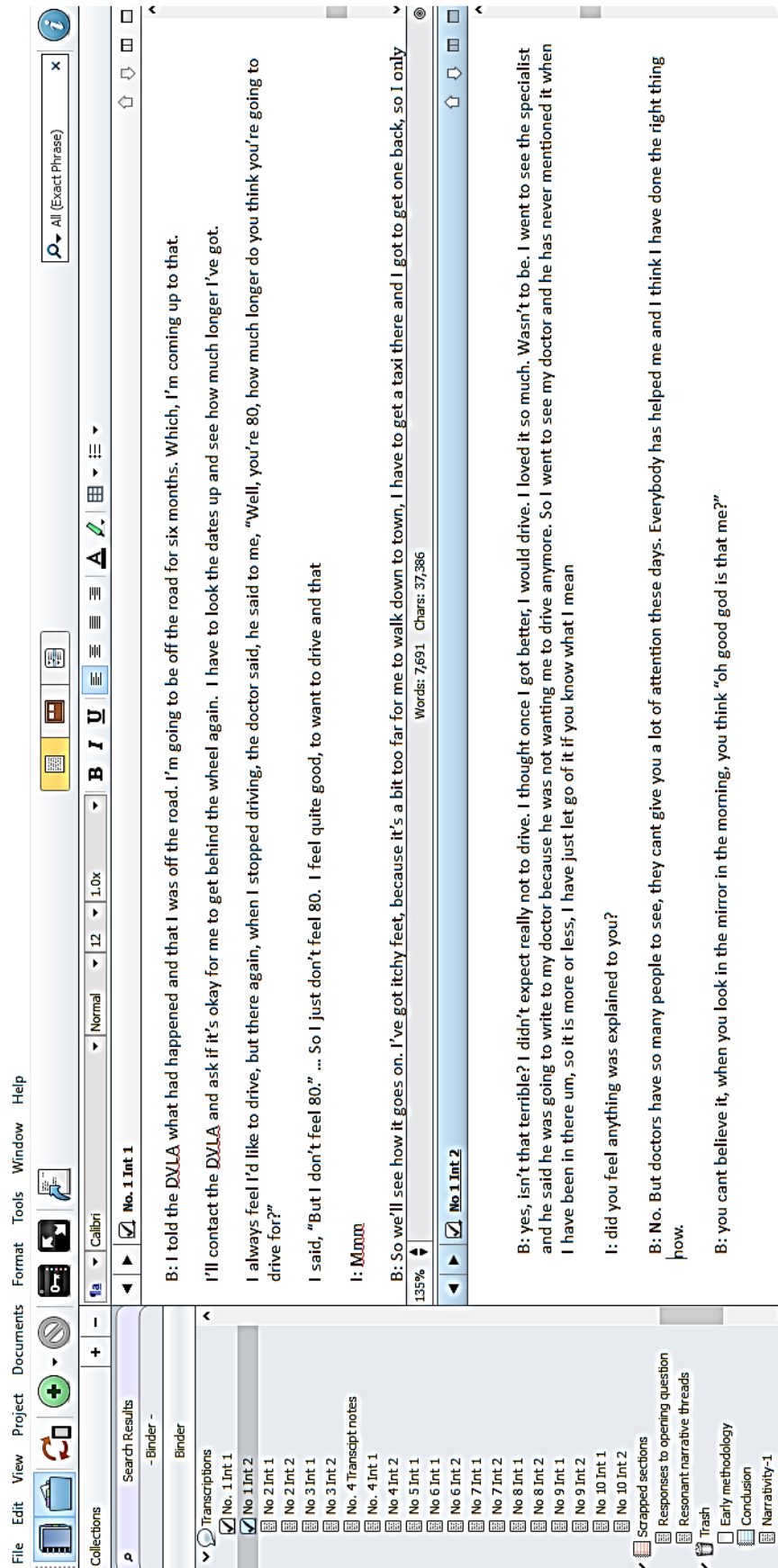
2. Status of Honorary Appointment Holder:

2.1 For the avoidance of doubt, the honorary appointment does not constitute a contract of employment with King's and you will not be entitled to any payment (including expenses, sick pay or holiday entitlement) as a result of the terms of the honorary appointment applying to you. This will not affect the terms and conditions of the contract of employment you already hold with your substantive employer.

2.2 The honorary appointment will terminate immediately if you:

- cease to be employed by your substantive employer, for whatever reason (including dismissal with or without notice and your own voluntary resignation); or commit any serious breach of King's policies or procedures; or

8: Scrivener screenshot example



9: Conference presentations relating to DProf research

Event	Presentation title	Institution	Date
Broken Narrative and the Lived Body	'I knew it wasn't me but I was told it was' - the broken self after brain injury and unbroken counter-stories	University of Monash @ Prato	18.04.16
BSA 48 th MedSoc Annual Conference	Narratives of traumatic brain injury and self-management following hospital discharge	Aston University, Birmingham	07.09.16
British Association for Applied Linguists Health and Science Communication SIG 'Experiences of illness and death: learning from the discourses of realities and fictions'	From 'cocoon to the real world' after traumatic brain injury: a narrative case study	Durham University, hosted at Open University	28.11.16
Nuffield Department of Primary Health Care Sciences 'Too Much Medicine' Conference	Collective performativity in nursing home to hospital transfer	University of Oxford	20.04.17
BSA 49 th MedSoc Annual Conference	Can Butler's theory of performativity be applied to (re)construction of identity following traumatic brain injury?	University of York	14.09.17
17th Biennial European Health and Medical Sociology Society Conference	Disrupting 'Self-Management': Broadening Understandings Through Narratives of Traumatic Brain Injury	University of Lisbon (ISCTE), Portugal	07.06.18
BSA 51 st Medical Sociology Annual Conference	Packaging and unwrapping of emotion in narratives of traumatic brain injury	University of York	13.09.19

10: Overview of participants

10a) Initial admission and interview details

Pseudonym	Age and gender	Occupation at time of injury	Mechanism of injury	Initial Glasgow Coma Scale (GCS) score/15	Neurosurgical intervention?	Other injuries sustained	Interval between injury and first interview	Interval first and second Interviews	Interviewed with whom?
Brenda	80 F	Retired clerk	Fall	13	Yes	No	6 months	8 months	Partner
Toby	21 M	Undergraduate student	Road traffic accident	9	No but neuro-intensive care	Yes	11 months	9 months	Mother
Mike	52 M	Company owner/director	Fall	3	Yes	Yes	6 months	7 months	Wife
Monte	29 M	Postgraduate student	Pedestrian hit by vehicle	13	No	Yes	7 months	7 months	Sister
Ewa	39 F	Single parent	Pedestrian hit by vehicle	3	Yes	Yes	14 months	No response	Brother
Claire	28 F	Legal professional	Fall	3	Yes	Yes	18 months	8 months	Sister
Walter	73 M	Retired teacher	Fall	Not recorded	Yes	No	3 years	7 months	Wife
Andy	33 M	Construction work	Assault	3	Yes	No	12 months	6 months	Partner
Chloe	19 M	Student	Fall	3	No but neuro-intensive care	No	2 years	8 months	Parents
Raminta	43 F	Shop assistant	Fall	4	Yes	No	2 years 10 months	6 months	Partner

10b) Categorisation of individuals' impairments from traumatic brain injury (at first research interview) *

Pseudonym	Clinical impairments	Description
Brenda	Cognitive-communication impairment; fatigue	Brenda was experiencing difficulties with sustaining her attention and concentrating on information, for example when reading or taking part in conversation. Combined with memory problems and reduced efficiency in processing complicated information, this meant that her fluency could be impacted within communication. This was worsened by anxiety when noticing her errors and by fatigue, which she described as an overwhelming feeling of tiredness that was not relieved by sleep.
Toby	Cognitive impairment; fatigue	Toby was experiencing some reduction in his ability to sustain his attention and to concentrate, with reduction in the ease with which he could remember and mentally manipulate information. His fatigue worsened these difficulties, leading to frustration with himself, and a tendency to become irritable with others more easily than before his injury.
Mike	Dysexecutive syndrome; dysphasia	'Dysexecutive syndrome' refers to disruption to a collection of thinking processes considered necessary for selecting and monitoring actions towards intended goals. Impairments impact on ways of coping with everyday life, work and relationships. Mike experienced a change (reported to him by others more than his own awareness) in regulating his contribution to conversation, with impulsivity and reduced flexibility in shifting his focus. 'Dysphasia' refers to speech and language disorders, where there is impairment of expression by speech or writing, and/or impairment of comprehension. Mike had difficulties in expressing himself fluently and understanding more complicated information.
Monte	Cognitive impairment; fatigue	Monte experienced reduced ability to sustain attention when engaged in tasks, to process complicated information quickly, and to remember events since his injury. He described difficulties in initiating tasks, linked with a profound feeling of loss of energy.
Ewa	Short-term and working memory impairment; dysexecutive syndrome	Ewa was experiencing problems with day to day learning, organising and remembering new information. Her problem-solving skills were affected by reduced flexibility when planning and evaluating her actions. She could become impulsive, frustrated and irritable, especially when tired or when attempting to deal with more than one task at a time.

Claire	Dysphasia (expressive more than receptive); post-traumatic epilepsy; fatigue	Claire was experiencing word-finding difficulties and needed to take her time to comprehend more complex sentences. This was associated with anxiety and reduced confidence in her communication skills. She also experienced epileptic seizures (fits), the medication for which caused side effects that exacerbated her fatigue.
Walter	Dysexecutive syndrome; global dysphasia; fatigue; short term memory impairment; post-traumatic epilepsy	Walter was experiencing reduction in problem-solving skills associated with a tendency toward more concrete thinking. He had difficulties with day-to-day learning and remembering new information since his injury. At times, he had difficulties expressing himself and in following more complicated information, particularly when communicating in the presence of background distractions. He experienced fatigue, exacerbated by sedative side effects of his medication for epilepsy, but remained very motivated to maintain his activity levels.
Andy	Fatigue; anterograde memory impairment	Andy was experiencing fatigue as an overwhelming, profound tiredness and described reduced motivation, which made everyday activities seem challenging to initiate and complete. His memory difficulties particularly related to problems with remembering new information since his injury.
Chloe	Mild cognitive impairment; low frequency anomic aphasia; hearing impairment	Chloe was experiencing some problems with her 'working memory': the short-term storage and use of information. She had relatively fluent speech and good comprehension abilities, but she experienced difficulty in word finding, particularly for words not used frequently in conversation, which worsened when anxious. She also experienced deafness in the left ear.
Raminta	Cognitive impairment; dysexecutive syndrome; anterograde memory impairment	Raminta experienced problems with her speed of processing for more complicated information, had reduced attention, and difficulties remembering new information since the injury. She could be impulsive when wanting to get her point across within communication, and could become distracted if attending to more than one task at a time.

** I have included these descriptions to provide some clinical contextualisation of the research participants. However, my intention within this thesis has been to explore issues that people bring up themselves, and navigate within social interactions. Further, these impairments and their degree of impact on function is not static but evolves over time and social context.*

Glossary

Agency can be viewed in contrasting ways: it is either a subject position determined by dominant narratives or it represents the 'self-creating' subject (Bamberg, 2004b). In this thesis, agency is understood in the context of iterability of identity positions that are continually reiterated and resignified. Agency arises through not accepting or adopting expected norms, thereby resignifying meanings and destabilising an identity position (Applebaum, 2010).

Assemblage refers to a whole entity that is characterised by relationships with external bodies and flows of affect (Feely, 2019). A component of a whole may be taken out and plugged into another assemblage, where its interactions will be different (DeLanda, 2019).

Citationality is a concept developed by Derrida (1978) in which the conjuring of something different comes about through repetition of what has gone before. By being "not quite" as before, the citation opens new possibilities for ways of being (Nakassis, 2013, p. 76).

Interpellation seeks to introduce a reality. It is an act of hailing where individuals acknowledge and respond to ideologies and then recognise themselves as particular subjects (Althusser, 1971; Butler, 1993).

Identity in this thesis refers to a continuous process of reiterating and resignifying one's position within and across discourses (Butler, 1990).

Hail to an identity - see 'interpellation' - for example, the hail "Hey you!" - to which we turn and respond, thereby recognising a subject position.

Neoliberalism within healthcare contexts refers to expectations that patients will take responsibility for their conditions or behaviours, framed as "outcomes" that can be measured. Patients are expected to manage and show improvement in these outcomes, away from healthcare services' resources.

Performativity refers to Butler's theory that there is no core identity, and that the subject is always involved in processes of acquiring identity through the reiteration of social norms. Performativity is "an understanding of continuous subjectivity, an understanding of the way in

which a subject is produced and acts within and through various conditions, and degrees of coercion” (Butler, 1993, p. 234).

Positioning in this thesis refers to processes by which positions are interactively selected, resisted and revisited in social interactions. Speakers are seen to assume positions in both the ‘told’ world of the story and the ‘here and now’ world of the telling. Positioning refers to the characters in relation to each other another in storytelling, and how the teller crafts the story in order to specify a ‘social location’ for the self in the act of telling (Bamberg, 2004a, 2004b).

Poststructural theories focus on the meanings people make in their socio-cultural-historical contexts and the way subjects *become* through discourse. Poststructuralism opens up opportunities for thinking differently about what we do, disrupting old certainties, replacing stereotypical thinking and opening possibilities in generation of something new (Davies, 2000).

Rehabilitation services in the NHS in England use similar processes to medical services more generally: assessing, diagnosing and treating. The key differences are that (1) medical services focus on the disease or condition, while rehabilitation focus on the consequences (disabilities’); and (2) the ‘treatment’ in rehabilitation involves iterative intervention from multidisciplinary professionals and assumes that the patient will be ‘engaged’ with activities determined through professionals’ expertise.

Self in poststructural understandings is constructed through language and action. The ‘relational self’ is understood as a social account, where a notion of ‘self and other’ replaces a ‘singular self’ (Frewin, 2002).

Supported self-management refers to a spectrum of healthcare intentions from broadly enabling people to live well with long term conditions, to a focus on their own responsibility for disease-control (Morgan et al., 2017)

Subject in poststructural theory is an effect of discourse: a subject is constituted in and through discourses but not fully determined by them.