

A thesis of clinical research and practice: Part A: [A Conceptual Review of Family Functioning in the Adult Brain Injury Literature]; Part B: [A Foucauldian Discourse Analysis examining how Clinicians construct the needs of Families of Adult Acquired Brain Injury Survivors]; Part C: Summary of clinical practice and assessments

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Abstract

The impacts of Acquired Brain Injury on both survivors of the injury, and on their family members, are profound. The consequences of Acquired Brain Injury are highly idiosyncratic. Equally, focusing on families, it is important to consider that all families are diverse. This thesis aimed to examine how families are considered following a brain injury in both clinical practice and research. The empirical paper (part two of this portfolio) was completed first, and the literature review (part one of this portfolio) emerged thereafter.

Part one of this portfolio is a conceptual review of family functioning in adult brain injury literature. The findings of this review observed many different conceptualisations of family functioning across the literature base, and highlighted several relevant aspects related to defining and measuring this concept. Quality appraisal of the included studies supported the need for future research, especially with regards to addressing social difference intersecting with family functioning in this population. Part two of this portfolio is an empirical paper adopting Foucauldian Discourse Analysis to consider clinicians views of family needs following an Acquired Brain Injury. The findings highlighted several wider discourses that participating clinicians working in neurorehabilitation contexts drew on, and how these collectively appeared to inform professionals' clinical practice. The implications of these papers on both clinical practice and research were considered.

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Declaration

I confirm that the submitted work is my own work and that I have clearly identified and fully acknowledged all material that is entitled to be attributed to others (whether published or unpublished) using the referencing system set out in the programme handbook/other programme research guidance. I agree that the University may submit my work to means of checking this, such as the plagiarism detection service Turnitin® UK. I confirm that I understand that assessed work that has been shown to have been plagiarised will be penalised.

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Part A: A Conceptual Review of Family Functioning in the Adult Brain Injury

Literature

Abstract

Acquired Brain Injury can have significant impacts on survivors and their family members. Developing an understanding of the variables that may be impacted by a brain injury, or may influence outcomes following a brain injury, holds implications for clinical services and clinical practice. Family functioning has been identified to be impacted by, and itself impact on outcomes, both in the context of health problems, and specifically in Acquired Brain Injury populations. Across the literature, there are different understandings and descriptions of family functioning, which contributes towards a lack of consistency in research considering this concept. Therefore, this conceptual review aimed to evaluate and describe how family functioning is defined and operationalised in literature including adult Acquired Brain Injury survivors and their family members. A systematic search across three electronic databases (PsycINFO, MEDLINE and Scopus) yielded twenty-six papers eligible for inclusion. Quality assessment of these papers observed some gaps across the current literature base. There were several different theoretical approaches adopted in the identified papers. Different attributes of family functioning were reviewed, as well as the perspectives of different family members and some of the complexities of family functioning. Multiple definitions and conceptualisations of family functioning were observed across included papers. Some issues with the current research base were highlighted, particularly in relation to the lack of diversity represented across studies, and the validity of existing theories and measurements for a brain injury population.

Introduction

Acquired Brain Injury (ABI) are documented to have significant impacts on the individual surviving the injury, as well as their family members. There is a body of literature that has considered the outcomes for caregivers and/or family members following a brain injury. One of the factors that has been identified as having an impact on outcomes for families and carers following a brain injury is family functioning (e.g., Baker et al, 2017). However, family functioning is conceptualised and operationalised in multiple ways in different research, across both the wider literature base and in ABI literature. This holds implications for how existing literature might inform both research and clinical practice. As such, it is important to review existing literature of family functioning in the context of an ABI, specifically focusing on how is conceptualised, defined, and measured.

Family Functioning

The concept of family functioning has emerged in literature since the 1970s (Dai & Wang, 2015). It is key to acknowledge that there is a lack of clarity with regards to a definition of family functioning in the broader literature base. Different models and authors stipulate different definitions. For example, the McMaster Model of Family Functioning stipulates that "the primary function of today's family unit appears to be that of a laboratory for the social, psychological, and biological development and maintenance of family members" (Epstein, Bishop, & Levin, 1978, p. 21). Another definition available comes from the Circumplex Model of Marital and Family Systems (Olson, 2000), which highlights three core dimensions of cohesion, flexibility, and communication. Presenting the model, the author explained that the three dimensions included in the circumplex model "emerged from a conceptual clustering of over fifty concepts developed to describe marital and family dynamics" (Olson, 2000, p. 144). In a review of family functioning, authors stipulate that

family functioning "embodies the characteristics of the family as a system" (Dai & Wang, p. 134).

Despite this lack of consensus, across different theories, models and definitions in the literature, there are some commonalities. The term family functioning refers to the qualities or characteristics of a family and their environment, and/or how families navigate tasks, and how all these factors support the development of all members of the family and the family system. Models and definitions of family functioning may pick up on different parts of these themes or highlight examples of different qualities or tasks of families deemed most pertinent.

Despite the lack of clarity around a definition of family functioning, the term often appears in literature without any consideration of the meaning of the term. The lack of consensus with regards to a definition of family functioning is an important part of the rationale for this conceptual review.

As part of defining family functioning, it is also important to consider the definition of family. Once again, family functioning literature does not stipulate a unified definition of family. In their review, Dai and Wang (2015) describe family as "the basic unit of society" (p. 134), and state that "a family is made up of every member of the family" (p. 134). Whilst the provision of any definition is useful, there are issues related to defining family that remain. There is a lack of consideration around immediate versus extended family influences, and of how individuals may choose to define their own family. How an individual chooses to define their own family, and who they are holding in mind, will impact the answers given in an assessment of family functioning, which will influence the outcome. Therefore, a key part of a conceptual review of family functioning will also involve consideration of how family may be defined across the literature included.

A recent review summarised two main theoretical approaches to family functioning; results-oriented and process-oriented (Dai & Wang, 2015). Results-oriented theories define family functioning by the features of a family and process-oriented theories of family functioning define the concept through the tasks a family needs to complete. There are several different theories that could be situated within both approaches to family functioning. These different theoretical approaches, and theories that sit within the approaches, importantly demonstrate some of the different conceptualisations of family functioning that exist. This highlights that in the wider literature, there is no singular definition of this idea and so it is not possible to necessarily infer what is meant by the term family functioning unless it is supplemented by the theory an author is drawing upon in using this term.

In addition to the above, there are several tools that have been developed to operationalise family functioning. Many questionnaires or scales to assess family functioning consider multiple dimensions, which reflect the theories and conceptualisations they may be drawing on. This is important to acknowledge, as the aims of the measures may therefore be to assess differently defined concepts or ideas to one another.

Different tools to assess family functioning may also be used differently, such as asking members of a family to self-report or relying on professionals to complete measures based on their interviews and observations of families. It is additionally important to acknowledge the subjectivity of using measures with families, especially as different members of a family may hold different perspectives. As such using the same measure with different members of a family may produce a different outcome and it is not necessarily possible to separate the attitudes and perceptions of the observer or informant from the concept being measures. Whilst psychometric properties to aid consideration of the reliability and validity of these tools, it is also important to consider whether the psychometric properties of the tools used have been assessed across different populations and cultures.

Adult Illness and Family Functioning

It is well documented that a range of both physical and mental illnesses can have significant impacts not only on those diagnosed with the illness, but also on their family members. Where a family member is experiencing a chronic illness, or health concern with long-term daily life consequences, family members and family environments can be impacted by changes in the daily routines due to management of the condition. In a review considering a range of chronic illnesses, authors identified evidence that family function and certain family behaviours were associated with the management of an adult's chronic condition, and the outcomes (Rosland, Heisler & Piette, 2012).

Acknowledging the relationship between family functioning and adult illness, a conceptual analysis of family functioning was completed (Zhang, 2018). The review adopted Roger's evolutionary concept analysis as the method to draw out the main conceptualisations and definitions of family functioning in the literature reviewed. The review highlighted family functioning to include how families are able to maintain relationships and communication with one another, how family roles may be fulfilled, and how families adjust to the new routines and cope with challenges. The author named that family functioning is a concept of interest to multiple disciplines, which may also impact how different researchers approach conceptualisation and operationalisation. The review additionally acknowledged the importance of considering different sociocultural and political contexts when considering how family functioning is defined. Recognising how family functioning is represented in the illness literature is important as it highlights the multi-dimensional nature of the concept, and the inconsistent conceptualisation.

ABI and Families

ABI has significant impacts on not just the survivors of the injury, but also on their families. The impacts on survivors and their families are long term and enduring (Holloway, Orr & Clark-Wilson, 2018). Both ABI populations and families are heterogenous.

Individual and family mental health and wellbeing (Baker et al., 2017), and quality of life (Knight, Devereux, & Godfrey, 1998) have been demonstrated to be impacted in the aftermath of an ABI. Several concepts have been shown to have an association with the rehabilitation, trajectory, or outcomes of survivors of ABI and their families. For example, the nature of the brain injury (Vangel et al, 2011), existing resilience (Anderson, Daher & Simpson, 2020), coping skills (Baker et al., 2017), and social support (Baker et al., 2017; Vangel et al., 2011) have all been found to affect family outcomes after ABI.

Certain health and psychological outcomes have been demonstrated to correlate between the survivor of an ABI and their family (Vangel, Rapport, & Hanks, 2011). For example, brain injury survivor's higher distress and lower life satisfaction were found to be associated with lower familial behavioural control (family rules and standards for behaviour). Survivors with higher levels of disability were also noted to be associated with caregivers reporting higher distress and lower life satisfaction. This highlights an important link between family members with regards to the trajectory of a family following an ABI.

Family Functioning and ABI

The presence of a brain injury has been noted to have an impact on family functioning, which has been broadly associated with both positive and negative outcomes following ABI (Baker et al., 2017). This relationship has been acknowledged in scoping review papers that are considering many different factors that may impact on families following an ABI. Due to the nature and purpose of scoping reviews, these often offer an overview of different factors that are implicated following a brain injury. This can result in

not being able to consider individual factors (such as family functioning) in depth, particularly with regards to how one specific concept has been conceptualised and operationalised in the included studies. It is acknowledged that further research is needed to help develop a more in-depth understanding of factors that correlate to ABI outcomes (such as family functioning), and the nature of these relationships (Vangel et al., 2011).

It is clear from the existing literature that there are multiple theories and approaches to family functioning (Dai & Wang, 2015). As was described in a review of family functioning including multiple adult illnesses, there were certain dimensions of the concept that emerged across different conceptualisations (Zhang, 2018). However, there were also a number of differences in the conceptualisations that were discussed in the review. As such, it is relevant that there is not one singular conceptualisation that was identified in the broader literature.

A previous review has focused on summarising and evaluating family functioning following a brain injury in children (Rashid et al., 2014). This review was helpful in drawing out some of the complexities of family functioning in this paediatric population. Equally, the review acknowledged it was limited by the quality of some of the studies included and recognised that family functioning was defined and measured differently across studies. Additionally, the review stated that where the same measurement tool was used, the authors were unable to complete a meta-analysis due to heterogeneity in the measurement timepoints and population groups. Thus, this review evidenced the challenges of inconsistent definition and measurement that have been observed in multiple populations are also relevant to brain injury.

Aims

Existing literature highlights the relevance of family functioning in the context of ABI, as it is identified as influential over outcomes for both survivors and family members. The significant impact of ABI on family members is documented in the population of adult

ABI survivors, where existing family factors may be impacted by the occurrence of a brain injury.

The issues that have been raised in broader literature around the multiple different conceptualisations and operationalisations of family functioning are equally relevant to the brain injury population. As such, it appears pertinent to offer a conceptual consideration of family functioning in adult ABI literature in the first instance, to explore and evaluate the current state of the evidence-base. Therefore, this conceptual review aims to evaluate and describe how family functioning is defined and operationalised in adult ABI literature. This review aims to consider the strengths and limitations of existing literature, and through this provide conceptual clarity to enable both researchers and practitioners to have enhanced understanding of how the evidence-base might be used to inform research and clinical practice.

Methods

Data sources and search strategy

A consultation was completed with a specialist interest group (Anchor Point). This group of clinicians have a specific interest in the experiences of families following ABI, and a consultation was completed with the research working group. This was particularly focused on the face validity of this review, and to support considerations of the implications of this review on clinical practice. This consultation emphasised the importance of drawing out the relationship between the theoretical underpinnings of measures used in research, and how these are interpreted both in literature and in clinical practice. With regards to the clinical implications, the consultation also supported developing a further understanding of how family functioning may be assessed and considered in clinical practice, which is important to reflect upon in comparison to how family functioning may be discussed in a research context.

The search strategy aimed to identify research studies that considered the relationship between having an adult family member who has survived an ABI and family functioning. All searches were completed by the researcher individually, however, the search strategy was discussed with research supervisors prior to commencing the search.

A systematic search was completed across three electronic databases. These included PsycINFO, MEDLINE and Scopus. The search strategy aimed to capture papers that focused on both ABI and family functioning, including any synonyms or alternative terms for these concepts. Full details of the search terms used across the database searches is outlined in appendix A. Due to the resources available, articles that were published in languages other than English were not included in this review.

In order to assess which papers to include in the conceptual review, all search results were downloaded to a reference manager (Zotero). The full list of texts was reviewed to remove any duplicate results. Results from the searches were reviewed by the researcher. Initial screening was based on the titles and abstracts, using the inclusion and exclusion criteria outlined below. For any remaining articles that appeared relevant to the review topic, or for any articles where the decision to include or exclude was unclear, a full text review was completed. Following the full text reviews, a decision was made on whether to include or exclude each article. The search and screening decisions were completed independently by the researcher, though supervision was available to discuss any queries, and any papers where the decision regarding inclusion could not be made independently by the researcher. Once screening had taken place the reference lists of the papers included in the review was cross-checked with all papers identified through searches. This was done with the purpose of ensuring all relevant papers had been identified.

Eligibility criteria

Empirical papers were included in this review if they met the following criteria;

- The survivors of the brain injury were required to be adults (i.e. over the age of eighteen years) at the time of the research taking place.
- The papers needed to be focused on survivors of acquired injuries (i.e. the individual cannot have been born with the injury).
- The study could be conducted at any time point after the brain injury, meaning the review aimed to capture research that focused on both recent and longer standing injuries.
- Family functioning was required to be one of the variables assessed in the paper (either independent or dependent).. This could have been defined by the author in any way as this review aims to capture these different definitions.

Where there was insufficient information about the demographics of the survivors of brain injury to determine whether these met inclusion criteria, the papers were not included. Published abstracts where the full text was not published/obtainable were also excluded. This was the case for four abstracts and represents a potential shortcoming of this review.

The search strategy was for papers completed prior to December 2022, which is when this literature search was completed. No start date was selected in order to try and capture as much of the research including historical research as possible. All study designs were considered for this review of family functioning, as it was looking to consider the current literature available. This means quantitative, qualitative and mixed method designs were eligible to be included in the review. No restrictions were placed on the type of empirical papers that could be included. Journal articles of all types, as well as dissertations were considered, as long as the full texts were available online.

Data extraction

The data that was extracted from the studies included information relevant to the:

- Study location.

- Study aims and/or hypotheses.
- Study design and/or analysis methods.
- Conceptualisation of family functioning (e.g., any definition provided, any theory referenced in relation to this).
- Inclusion/exclusion criteria.
- Descriptive statistics of the participant population and/or brain-injured sample (e.g. age, gender, ethnicity, education, financial status, brain-injury related descriptive).
- Operationalisation of family functioning in the study (e.g., measures selected, timing of assessing family function, how measures were implemented).
- Any additional variables included or controlled for in the study.
- Outcomes of the study.

Quality assessment

Quality assessments were completed for each of the papers included in the review.

The quality of the studies was assessed by the researcher using the Mixed Methods Appraisal Tool (Hong et al., 2018). This tool was selected for quality appraisal due to the range of methods adopted by the studies that were screened and deemed eligible for inclusion in this review. With this in mind, using the Mixed Methods Appraisal Tool enabled the same quality appraisal tool to be meaningful for the different study designs. Due to the constraints of this review, it was not possible to have two reviewers rate each study. However, any queries about quality ratings were raised in research supervision and discussed to reach a consensus. In line with recommendations by Hong and colleagues (2018), studies were not given numerical quality ratings with the MMAT. Rather the quality of the included papers was considered qualitatively and taken into account when drawing any conclusions.

Data synthesis

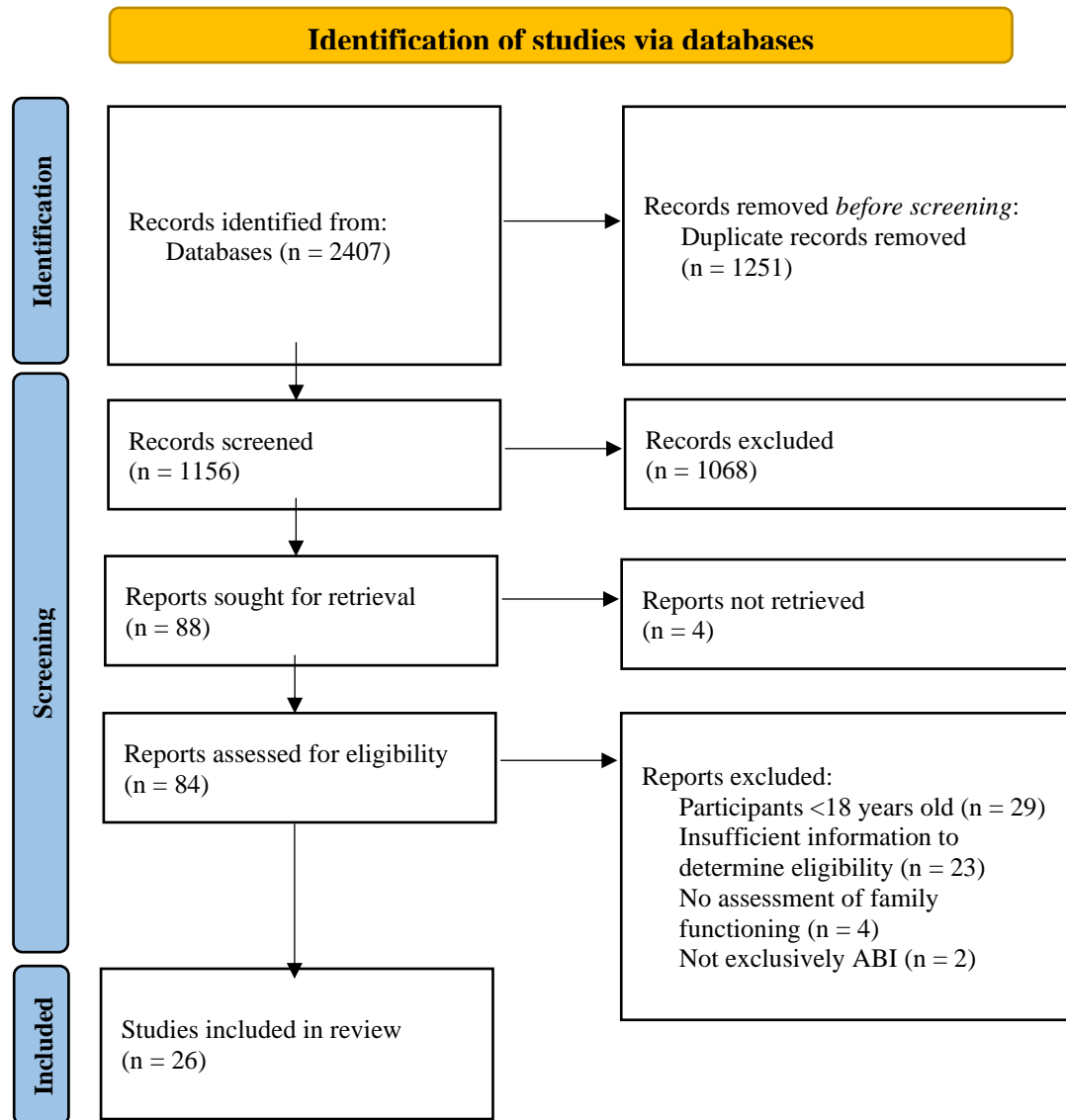
The results were synthesised using an adapted narrative qualitative synthesis. The synthesis of this data was completed drawing on the approach as described by Popay and colleagues (2006). The extracted data were noted descriptively, which also enabled consideration of any elements or variables constructed or measured similarly across different studies. The first stage of this was developing a preliminary synthesis to offer an initial description of the data extracted from the included studies. This preliminary synthesis often enables patterns to emerge from the data. Thereafter, relationships within and between studies could be explored. It was important to consider variability in definition of family functioning, study population, family functioning measures and implementation.

Results

Figure 1 provides an overview of the process of conducting this review, and table 1 provides an overview of the included studies. The conceptualisations of family functioning are discussed below, including the different theoretical approaches, attributes of family functioning, perspectives of different family members and some of the complexities of family functioning.

Figure 1.

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram



Note: From Page et al. (2021)

Table 1.*Summary of included studies (n = 26)*

Authors (Year)	Country	Family Functioning Models	Participant Demographics (Gender, Age, Ethnicity, Education, Employment, Relationship; all demographics reported only if available)	Brain Injury Characteristics	Family Functioning Measures
Addis (1995)	USA	Circumplex Model of family functioning Family systems theory	49 families <u>Brain Injured Individuals</u> : Gender (37% female, 73% male), Age (average 33 years) <u>Family Members</u> : Gender (88% female, 12% male), Age (average 50 years), Relationships (61% parents, 33% spouse, 4% sibling, 2% significant other)	Average 5 years post-injury (range 1-20 years)	Family Adaptability and Cohesion Evaluation Scale Third Edition (FACES-III) (parent-sibling and couples functioning versions) Completed by caregiver
Anderson et al. (2002)	Australia	McMaster Model of family functioning	64 families <u>Brain Injured Individuals</u> : Age (average 46 years), Ethnicity (all Anglo-Australian) <u>Family Members</u> : Gender (73% female, 27% male), Age (average 45 years), Ethnicity (98% Anglo-Australian, 2% Mauritian), Employment (80% employed, 60% low-mid income, 40% >\$40,000, 8% >\$70,000)	All severe Traumatic Brain Injury (TBI) resulting from motor traffic accidents, falls, work related, assaults, sports injuries Average 43 months post-injury	Family Assessment Device (FAD) Self-report completed by family members
Barclay (2013)	USA	McMaster Model of family functioning	60 ABI survivors Gender (78% male, 22% female) Age (average 43 years), Ethnicity (62% Caucasian/White,	Injuries resulting from stroke (35%),	FAD

			32% African American/Black, 5% Hispanic, 2% Asian/pacific islander), Education (largest concentration 28% high school graduates), Employment (pre-injury income ranged up to \$100,000)	acceleration/deceleration (43%), other (22%)	Self-report by brain injury survivors
Boyle (1997)	USA	Family functioning operationally defined by the dimensions of the FAD	34 families & control group <u>Brain Injured Individuals</u> : Gender (100% male), Age (all required to be 18+) <u>Family Members</u> : Gender (59% female, 41% male), Age (average 51 years), Ethnicity (88% Euro-American, 9% African American, 3% Native American), Relationship (All parents)	Closed head injuries (or non-head injured control group) Average time post-hospitalisation 12 months	FAD Completed by family members
Bull (1999)	USA	Family systems theory Family environment	40 families <u>Brain Injured Individuals</u> : Gender (60% male, 40% female), Age (average 32 years), Ethnicity (65% European American, 13% African American, 13% American Indian, 10% Hispanic) <u>Family Members</u> : Relationship (53% parents; 28% spouses/significant others, 5% siblings, 10% friends, 5% children)	Severity of injury (25% mild Glasgow Coma Scale (GCS) 13-15, 30% moderate GCS 9-12, 45% severe GCS 1-8) Range 1-7 years post-injury	FACES-II Completed by family members
Cariello et al. (2020)	Mexico & Columbia	Family systems approach	109 TBI survivors Gender (83% male, 17% female), Age (all aged 18+ years), Education (average 10 years), Employment pre-injury (61% FTE, 16% PTE, 7% homemaker, 8% student, 1% pension, 1% retired)	Injuries resulting from Motor Vehicle Accident (MVA) (51%) pedestrian accident (6%), gunshot (2%), acts of violence (16%), sports injury (1%), fall (21%), other (2%) Average 1.8 months post-injury (data)	FAD Spanish version Completed by brain injury survivors

			collected multiple times over 4 months)		
Charles et al. (2007)	Australia		6 families <u>Brain Injured Individuals</u> : Gender (66% male, 33% female), Age (range 26-49 years), Employment (pre-injury range of jobs, many unable to return to work) <u>Family Members</u> : Whole families included, Relationships (spouses and children)	Injuries resulting from MVA (50%), brain tumour, aneurism, stroke Range 2-30 years post-injury	FAD General functioning subscale Dyadic adjustment scale Self-report (unclear who completed this)
Chinnery (2005)	USA		45 families <u>Brain Injured Individuals</u> : Age (Average 49 years), Ethnicity (95% White), Education (average 14 years) <u>Family Members</u> : Gender (86% female, 13% male), Age (average 49 years), Relationship (all spouses), Education (average 15 years)	Where known, majority severe brain injury Injuries resulting from MVA (53%), falls (29%), anoxic injury (11%), blow to the head (7%) Average 68 months post-injury	FAD Completed by family members
Cox et al. (2020)	Netherlands	McMaster Model of family functioning	77 families <u>Brain Injured Individuals</u> : Gender (66% male, 34% female), Age (average 59 years), Education (44% higher education), Employment (69% employed pre-injury) <u>Family Members</u> : Gender (34% male, 66% female), Age (average 58 years), Relationship (all partners), Education (31% higher education), Employment (61% employed pre-injury)	Injuries resulting from ischemic stroke (58%), hemorrhagic stroke (29%), TBI (10%), oncology post-surgery (1%), encephalitis (1%)	FAD General functioning subscale Dutch version Completed by brain-injured individuals and family members independently

Curry (2006)	USA	McMaster Model of family functioning Family Strengths Theory	31 families <u>Brain Injured Individuals</u> : Gender (74% male, 26% female), Age (average 44 years); Ethnicity, (94% White/Caucasian, 3% Asian, 3% American Indian), Education (94% high school graduate), Employment (27% and 13% employed) <u>Family Members</u> : Gender (84% female, 16% male), Age (average 57 years), Ethnicity (all White/Caucasian), Relationship (52% parents, 48% spouses), Education (94% high school graduate)	Injuries resulting from MVA (70%), falls (6%), athletic injuries (10%), bullet (3%), surgery (10%)	FAD American Family Strengths Inventory Completed by family members
Curtiss et al. (2000)	USA	Circumplex Model of family functioning Family structure	21 families <u>Brain Injured Individuals</u> : Gender (100% male), Age (average 37 years), Ethnicity (70% White, 20% Black, 10% Hispanic), Education (average 13 years), Employment (either active military or military veteran) <u>Family Members</u> : Age (average 34 years); Ethnicity (58% White, 21% Black, 11% Hispanic, 5% Asian, 5% other), Relationship (all spouses)	Non-penetrative ABI, Average GCS 5.4 (range 3-13) Average 10 weeks post-injury	FACES-II completed twice (once retrospective, once current) Completed by family members
Douglas & Spellacy (1996)	Australia	Family System Theory	30 families <u>Brain Injured Individuals</u> : Gender (60% male, 40% female), Age (average 30 years), Education (range 57% partially completed high school – 20% university degree), Employment (33% employed post-injury) <u>Family Members</u> : Gender (83% female, 17% male), Age (average 47 years), Relationship (parents and spouses)	Closed head injuries resulting from MVA Average 84 months post-injury	Family Environment Scale Form R Completed by brain-injured individuals and family members independently

Fischer (1997)	UK	Expressed emotion Family expectations Family environment Family structure Circumplex model of family functioning McMaster model of family functioning	5 families <u>Brain Injured Individuals</u> : Gender (80% male, 20% female), Age (range 18-34 years), Ethnicity (100% White European) <u>Family Members</u> : Gender (63% female, 38% male), Age (range 45-62 years), Ethnicity (100% White European), Relationship (Parents - mothers of all families, fathers of 3 families), Employment (all mothers and 1 father reduced/stopped working)	Injuries resulting from MVA (80%), secondary to surgery (20%) Range 2-15 years post-injury	FACES-II FAD Family Environment Scale Five Minute Speech Sample Semi-structured interview Completed by family members
Geurtsen et al. (2011)	Netherlands	McMaster Model of family functioning	41 families <u>Brain Injured Individuals</u> : Gender (66% male, 33% female), Age (average 24 years) <u>Family Members</u> : Gender (68% female, 32% male), Age (average 48 years) Relationship (80% parent, 15% spouse, 5% sibling)	ABI Severity of injury (80% severe GCS 3-8, 20% mild GCS 13-15) Average 4.6 years post-injury	FAD Dutch version Completed by primary caregiver family members
Kelly et al. (2013)	Australia		41 families & age/gender matched controls <u>Brain Injured Individuals</u> : Gender (71% male, 29% female), Age (average 39 years), Education (average 13 years), Employment (80% unemployed) <u>Family Members</u> : Relationship (44% parents, 47% spouses, remainder siblings/children/close friends)	Injuries resulting from MVA (54%), assault (7%), work related incidents (2%), falls (20%), encephalitis (10%), cerebrovascular accident (7%) Average 5 years post-injury	FAD Completed by brain-injured individuals and family members independently, also completed by control group
Kosciulek (1994)	USA	Resiliency Model of Family Stress,	150 families <u>Brain Injured Individuals</u> : Age (18+ years) <u>Family Members</u> : Age (average 49 years), Ethnicity (99% White, remainder not	At least one year post-injury	FAD General functioning subscale

		Adjustment, and Adaptation	reported), Relationship (51% mother, 26% wife, remainder not reported), Employment (median family income \$29,800)		Completed by primary caregiver family members
Kosciulek (1995)	USA	Family stress and coping theory	150 families <u>Brain Injured Individuals</u> : Age (18+ years) <u>Family Members</u> : Age (average 49 years), Ethnicity (99% White, remainder not reported), Relationship (51% mother, 26% wife, remainder not reported), Employment (median family income \$29,800)	At least one year post-injury	FAD Completed by primary caregiver family members
Kosciulek (1997)	USA	Resiliency Model of family stress, adjustment and adaptation	87 families <u>Brain Injured Individuals</u> : Gender (71% male, 29% female), Age (average 36 years) <u>Family Members</u> : Gender (83% female, 17% male) Age (average 51 years), Relationship (62% parent, 26% spouse, 7% sibling, 5% other), Education (range 1% less than 8 th grade – 6% graduate/professional degree), Employment (median income \$34,845)	Average 8 years post-injury	FAD General functioning subscale Completed by primary caregiver family members
Laratta et al. (2021)	Italy		35 families <u>Brain Injured Individuals</u> : Gender (29% female), Age (average 58 years), Education (range 14% elementary school – 17% university), Employment (71% unemployed) <u>Family Members</u> : Age (Average 56 years), Relationship (all spouses), Education (range 11% elementary school – 23% university), Employment (51% unemployed)	Injuries including Vascular (57%), Traumatic (43%) Measures taken at hospital discharge and two years later	Dyadic Adjustment Scale Family Relationship Index Completed by brain-injured individuals and family members independently

Maitz (1990)	USA	Family systems model	<p>Criterion group 43 families & comparison group 18 families</p> <p><u>Brain Injured Individuals</u>: Gender (60.5% male, 39.5% female), Age (average 42 years), Education (range 51% Junior High – 23% university), Employment (family earnings 82% <\$20,000, 13% %20-40,000, 5% >\$40,000)</p> <p><u>Family Members</u>: Demographics not reported</p>	<p>Injuries resulting from MVA (79%), Falls (9%), other (12%)</p> <p>Average 6 years post-injury</p>	<p>FACES-III</p> <p>Completed by brain-injured individuals and family members independently</p>
Ponsford et al. (2003)	Australia	McMaster Model of family functioning	<p>143 families</p> <p><u>Brain Injured Individuals</u>: Gender (70% male, 30% female), Age (average 34 years), Education (average 11 years)</p> <p><u>Family Members</u>: Relationship (49% parents, 34% spouses, 11% siblings, 4% children; 49% of family member participants were primary caregivers)</p>	<p>Severity of injury (72% severe GCS 3-8, 15% moderate GCS 9-12, 13% mild GCS 13-15)</p> <p>Injuries resulting from MVA (88%), work-related injuries (12%)</p> <p>Average 3 years post-injury</p>	<p>FAD</p> <p>Completed by brain-injured individuals and family members independently</p>
Scholten et al. (2020)	Netherlands	McMaster Model of family functioning Family adjustment	<p>78 families (157 families in study, remainder were spinal cord injury)</p> <p><u>Brain Injured Individuals</u>: Gender (49% female, 51% male), Age (average 59 years), Nationality (16% non-Dutch)</p> <p><u>Family Members</u>: Gender (55% female, 45% male), Age (Average 56 years), Nationality (8% non-Dutch), Relationship (78% partners, 9% parents, 7% children, 5% other family/friends)</p>	<p>87% non-traumatic injury</p> <p>Location (40% left, 33% right, 18% both sides, 4% brainstem, 5% unknown)</p> <p>Measures completed at admission, discharge and 3 or 6 month follow up</p>	<p>FAD general subscale</p> <p>Completed by brain injury survivors only if they did not live alone</p>
Schönberger et al. (2010)	Australia	McMaster Model of family functioning	<p>98 families</p> <p><u>Brain Injured Individuals</u>: Gender (70% male, 30% female), Age (average age at injury 36 years), Education (average 12 years)</p>	<p>Severity of injury (61% GCS 3-8, 12% GCS 9-12, 26% GCS 12-15)</p> <p>Injuries resulting from MVA (71%), pedestrian</p>	<p>FAD General subscale</p> <p>Completed by family members</p>

			Family Members: Gender (21% male, 79% female), Age (average 45 years), Relationship (42% parent, 42% spouse, 5% siblings, 8% child, 5% other)	(15%), bicycle accidents (3%), work related accident (3%), other (2%) Measures completed at 2 and 5 years post-injury	
Temple et al. (2016)	USA	McMaster Model of family functioning Family resources	166 TBI survivors Gender (78% male, 22% female), Age (average 33 years at time of injury), Ethnicity (13% White, 25% Black, 63% Hispanic), Language (50% English speaking, 50% Spanish speaking), Education (average 11 years), Employment (range 18% <\$10,000 – 17% >\$40,000)	Injuries resulting from MVA (42%), motorcycle accident (4%), falls (21%), assault (24%), gunshot (1%), other (9%) Measures completed within 3 weeks post-injury and 3 months post-injury	FAD General subscale Completed by brain-injured individuals
Tramonti et al. (2015)	Italy	Circumplex model of family functioning	30 families <u>Brain Injured Individuals</u> : Gender (53% male, 47% female), Age (average 61 years) <u>Family Members</u> : Gender (66% female, 33% male), Age (Average age of females 56 years, average age of males 63 years), relationship (53% partners, 27% adult children, 20% parents)	Injuries resulting from ischemic stroke (30%), haemorrhagic stroke (13%), aneurysm (20%) rupture, neoplasia (<1%), herpetic encephalopathy (<1%), TBI (30%) Average 3 months post hospital admission	FACES-III Completed by family members
Vangel et al. (2011)	USA	Family systems theory	109 families <u>Brain Injured Individuals</u> : Gender (75% male, 25% female), Age (average 43 years), Ethnicity (67% African America, 32% White, 1% Hispanic), Education (range 6-18 years)	Severity of injury (Average GCS at admission 8.7) Follow-up completed at 1, 2-, 5-, 10-, and 15-years post-injury	FAD General functioning & behavioural control subscales Completed by family members

Family Members: Gender (82% women, 18% men), Age (average 47 years), Ethnicity (66% African American, 32% White, 1% Asian or Pacific Islander, 1% Native American), Relationship (39% parents, 17% spouses, 9% romantic partners, 20% other relatives, 15% friends), Education (range 5-18 years)

Quality Assessment

All included studies were identified to have a clear research question, with collected data designed to address the raised research questions (screening questions on the MMAT; Hong et al., 2018).

Twenty-one studies were quantitative non-randomised studies (1 Addis, 1995; Anderson et al., 2002; Barclay, 2013; Boyle, 1997; Cariello et al., 2020; Chinnery, 2005; Cox et al., 2020; Curtiss et al., 2000; Douglas & Spellacy, 1996; Fischer, 1997; Geurtsen et al., 2011; Kelly et al., 2013; Kosciulek, 1994; Kosciulek, 1997; Laratta et al., 2021; Ponsford et al., 2003; Scholten et al., 2020; Schönberger et al., 2010; Temple et al., 2016; Tramonti et al., 2015; Vangel et al., 2011), two were quantitative descriptive studies (Kosciulek, 1995; Maitz, 1990), and three were mixed methods including qualitative and quantitative non-randomised components (Bull, 1999; Charles et al., 2007; Curry, 2006).

Overall, most studies were deemed to have participants representative of their target population, though not all studies aimed to have a target population inclusive of all ABI survivors. Some identified more specific sample populations such as Traumatic Brain Injury survivors, or veterans. Studies generally selected measures of family functioning that had been assessed for reliability and validity, though not all studies reported on these psychometric properties. However, it is important to note that the psychometric properties for the measures used were not developed or assessed specifically for ABI populations. One of the issues that emerged across a range of papers was the lack of confounders accounted for in the study design and analysis. For a full summary of the quality assessment, see appendix B.

Theoretical Approaches

The studies included in this review based their research on several different theoretical approaches to family functioning. It is also important to note that some studies did

not go into detail about the theoretical approach to family functioning that was being drawn on.

The McMaster Model of Family Functioning (Epstein et al., 1978) was drawn on by several studies (Epstein, Bishop, & Levin, 1978) was drawn on by several studies (Anderson et al., 2002; Barclay, 2013; Boyle, 1997; Cox et al., 2020; Fischer, 1997; Geurtsen et al., 2011; Kelly et al., 2013; Kosciulek, 1994; Kosciulek, 1995; Kosciulek, 1997; Ponsford et al., 2003; Scholten et al., 2020; Schönberger et al., 2010; Vangel et al., 2011). This theory can be described as a process-oriented theory of family functioning (Dai & Wang, 2015). The theory describes the function of a family to be to provide an appropriate environment for the family members to develop, the process of which includes completing basic tasks, developmental tasks, and crisis tasks.

The studies varied regarding the level of detail in which they described this theory, and how this informed their research designs. Boyle (1997) commented that the theory may not encompass all aspects relevant to the functioning of a family, but it highlighted those relevant to families experiencing clinical difficulties, represented by the six dimensions of the model. These are problem-solving, communication, roles, affective responsiveness, affective involvement, and behavioural control (Epstein et al., 1978). Barclay (2013) offered a conceptual definition of family functioning as the “general functioning health” of a family and reported the McMaster theory as an operationalisation of this concept.

The Circumplex Model of Marital and Family Systems (Olson, 2000) was another theory drawn on by studies (Curtiss et al., 2000; Fischer, 1997; Tramonti et al., 2015). This is an example of a results-oriented theory of family functioning (Dai & Wang, 2015). This theory summarises three dimensions of family intimacy, family adaptability and family communication. The theory also outlines multiple levels to each of these dimensions as a way of categorising a family.

Family systems theories were named by several papers (Addis, 1995; Bull, 1999; Cariello et al., 2020; Fischer, 1997). Systems theory represents an overarching school of thought that draws on different models within it to conceptualise family functioning. Whilst different papers cited different authors, there was a commonality in the references to systemic ideas, and how these could provide a theoretical underpinning for research into family functioning in ABI populations. Addis (1995) spoke of how the theory holds centrally the relationships between family members, the circular and dynamic nature of families, and described families as interdependent. The roles and task functions assigned to different family members were noted to implicate how the family system functions and is maintained. Similarly, Bull (1999) described how family systems theories understand individual development and difficulties in the context of the family system, and therefore the impact of the system on the functioning of each individual member, as well as the family as a whole. The authors considered how an individual's behaviour could be understood as a result of family environment. Applying these ideas in the context of brain-injured individuals, one study described how family systems theory demonstrated how a brain injury may impact on all members of a family and may highlight the strain and sudden changes experienced by family members (Cariello et al., 2020). Curry (2006) drew on family strengths theory, which shares similarities with family systems theory, in particular emphasising the connectedness of family members and the impact of an event occurring to one family member on the whole family system. However, the paper additionally emphasised focusing on positives and strengths.

Fischer (1997) drew on multiple different theoretical approaches to family functioning. The operationalisation in this study also used multiple measurement tools corresponding to the theories described. One theory not mentioned above that the paper drew on was expressed emotion, considering the possible attitudes expressed towards a family

member experiencing difficulties. This paper defined expressed emotions in terms of the critical, hostile or overinvolved attitudes a family member may express towards an individual with psychiatric difficulties, though authors acknowledged these ideas would also apply to other illnesses.

As such, the studies drew on a range of theoretical approaches to family functioning and related theories to underpin their research. It is noteworthy that there were many overlaps between the different theories. However, there were also some key differences in factors included in the different theories that will therefore emerge in any results or findings reported.

Attributes of Family Functioning

General Family Functioning versus Specific Attributes

Some studies focused on family functioning as a general concept, whereas others drew out particular aspects of family functioning. The different theoretical approaches outlined above, and associated measurements, incorporated multiple, at times overlapping, attributes of family functioning.

One of the measures used in multiple studies was the Family Assessment Device (FAD) (Epstein, Baldwin & Bishop, 1983). This is a self-report measure that corresponds to McMaster's Model of Family Functioning (Epstein et al., 2003). The tool includes seven subscales: problem solving, communication, role function, affective responses, involvement, behaviour control and general functioning. Initial psychometric properties of the FAD were outlined by Epstein and colleagues (1983). The studies that used this measure did so in different ways. Some used all subscales of the FAD (Anderson et al., 2002; Barclay, 2013; Boyle, 1997; Chinnery, 2005; Curry, 2006; Fischer, 1997; Geurtsen et al., 2011; Kelly et al., 2013; Kosciulek, 1995; Ponsford et al., 2003). Other studies used the general functioning subscale (Cariello et al., 2020; Charles et al., 2007; Cox et al., 2020; Kosciulek, 1994;

Kosciulek, 1997; Scholten et al., 2020; Schönberger et al., 2010; Temple et al., 2016). One of the studies selected to use the general functioning and behavioural subscales, as indicators of general family functioning and a measure of behavioural control (Vangel et al., 2011).

Another measure used was the Family Environment Scale (Moos, Insel & Humphrey, 1974) (Douglas & Spellacy, 1996; Fischer, 1997). This measure aims to assess and describe social and environmental characteristics of a family along three dimensions: family relationships, personal growth, and system maintenance. Three self-report forms exist to measure perceptions of the family environment, views of the ideal family environment and expectations of family settings. One study used the form to measure participants' perceptions of their family environment and created a composite variable including the expressiveness and conflict scales of the relationship dimension (Douglas & Spellacy, 1996). These were chosen as researchers assessed them to be reliable indicators of distressed versus non-distressed family functioning.

Adaptability and Adjustment in the context of ABI

One of the features drawn out in the conceptualisations of family functioning in the context of ABI was adaptability and adjustment. These ideas are highlighted in some theoretical approaches to family functioning; for example, family adaptability is one of the three core dimensions of the circumplex model of marital and family systems (Olson, 2000).. The descriptive conceptualisation of family functioning in the papers often drew focus to the dimension of adaptability, considering how this may be pertinent to families who are living with a brain injured family member.

Several papers described the dimension of adaptability as relevant to their research (Addis, 1995; Curry, 2006; Fischer, 1997; Maitz, 1990; Tramonti et al., 2015). One author described family adaptation as the result of the efforts made by families to manage the demands of stressors or crises (Kosciulek, 1995; Kosciulek, 1997). Describing the rationale

for the chosen outcome variables, Scholten and colleagues (2020) stated that the results indicated how family dyads were managing the illness of the brain-injured family member. One study explicitly noted how outcomes for the brain-injured individual were influenced by how successfully a family manages to adapt to the injury (Vangel et al., 2011). Results of another study were interpreted to indicate the ability of the participants to adjust following ABI to protect couple relationships (Laratta et al., 2021). Another paper described changes that occur after an ABI in a family and how behavioural indicators provide insight into how a family adapt to an ABI (Curtiss et al., 2000).

Perspectives

Conceptualising Family

An important consideration within family functioning is who was conceptualised as family. A small number of studies had brain-injured individuals as the only participants, and did not include family members in the study methods (Barclay, 2013; Cariello et al., 2020; Temple et al., 2016). Several studies included partners or spouses of the brain-injury survivor alongside brain-injured individuals (Anderson et al., 2002; Chinnery, 2005; Cox et al., 2020; Curtiss et al., 2000; Laratta et al., 2021; Maitz, 1990). Parents of brain injury survivors were another group of family members named by one study (Boyle, 1997). The majority of studies included a mixture of different family members as participants alongside the brain-injured participants (Addis, 1995; Bull, 1999; Charles et al., 2007; Curry, 2006; Douglas & Spellacy, 1996; Fischer, 1997; Geurtsen et al., 2011; Kelly et al., 2013; Kosciulek, 1994; Kosciulek, 1995; Kosciulek, 1997; Ponsford et al., 2003; Scholten et al., 2020; Schönberger et al., 2010; Tramonti et al., 2015; Vangel et al., 2011).

There were some differences with conceptualising “family”. Whilst Barclay (2013) included only brain-injured individuals as participants, they defined family as the “survivor’s self-identified family”, as opposed to dictating a particular familial relationship. This may

affect who participants were reflecting on when they completed measures of family functioning. Another study had a small portion (less than ten percent of the study sample) being “close friends”, who were required to have substantial weekly contact with the brain-injured individual and were described as a “go-to person”.

Family in Study Procedures

Recognising which family members were included in the different studies is important when considering who completed the measures, and the perspectives they may have. A large number of studies had family functioning measures completed by family members or carers on behalf of the whole family (Addis, 1995; Anderson et al., 2002; Boyle, 1997; Bull, 1999; Chinnery, 2005; Curry, 2006; Curtiss et al., 2000; Fischer, 1997; Geurtsen et al., 2011; Kosciulek, 1994; Kosciulek, 1995; Kosciulek, 1997; Schönberger et al., 2010; Tramonti et al., 2015; Vangel et al., 2011). The three papers who included only brain-injured individuals as participants had these individuals complete the measures of family functioning (Barclay, 2013; Cariello et al., 2020; Temple et al., 2016). Another portion of included papers had family functioning measures completed by the ABI survivors and their family members independently (Cox et al., 2020; Douglas & Spellacy; Kelly et al., 2013; Laratta et al., 2021; Maitz, 1990; Ponsford et al., 2003).

Some papers acknowledged the challenges of deciding who would complete the measures of family functioning. Ponsford and colleagues (2003) justified their decision to use the family member’s measures in the analysis due to the severity of cognitive impairment of the brain-injured participants. Another included study’s aim was to look at the agreement between family functioning reports by brain-injured individuals and family members’, and observed poor agreement (Cox et al., 2020). This supports the idea that considering who is conceptualised as “family”, and how this translates operationally in studies, is important as it may influence the observed outcomes.

The selection of measures in relation to the above is also important to consider. Most studies selected measures that considered family functioning more generally and were inclusive of different types of relationships. Some measures focused on specific relationships in families. For example, two studies specified that they included the couple's version of the Family Adaptability and Cohesion Evaluation Scale (FACES) (Addis, 1995; Curtiss et al., 2000). Addis (1995) additionally described implementing a parent and sibling version of the FACES to consider parent-child interactions. The FACES, now on its fourth edition (Olson, 2011), corresponds to the circumplex model of marital and family systems (Olson, 2000). This measure assesses across three dimensions: cohesion, flexibility, and communication.

Another study focused on couple functioning and operationalised this using the Dyadic Adjustment Scale (DAS) and Family Relationship Index (FRI). The DAS (Spanier, 1976) considers the functioning of a couple along four subscales: dyadic satisfaction, dyadic consent, dyadic consensus and affective expression. The FRI (Hoge et al., 1989) considers the quality of family in marital relationships across the three dimensions of family cohesion, communication and conflict.

Caregiving

Some of the included papers also considered caregiving in relationships following a brain injury. Some studies specified the involvement of family members who were caregivers or primary caregivers of the brain-injured individuals (Addis, 1995; Anderson et al., 2002; Curry, 2006; Geurtsen et al., 2011; Kelly et al., 2013; Kosciulek, 1994; Kosciulek, 1995; Kosciulek, 1997). Even if not explicitly cited in a paper as a carer or primary caregiver, the included family members may likely be offering some support to the brain-injured individual. This is noteworthy as providing care to another person is likely to impact on that relationship and may be a significant shift in the nature of the relationship from before the event of the brain injury.

Complexities of Family Functioning

Family Functioning over Time

Many of the studies adopted a cross-sectional design and assessed family functioning at one time point. One of the limitations of these designs when considering family functioning was around what might predict family functioning at the time point of the study. This raised issues of causality, as some possible predictor variables remained unknown and unassessed. One paper highlighted how the higher prevalence of cross-sectional research compared to longitudinal research was a limitation in the field (Schönberger et al., 2010).

Some research designs included a measurement of family functioning over multiple time points. One of the ways in which family functioning was conceptualised in relation to time was considering family functioning prior to the brain injury occurring. One study operationalised pre-injury family functioning using the FACES-II, requesting family members completed the measure once recalling a stressful event from the six months prior to the injury, and once considering their current family circumstances. The retrospective version was taken to indicate pre-injury family functioning, and the current version present family functioning (Curtiss et al., 2000). There are issues with the reliability and validity of using the measure retrospectively, the ability of a family member to accurately recall the previous six months, and the priming of the participant's historical report around a stressful time. Another study described a pre-injury interview, where participants were asked to reflect on prior to the injury to develop an understanding of pre-injury family functioning (Temple et al., 2016). Curry (2006) operationalised pre-injury functioning through caregiver report. It is an understandable challenge for studies to assess pre-injury family functioning as participants will not have a pre-existing measure, and only become eligible for inclusion post-injury. However, it is important to note that most research does not give any consideration to pre-injury functioning and the impact this may have on functioning post-ABI.

The included studies varied with regards to how long after the event of the ABI family functioning was assessed. Some papers specified a particular timepoint since the injury in the aims of the research, other papers reported this but did not include it in analysis, and some papers did not provide any information on the time since the injury. The available data indicated the earliest measurement across papers took place when the ABI survivors were still within inpatient acute or rehabilitation services (Cariello et al., 2020; Curtiss et al., 2000; Laratta et al., 2021; Scholten et al., 2020; Temple et al., 2016; Tramonti et al., 2015). The longest duration since the brain injury was sustained ranged up to thirty years post-injury (Kosciulek, 1997). The time since the brain injury was sustained often varied between the participants of a single paper. For some papers, this ranged over decades.

The issue of whether family functioning is stable over time or changeable was highlighted in the research. Cox and colleagues (2020) reported family functioning to be dynamic and variable across time, specifically considering the changes in roles post-ABI and throughout the different post-injury phases. Conversely, Geurtsen and colleagues (2011) described family functioning and dynamics to be stable characteristics. Several studies that measured family functioning at multiple timepoints were assessing specific intervention programs, in which they were considering the possibility of interventions influencing family outcomes (Charles et al., 2007; Geurtsen et al., 2011; Kelly et al., 2013). These studies conceptualised that family functioning may be changeable and influenceable through families engaging in interventions.

Sample Demographics and Social Difference

The included studies were conducted in a variety of different countries. These included America (Addis, 1995; Barclay, 2013; Boyle, 1997; Bull, 1999; Chinnery, 2005; Curry, 2006; Curtiss et al., 2000; Kosciulek, 1994; Kosciulek, 1995; Kosciulek, 1997; Maitz, 1990; Temple et al., 2016; Vangel et al., 2011), Australia (Anderson et al., 2002; Charles et

al., 2007; Douglas & Spellacy; Kelly et al., 2013; Ponsford et al., 2003; Schönberger et al., 2010), the Netherlands (Cox et al., 2020; Geurtsen et al., 2011; Scholten et al., 2020), Italy (Laratta et al., 2021; Tramonti et al., 2015), England (Fischer, 1997) and Mexico and Columbia (Cariello et al., 2002). It is important to note that the research in this field has primarily been completed in Western, industrialised countries. Most studies described the ethnicities of the included participants, including the family members and brain-injured individuals, however, some did not provide this information (see table 1).

Some studies used translated versions of measures in their research to enable participants to engage. For example, one paper explained participants had completed the Spanish translation of the Family Assessment Device (FAD) (Cariello et al., 2002). Another translated measure used was the Dutch translation of the FAD (Cox et al., 2020; Geurtsen et al., 2011). The FAD was reported to have shown good reliability and validity across a range of cultures (Barclay, 2013). However, it is important to consider that statistical reliability and validity may not necessarily highlight qualitative differences in how family and caregiving are viewed. Direct language translations do not necessarily involve explicit consideration of cultural sensitivity of the concepts assessed. One study described the relevance of cultural factors in Latin America, where family dynamics were demonstrated to impact rehabilitation following a brain injury (Cariello et al., 2002). This was explained as being associated with cultural values and familialism, referring to a cultural value that prioritises the importance of families, as well as close and supportive relationships. Familialism also considers how the identity of the individual is influenced by their role in a family. This highlights a complexity of assessing family functioning, as research studies, and the measures adopted in them, do not necessarily consider these cultural elements of family identity.

With regards to issues of social difference, it is also important to consider the education and financial status of participants. Once again, papers differed with whether

education or employment data were recorded. Six papers did not report any demographic information about the education or employment of participants, sixteen reported some information on employment status or earnings, and fifteen reported some information related to the education status of participants (table 1). Considering the data available, many studies had participants from a range of educational backgrounds, and with a range of employment/financial status'. An issue acknowledged by a number of papers was that a significant number of individuals either took part time work or could not return to work following the ABI, either as a survivor due to the nature of the injury, or as a carer due to caring responsibilities (Charles et al., 2007; Curry, 2006; Douglas & Spellacy, 1996; Fischer, 1997; Kelly et al., 2013; Laratta et al., 2020). Curry (2006) recognised the intersection between employment/financial status and relationship; where the family members included in the study were parents to the ABI survivor, there were still two individuals able to support with working, household demands and caregiving. If the family member was a spouse to the brain injury survivor, there was often only one person to manage these demands. It is important to consider these social differences (Burnham, 2012), as the identities of individuals and families are likely to impact on their functioning.

Control variables

One of the considerations of the quality appraisal of the included studies revolved around whether possible confounders were accounted for in the design and analysis (Hong et al., 2018). Across many of the studies this was noted to be an issue, with a lack of control variables mentioned in the papers (appendix B). A small number of studies did explicitly discuss factors that were controlled for in their design and/or analysis. Barclay (2013) described that the control variables for the project included age, gender and level of functioning. Two studies reported having comparison groups of non-clinical and non-head-injured individuals (Kelly et al., 2013; Maitz, 1990), which were included in their analysis.

Other studies did report some demographic variables; however, these were not necessarily considered in the analysis.

Discussion

The aim of this conceptual review was to evaluate and describe how family functioning is defined and operationalised in adult ABI literature. Across the research included in this review, different studies looking at family functioning the context of brain injuries were observed to conceptualise and operationalise this idea in various ways. These different conceptualisations are, to an extent, representative of the multiple theoretical approaches to family functioning that exist in the wider literature base (Dai & Wang, 2015). Equally, a conceptual review of family functioning in the context of an adult family member with an illness observed different studies included a range of aspects in their conceptualisation of family functioning (Zhang, 2018). As such, the variability of descriptions is not exclusive to literature in an ABI context.

A variety of tools that have been designed to measure family functioning have been utilised in empirical research with families and individuals following a brain injury. Additionally, measurement of family functioning in ABI research has been implemented in different ways. With regards to administration, there was variation in who completed the measure, and whether a measure was given in full, or just selected subscales. There were also differences in when family functioning was assessed, including considerations of pre-injury functioning and duration of time post-injury.

The theory of family functioning that was drawn on by the highest proportion of included studies was the McMaster Model (Epstein et al., 1978). Some other theories were drawn on, either explicit theories of family functioning (e.g., Olson, 2000) or of concepts that may be overlapping, such as family systems theory and expressed emotion. Importantly, none of these theories were developed specifically to consider families following a brain injury.

This is an important limitation of the existing evidence-base, and possible direction for future research. Generally, family functioning theories were applied in their entirety, however, a small number of studies chose to focus on specific attributes of family functioning that were deemed to be more relevant to their research aims. However, caution should be applied when researchers focus in this way as it is important for readers to have clarity and researchers to be transparent about the aims and conceptualisation of an idea, and to state the impact of this on measurement tools used and conclusions drawn.

Several of the included studies drew focus to aspects of family functioning that were deemed more relevant for brain injury populations. This included focusing on adaptability after a significant or stressful event. These aspects are highlighted in theories of family functioning (e.g., Epstein et al., 1978; Olson, 2000). Surviving a brain injury is a significant event which impacts the individual who sustained the injury, and also on their family (Baker et al., 2017; Holloway et al., 2018; Vangel et al., 2011). As such, ideas around how a family is able to manage and adjust in the aftermath of a stressful event are pertinent for this population.

Additionally, issues around who is reporting family functioning and the possible perspective bias are particularly relevant to the ABI population. The poor agreement ratings between ABI survivor and family members reports (Cox et al., 2020) are important to note, especially given that different studies selected different informants as the participants. The ability of brain injury survivors to complete measures without support was highlighted by some of the included papers. It cannot be assumed that all ABI survivors do or do not have the skills required for this, and abilities will vary between individuals. This would be important for future research to further examine, as the validity of family functioning assessment is implicated in both research and clinical practice with an ABI population. Survivors of ABI vary hugely with regards to the type and severity of cognitive impairments,

and this has implications for the validity of self-report questionnaires. These considerations are relevant to thinking about the impact of social difference, and in particular ability (Burnham, 2012). These issues highlight a possible limitation in the reliability and validity of measures used to assess family functioning in this population.

Some of the included papers drew out particular issues of social difference in ABI, which add another level of complexity in such a diverse and idiosyncratic population. Overall, across the literature base there was limited information provided on sample demographics related to social difference (Burnham, 2012). Therefore, it is difficult for this review to interpret how representative existing literature is of these populations. Research has been predominantly conducted in Western, industrialised countries. It is important to note that ABI survivors and their families may also often struggle with financial issues following the injury, as many are unable to return to working in the same capacity. Issues of inequality are pertinent as these can impact on family life and family functioning. Developing an understanding of the impact of social differences on families with brain injuries is an important context that is not fully developed in existing research.

Across the literature different methods are used. Quality assessment of the included studies highlighted some issues around possible confounding variables and issues of causality resulting from the selected methods and designs of the studies. Very few studies included a control group, and most studies did not consider possible confounding variables that could impact on current family functioning, for example family history prior to the brain injury. Studies that did consider this had some issues with the extent to which they were able to assess these factors accurately and reliably. Some of these concerns are understandable due to the challenging nature of researching populations who have sustained an injury but must nonetheless be highlighted, as this limits the conclusions that can be drawn. A previous review of family functioning in child brain-injury survivors highlighted some issues around

the quality of included studies, and how the concept was implemented differently across the literature (Rashid et al., 2014). As such, some of the limitations highlighted in this review are consistent with what has been identified previously in the paediatric brain injury population.

Considering the implications of this review, it has attempted to provide some conceptual clarity of family functioning in research involving adult brain injury survivors, which may support understanding of the literature. The different conceptualisations highlighted hold implications for the extent to which data can be summarised across different studies. It is instead suggested that authors should aim to be transparent, and readers to carefully consider, the conceptualisation of family functioning used in a paper to consider the wider applicability of a piece of research. In clinical practice, an approach that aims to understand the functioning of an individual family following a brain injury may be adopted, and this conceptual review may offer insights with regards to what to assess or consider. As family functioning has been identified as a possible predictive factor of family outcomes after a brain injury (Baker et al., 2017), the conceptualisation of this variable holds implications for the extent to which family functioning may have an influence on possible outcomes.

It is important to consider the limitations of this review. The conceptual review was completed by a single author. Whilst a supervision team supported the project offering an opportunity to discuss specific queries, this limitation remains noteworthy. A further methodological limitation is that four full records were not able to be obtained in the screening phase of this review, as only abstracts were available. The identified studies are predominantly Western studies, and there are limited discussions of the sociocultural contexts of the research. Acknowledging the role of cultural norms, socio-economic status and further aspects of social difference (Burnham, 2012), these aspects are important to consider. Additionally, this review identified predominantly quantitative studies with a small number of mixed methods studies. Clinically, the functioning of a family may often be assessed by a

clinician, perhaps supported by a quantitative measure, but also supported by qualitative information. Therefore, it is important to consider how research methods map onto clinical practices with regards to the assessment of family functioning, and the limitations of the existing evidence in this regard.

With regards to recommendations, it is not possible to suggest a singular optimal conceptualisation of family functioning. As named in the limitations of this review, future research should further consider aspects of social difference and diversity, and how these may impact on family functioning in the context of adult ABI survivors and their families. As this review has highlighted several issues around the conceptualisation of family functioning, it feels important that researchers provide clarity around how this concept is being defined to enable readers to more fully understand any conclusions drawn. Existing theories of family functioning were not developed specifically for families including a brain injury survivor. As it is understandable and expected that families may experience changes following a significant life event such as a family member having a brain injury (Baker et al., 2017; Holloway et al., 2018), a direction for future research may be to develop a bottom-up theory with this population, or to further evaluate how existing theories and measures may apply to the ABI population.

Conclusion

This conceptual review of family functioning in the adult brain injury literature has highlighted the variety of different conceptualisations that are evident in research. Some of these different conceptualisations are representative of the wider family functioning literature, and others emerge as particular issues in relation to researching a brain-injured population. In considering how the existing literature might be useful to stakeholders, it is important therefore, that researchers be transparent, and readers hold in mind, how family functioning is being conceptualised in a particular piece of research, and in their own clinical

practice. Additionally, there remain important directions for future research, including diversifying the evidence-base, and developing a theory of family functioning specific to ABI survivors.

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List of Appendices to the Review Paper

List of Appendices

Appendix A. Full Search Strategy

Appendix B. Quality Assessment of Included Studies

Appendix A. Full Search Strategy

Table 2.

PsycINFO Search Strategy

TI (“traumatic brain injur*” OR “head injur*” OR “acquired brain injur*” OR “head injur*” OR “ABI” OR “TBI” OR “brain damage”) OR AB (“traumatic brain injur*” OR “head injur*” OR “acquired brain injur*” OR “head injur*” OR “ABI” OR “TBI” OR “brain damage”) OR DE "Traumatic Brain Injury" OR DE “Brain Damage
AND
TI (“family function*” OR “family relation*” OR “family cohesi*” OR “family conflict” OR “family dysfunction*” OR “parent child relation*” OR “family dynamic*” OR “expressed emotion” OR “Family communication” OR “Family intimacy” OR “Family adaptability” OR “family coping”) OR AB (“family function*” OR “family relation*” OR “family cohesi*” OR “family conflict” OR “family dysfunction*” OR “parent child relation*” OR “family dynamic*” OR “expressed emotion” OR “Family communication” OR “Family intimacy” OR “Family adaptability” OR “family coping”) OR DE “Family Relations”

Table 3.

Scopus Search Strategy

Search within Article title, Abstract, Keywords “traumatic brain injur*” OR “head injur*” OR “acquired brain injur*” OR “head injur*” OR “ABI” OR “TBI” OR “brain damage”
AND
Search within Article title, Abstract, Keywords “family function*” OR “family relation*” OR “family cohesi*” OR “family conflict” OR “family dysfunction*” OR “parent child relation*” OR “family dynamic*” OR “expressed emotion” OR “Family communication” OR “Family intimacy” OR “Family adaptability” OR “family coping”

Table 4.

MEDLINE Search Strategy

TI (“traumatic brain injur*” OR “head injur*” OR “acquired brain injur*” OR “head injur*” OR “ABI” OR “TBI” OR “brain damage”) OR AB (“traumatic brain injur*” OR

“head injur*” OR “acquired brain injur*” OR “head injur*” OR “ABI” OR “TBI” OR
 “brain damage”) OR (MH "Brain Injuries") OR (MH "Brain Injury, Chronic") OR (MH
 "Head Injuries, Penetrating") OR (MH "Brain Injuries, Diffuse") OR (MH "Brain Injuries,
 Traumatic") OR (MH "Brain Damage, Chronic")

AND

TI (“family function*” OR “family relation*” OR “family cohesi*” OR “family conflict”
 OR “family dysfunction*” OR “parent child relation*” OR “family dynamic*” OR
 “expressed emotion” OR “Family communication” OR “Family intimacy” OR “Family
 adaptability” OR “family coping”) OR AB (“family function*” OR “family relation*” OR
 “family cohesi*” OR “family conflict” OR “family dysfunction*” OR “parent child
 relation*” OR “family dynamic*” OR “expressed emotion” OR “Family communication”
 OR “Family intimacy” OR “Family adaptability” OR “family coping”) OR (MH "Family
 Relations")

Appendix B. Quality Assessment of Included Studies

Table 5.

Mixed Methods Appraisal Tool for Quantitative Non-Randomised Studies

Authors (Year)	Are there clear research questions?	Do the collected data allow to address the research questions?	Are the participants representative of the target population?	Are the measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?
Addis (1995)	Yes	Yes	Yes	Yes	Yes	No	Yes
Anderson et al. (2002)	Yes	Yes	Yes	Can't tell Not all psychometrics reported	Yes Some attrition – participants removed from analysis	No No confounders named or control for	Yes
Barclay (2013)	Yes	Yes	Yes	Yes	Yes	Somewhat Controlled for age, gender, level of functioning	Yes
Boyle (1997)	Yes	Yes	Yes Limited sample thoroughly described	Yes	Yes	Can't tell Control group, limited demographics reported	Yes

Cariello et al. (2020)	Yes	Yes	Yes	Yes	No Missing data between 0-7%. Input with expectation maximisation algorithm	No	Yes
Chinnery (2005)	Yes	Yes	Yes	Yes	Yes Only included participants for whom complete data available	No	Yes
Cox et al. (2020)	Yes	Yes	Yes	Yes	Yes Exclude any participants with incomplete data	Somewhat Account for perspectives	Yes
Curtiss et al. (2000)	Yes	Yes	Yes Study restricted to veterans	Yes Describe “good” versus “adequate” reliability and validity	Yes Removed one participant with incomplete data	Somewhat Some demographics discussed, not all measures	Yes
Douglas & Spellacy (1996)	Yes	Yes	Yes	Can’t tell Some psychometrics not reported	No 4 incomplete	Yes	Yes
Fischer (1997)	Yes	Yes	Can’t tell Small sample of case studies	Yes	Yes	No	Yes

Geurtsen et al. (2011)	Yes	Yes	Yes Exclude more complex presentations	Can't tell Limited reporting of psychometrics	No Data available for 92.7% of participants	No	Yes
Kelly et al. (2013)	Yes	Yes	Yes Exclude some complexities	Yes	Yes Control group included	Yes	Yes
Kosciulek (1994)	Yes	Yes	Yes	Yes	Yes Exclude participants with incomplete data	Can't tell Describe, but do not account for confounders	Yes
Kosciulek (1997)	Yes	Yes	Yes	Yes	Yes Exclude participants with incomplete data	No Confounders not described	Yes
Laratta et al. (2021)	Yes	Yes	Yes Excluded severe deficits	Can't tell Reliability and validity not described	Yes	No Confounders not described	Yes
Ponsford et al. (2003)	Yes	Yes	Yes	Yes	Yes	Somewhat Some results compared to data from control groups	Yes
Scholten et al. (2020)	Yes	Yes	Yes Excluded more complex presentations	Yes	Yes Some excluded for incomplete data	Can't tell Compared demographics, did not cite confounding variables	Yes

Schönberger et al. (2010)	Yes	Yes	Yes	Yes	Yes	No	Yes
Temple et al. (2016)	Yes	Can't tell Lack of detail about "preinjury" interview	Yes	No Lack of detail about "preinjury" interview	Yes Participants who did not attend follow-up excluded	No Lack of detail about "preinjury" interview	Yes
Tramonti et al. (2015)	Yes	Yes	Yes	Can't tell Psychometrics not reported	Yes	No No reported confounding variables assessed	Yes
Vangel et al. (2011)	Yes	Yes	Yes	Can't tell Psychometrics not reported	Yes	Can't tell Some other variables assessed	Yes

Table 6.*Mixed Methods Appraisal Tool for Quantitative Descriptive Studies*

Authors (Year)	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?
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Kosciulek (1995)	Yes	Yes	Yes	Can't tell Lack of sufficient demographics about ABI participants	Yes	No High non-response rate	Yes
Maitz (1990)	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table 7.

Mixed Methods Appraisal Tool for Mixed Methods Qualitative and Quantitative Non-Randomised Studies

	Bull (1999)	Charles et al. (2007)	Curry (2006)
Are there clear research questions?	Yes	Yes	Yes
Do the collected data allow to address the research questions?	Yes	Yes	Yes
Is the qualitative approach appropriate to answer the research question?	Yes	Yes	Yes
Are the qualitative data collection methods adequate to address the research question?	Yes	Yes	Yes
Are the findings adequately derived from the data?	Yes	Yes	Yes
Is the interpretation of results sufficiently substantiated by data?	Yes	Yes	Yes
Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes	Yes	Yes
Are the participants representative of the target population?	Yes	Yes	Yes
Are the measurements appropriate regarding both the outcome and intervention (or exposure)?	No	Yes	Yes

		Report “good” validity and reliability, do not report the statistics	
Are there complete outcome data?	Yes	Yes	Yes
Are the confounders accounted for in the design and analysis?	No	No	No
		Families described in detail individually	Some accounting for pre-injury factors
During the study period, is the intervention administered (or exposure occurred) as intended?	Yes	Yes	Yes
Is there an adequate rationale for using a mixed methods design to address the research question?	Yes	Yes	Yes
Are there different components of the study effectively integrated to answer the research question?	Yes	Yes	Yes
Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Yes	Yes	Yes
Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes	Yes	Yes
Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes	Yes	Yes

Part B: A Foucauldian Discourse Analysis Examining how Clinicians Construct the Needs of Families of Adult Acquired Brain Injury Survivors

Abstract

Existing models and empirical evidence can help understand the experiences families may have following an Acquired Brain Injury. Whilst there are commonalities in experiences, the journeys of families, in particular with an Acquired Brain Injury, are idiosyncratic. Literature bringing forth perspectives of both service providers and service users acknowledges the varying experiences families may have interacting with services following a brain injury. This research project was motivated to explore how family needs are constructed by professionals in clinical settings. The research question posed was; How do clinicians with experience of working in neuro-rehabilitation services construct the needs of families of survivors of Acquired Brain Injury? Semi-structured focus groups and interviews were conducted with multidisciplinary professionals who had over one year of experience working with families following an Acquired Brain Injury. A Foucauldian Discourse Analysis produced four discourses that were observed in the analytic text. These discourses were named; evidence-based theoretical constructs, models, and strategies; taking a relational approach; beyond diagnosis; and consumerism. The subject positions offered by these discourses were also considered in the analysis. Participants drew on each of these discourses, which appeared to collectively inform their constructions of the needs of the families with a brain injury survivor that they encountered.

Introduction

How ABI impacts on families

Acquired Brain Injury (ABI) can have a profound impact on survivors and on their families (Charles & Butera-Prinzi, 2008). Several psychological models have attempted to encapsulate how ABIs impact families. The family tasks model (Butera-Prinzi, Charles & Story, 2016) describes how families may be required to navigate multiple “tasks” in the aftermath of an ABI. These are described to include grieving and dealing with emotional trauma, restructuring roles and responsibilities in the family, developing new identities and growing through adversity following an ABI. However, it is important to acknowledge that this model lacks a well-defined empirical basis. The model was developed based on the observation and practice of a service over several decades. It highlights the complexity of what individuals, and their families are managing following an ABI. A meta-analysis of narrative structures identified families were negotiating the changes in their lives following the injury, attempting to maintain their family equilibrium, and considering how to move forward following the ABI (Whiffin et al., 2021). As such, families may be managing many changes in the aftermath of an ABI. The above papers acknowledge these changes and may contribute towards explaining the needs families may have in this context.

The dynamics between the individual who has suffered an ABI and their family have also been considered in research. There is a relationship between family functioning and the progress of an individual following ABI. Sander et al. (2002) found that outcome measures demonstrated individuals had increased improvement through rehabilitation following an ABI where family functioning was assessed to be healthier. In addition, outcomes for individuals and family members, such as wellbeing, are observed to correlate with one another (Vangel, Rapport, & Hanks, 2011). It is also important to consider possible reverse

causality; positive family functioning may support rehabilitative progress, but equally the survivor of an ABI making good progress may have a positive impact on family functioning.

Several studies have examined constructs that may be related to outcomes for families following an ABI. This literature contributes to the current working understanding of the impacts of ABI on families. Family members adopting new roles as carers can be vulnerable to potential negative quality of life outcomes (Knight, Devereux, & Godfrey, 1998). The research noted that distress associated with emotional and behavioural changes following an ABI appeared predictive of burden in the years following. Further research suggests cognitive impairments following ABI may be associated with greater carer giver distress relative to physical disability (Vangel et al., 2011). A recent review of literature identified associations between traumatic brain injury and higher levels of carer burden, poorer family functioning and mental health difficulties in carers (Baker et al., 2017).

Some literature has begun to examine the idea of carer resilience and quality of life. This is perhaps a response in the field to the bias towards examining negative impact or burden in families (Bowen, Yeates & Palmer, 2010), widening the focus to include concepts or constructs that may improve or support positive family outcomes. Perceived social support, good family functioning and having coping skills have also been identified as protective for family caregivers (Baker et al., 2017; Vangel et al., 2011). Increased resilience, defined in this research as an ability to adapt when facing difficulty, may impact on positive outcomes for family members of survivors of ABI (Anderson, Daher & Simpson, 2020). Distinguishing between individual resilience and family resilience, Butera-Prinzi and colleagues (2016) propose that resilience should be conceptualised as fluid following ABI due to the ongoing changes families may face. It must be noted that the amount of research focusing on resilience and positive outcomes for caregivers and family members after ABI is less than the amount of research focusing on burden and negative outcomes (Baker et al.,

2017). However, existing evidence highlights several factors can have both positive and negative impacts for families following an ABI. An important limitation of existing literature is that the high prevalence of correlational research means it is difficult to draw conclusions about causality, and the specific mechanisms underlying the relationships between researched concepts and family outcomes remains poorly understood (Vangel et al., 2011).

Overall, the research evidence described above outlines many elements of their lives that individuals and their families may be navigating following a family member surviving an ABI. In addition, several factors are described that affect outcomes for both the individual and the family in the aftermath of an ABI. Therefore, it is important to also consider how services commissioned to work with this population may incorporate this research into their practice.

Healthcare services supporting families following ABI

The research described above holds implications for how healthcare services might support families in this context. Whiffin et al. (2021) suggest that healthcare services, which are often primarily structured around supporting the individual who has suffered an ABI, are also placed well to support the family. There are multiple ideas about what elements of healthcare support may be important in this work.

Some research has investigated what may be important for services and professionals when working with both survivors of ABI and their family members. One project looked at client-centred care in inpatient rehabilitation services in Canada, where the “client” was viewed to include both the ABI survivor and their family members. The research identified that factors including teamwork, addressing environment and changes, and effective communication were important elements of practice (Bamm et al., 2015). Choustikova et al. (2020) also examined the experiences of family members of the survivor of an ABI in acute hospital settings. Similarly, a calm environment and the communication of information via

multiple methods emerged as important factors in the care of family members. Another research project completed surveys with family members where there had been an ABI to hear about their experiences, including perceptions of health and social care services (Holloway and Tasker, 2019). The research highlighted that families highly valued professionals who came across as human, professionals' who demonstrated their knowledge of both ABI and the impact of an ABI on the family, and families valued having a single focal point for care. Another piece of research also highlighted the helpfulness of clinicians who are both human and empathic, as well as knowledgeable and able to share this knowledge appropriately with families (Holloway & Ellis-Hill, 2022). These studies draw out some of the elements of care that families appreciate and report finding important following a family member surviving an ABI.

Involving families in the rehabilitation journey is recommended (Foster et al., 2012). For example, involving families with services in the early stages following ABI may enable them to continue to promote rehabilitation outcomes once an individual is discharged from inpatient services (Choustikova et al., 2020). A model outlining collaborative practices where family expertise is acknowledged and incorporated highlighted further possibilities to support survivors and their family members (Sohlberg et al., 2001) As such, all stakeholders may benefit from working with families as well as individuals within the rehabilitation process. However, in practice family support may be lacking, or difficult for families to access (Norman et al., 2020).

Alongside exploring concepts that can be helpful for healthcare services working with family members following an ABI, research has also identified some challenges of family-centred working following ABI. Services working with survivors of ABIs tend to be developed and commissioned primarily focusing on supporting and rehabilitating the individual who has survived the ABI. As such, if working with families, clinicians may need

to navigate how to support both the individual and family. A tension of family-centred work can be when this is perceived to undermine patient-centred work, for example in the negotiation of goals, which may be different for different family members (Levack et al., 2008). There are also challenges for services implementing client- and family-oriented care, as this can be more time-consuming and thus draws more heavily on service resource (Bamm et al., 2015). Therefore, whilst the literature suggests it is beneficial to work with family members following an ABI, services and professionals may need to carefully consider how they are able to do this within service and individual contexts.

When considering how professionals and services may support families it is important to acknowledge that there is a lack of clinical guidelines available to services on how to involve family members in the rehabilitation journey following an ABI (Foster et al., 2012). Guidelines developed drawing together an evidence-base are important tools to support clinicians and services to provide effective and consistent care. As described above, the experiences of some families indicate the provision of support can be inconsistent at times. (Holloway et al., 2019). Some services have developed their own structure to support family engagement. Foster and colleagues (2012) acknowledged eight key factors incorporated into their service approach, which the service was structured around. These included the priorities of families, skills of professionals, and concrete ideas that the service may wish to implement and share with families.

Existing research speaks to the importance of involving families in rehabilitation following the ABI of a family member. In practice, clinicians may make decisions about what support to offer individuals and families using their services, based on their own knowledge, and understanding of the existing evidence-base. Additionally, due to the idiosyncratic nature of working with families and ABIs, it may be relevant to draw on expert knowledge from clinical practice as a way of engaging with this client group. Guidelines often offer helpful

summaries of this information, but where these may be lacking, the evidence can still be considered. Working in multi-disciplinary teams and receiving supervision to support clinical practice is highlighted as important to support clinicians working with families following ABI (Evans-Roberts, Weatherhead & Vaughan, 2013). Equally, trained professionals may often draw on transferable skills and knowledge to assess and evaluate families.

Families' experiences of healthcare services and professionals following an ABI

When the perspectives of families are drawn out, the idiosyncratic nature of their experiences emerges. The processes of the tasks in the family tasks model are noted to vary between families (Butera-Prinzi, Charles & Story, 2016), and at different times according to the family life cycle (McGoldrick, Carter, & Garcia-Preto, 2014). The impact of an ABI on families can also change over the course of time (Holloway et al., 2019). Thus, there are differences both between families and within families over time. Given the long-term and dynamic nature of families' navigation of tasks following ABI, it is important for clinicians to be able to assess needs in this context.

Literature focusing on how services work with family members, and family members' perception of support has primarily drawn on qualitative methods, often using thematic analysis. These methods consider how families' subjective experiences may offer insight into their realities and their contexts. This has allowed for a curiosity about families' varied experiences (Butera-Prinzi et al., 2016; Holloway et al., 2019), and summarising observations of patterns that emerged across experiences. This literature offers important insights that services and individual clinicians may wish to take into consideration in delivering support to families following an ABI.

The stories of families following an ABI demonstrate that certain needs may be unmet by current service provisions. A literature review found that family members' unmet informational and practical support needs related to reported distress following ABI and

associated neurobehavioral changes (Fisher et al., 2020). Another research group conducted interviews with family members of ABI survivors, focusing on their views of both formal and informal support (Holloway et al., 2019). They noted varied experiences of support, with family members' reporting positive and challenging experiences. For example, families spoke of not feeling understood by professionals, a lack of joined-up care and feeling excluded or isolated. Equally, the value of professional expertise and professionals who acted humanely were regarded highly by families. The paper additionally recognised that poor support exacerbated difficulties and increased family members' sense of isolation. Additionally, in one qualitative study, families reported often feeling they did not receive sufficient guidance from professionals, which was challenging when they were then required to become caregivers for the family member who had survived the ABI upon their discharge from the hospital environment (Choustikova et al., 2020).

In a UK-based study, surveys and interviews were completed with survivors of ABIs, family members of those who have survived ABIs, and professionals working in health and social services with these populations (Norman et al., 2020). Analysis highlighted that all groups of professionals recognised a lack of knowledge from healthcare professionals about ABI contributing to several challenging experiences for families in their journeys of accessing support and reintegrating following discharge from acute services. Discussing the implications of this research for policy and practice, the authors acknowledged particular training needs that may enhance professionals' knowledge and through this improve the experiences that survivors of ABIs and their family members have of services. Holloway et al. (2019) also observed that different families reported a difference in the availability and quality of support in the UK. Thus, different studies have observed several difficult experiences for families accessing services.

Aims

The current evidence-base around working with families following an ABI offers helpful insights into the tasks families may be navigating and how services might be able to support families. Whilst there are theories and models that inform what may be helpful for families after an ABI, the idiosyncratic nature of families and ABIs is important to consider. Whilst there are commonalities in the experiences families may have following ABI, as highlighted in the theories and models presented above, individual families are likely to have different experiences. The stories of family members highlight their varied experiences of engaging with healthcare services. This suggests it may be useful to explore how professionals are constructing the needs of families in their clinical practice, and what discourses may be informing this.

This research aims to explore how clinicians speak their work with family members after there has been an ABI in the family. Specifically, the project aims to answer the research question; How do clinicians with experience of working in neuro-rehabilitation services construct the needs of families of survivors of ABI?

Methods

Research Design

A social constructionist epistemology enables consideration of how perceptions of the needs of families are constructed and given meaning through the language used by professionals. Adopting a relativist ontology in this research means that the experiences of participants are seen as subjective, and knowledge and truth are considered to exist relative to the perspective of the observer and their context. These principles are the context of this research and inform the design of the project as explained below.

Consultation with service users and carers was a crucial part of designing this research. The University of Surrey Service User and Carer Advisory Group were formally conferred with on two separate occasions during the design of this research. Involving

individuals with lived experience of using services is an important element of designing and completing research (Domecq et al., 2014) and is highlighted in research guidance. For this research, consultation in the early stages was helpful to hear about the stories of members of the advisory group, and their experiences with health services. This raised some important considerations to hold in mind whilst designing a piece of research that primarily focused on speaking with professionals about their work. Additional consultation was sought on the draft focus group and interview guide, and this discussion led to the amendment of this guide to create the final version.

Discourse analysis focuses on the role of language in the construction of social reality (Willig, 2008). Foucauldian discourse analysis, based on the ideas of Michel Foucault, is concerned with the availability of discourses in culture/society, and the positions this availability or lack thereof may place people in. It also considers the implications of this in both enabling or limiting what individuals feel able to say. The analysis considers the interactions between discourses, subjective experiences, and practices (Willig, 2008). Michael Foucault did not describe a systematic method by which a discourse analysis should be conducted, but rather offered an approach to considering data. Therefore, the process outlined by Willig (2008) was adopted for this research and is outlined in the planned analysis description below.

Another key idea within Foucauldian discourse analysis is the notion of power (Willig, 2008). The concept of power has been considered by many different individuals, however, there is no single agreed upon definition. One definition proposes power can be defined in terms of influence over others (French & Raven, 1959). The bases of social power (French & Raven, 1959) is a theory that draws out five bases of power: reward power, coercive power, legitimate power, referent power and expert power. Whilst these five bases are proposed as separate, the authors acknowledge that power may not necessarily be limited

to one single source. Lukes (2005) described three dimensions or faces of power. The first dimension is decision making power, which is direct and overt. The second dimension is non-decision-making power, which highlights the context in which decisions are made and considers potential issues alongside current issues. The final dimension described is ideological power over what people may think or what is valued as important. These theories of power are helpful in considering how power may be emerging in discourses, and what position this allows different people or services to take.

Within this research project, the ability to involve consideration of power differentials in the analysis was felt to be important. The discourses within this project occur between the researcher and participants, who are professionals working with families following an ABI. As such, professional-client power differences (Proctor, 2008) were important to consider. It felt important not to place clinicians participating in the research in an all-knowing position, taking their subjective experiences not just as one socially constructed understanding, but to also consider how these discourses may impact their working with families following an ABI. This research aimed to acknowledge and consider how power functions in the context of healthcare services working with families following ABI, and what the benefits and challenges of this may be. This seems particularly important with this population, especially due to the vulnerability of individuals and families in terms of physical, psychological, and emotional impacts of ABI.

Participants and Recruitment

Participants were recruited through opportunity sampling, with the research advertisement (appendix A) disseminated via relevant email networks with prior consent from gatekeeper contacts. The project was also advertised via social media, including via Facebook and Twitter. The advert was shared to some relevant private groups on Facebook with permission from gatekeeper contacts. The inclusion criteria necessitated participants had

at least one year of either current or previous clinical experience of working in services, where the primary aims of the service included neurorehabilitation. Participants were required to speak English and be over the age of eighteen years. As recruitment and data collection was conducted remotely, there were no geographical restraints. Participants were able to take part if they met inclusion criteria and excluded if they did not. Ethical approval was obtained from the University of Surrey ethical committee. Participants were provided with detailed information about the research project (appendix B), given the opportunity to consider this information and ask any questions, and then asked to provide written consent either via hand-written or electronic signature prior to participation in the research (appendix C).

A total of twelve participants took part in this research. Qualitative research methodologies concern themselves with the richness of data and analysis. As such qualitative research aims to achieve saturation in sampling, where further richness is no longer obtained through additional data collection, indicating that adequate data has been collected to enable analysis (Morse, 2015). It is suggested that sample size should be based on these principles, alongside acknowledging the scope of a research project due to the time-consuming nature of qualitative methodologies and discourse analysis (Goodman, 2017). Preliminary consideration of the data obtained after completing the focus group and individual interviews with these twelve participants, as well as discussion in research supervision, supported the decision to conclude recruitment at this point.

Of the participants, there were four participants who participated in one focus group, and eight participants who participated in individual interviews. One participant planned to take part in the focus group, but needed to withdraw due to illness, and therefore completed an individual interview instead. A further four individuals expressed an interest in participating, but either did not respond to further invitation to take part or dropped out due to

other commitments. No participants withdrew after taking part in a focus group or interview. Participants had a range of professional backgrounds including clinical psychology and neuropsychology, occupational therapy, family therapy, support work and case management. Participants' years of experience working with families in the context of ABI ranged from three years to twenty-five years. Participants had an average of eleven years of experience working in this area.

Data Collection

A combination of semi-structured focus groups and interviews were selected as the method of data collection to generate analytic text. Focus groups were selected due to the additional element of interaction and conversation using this method, which also mirrored the nature of multi-disciplinary working in neurorehabilitation. The perspectives of different attendees also stimulated discussion. The interaction between participants added an additional element to the analysis (Lambert & Loisel, 2008). Interviews allowed exploration with participants on an individual level, adding an additional level of depth (Lambert & Loisel, 2008). These individual spaces were beneficial in allowing participants to offer their own perspectives and expand on these in the allocated time, without being driven to one route of conversation due to the nature of being in a collective group discussion. Conversations are useful in collecting data for discourse analysis (though this is not mandatory) due to the additional richness provided for analysis (Goodman, 2017).

The topic guide (appendix D) was developed to encourage open discussion that remained relevant to research question and the area of the needs of families following an ABI. This was developed drawing on available literature and research, in addition to materials shared by the Bouverie Institute with La Trobe University, who kindly shared the topic guides that had been used in similar research. The topic guide for this project was also developed with support from the consulted service user and carer network group, who

contributed their ideas and reflections to help shape the final topic guide used. This was used consistently, yet flexibly as appropriate during the focus group and interviews (Willig, 2008). Prompts were also included in the topic guide to allow further exploration of the questions and to stimulate the discussions as needed. The semi-structured nature of these methods enabled the interviewer to guide the focus groups and interviews to ensure discussions remained relevant and encourage the development of rich data, whilst also enabling participants to draw on their own discourses in relation to the object of interest. Specific demographic information was collected as was felt to be relevant to help contextualise to the participants (Willig, 2008). These demographics included participants' length of experience in neurorehabilitation services and professional background.

The focus group lasted ninety minutes, and the individual interviews were between thirty and sixty minutes long. Focus groups and interviews were conducted remotely via Microsoft Teams and were recorded using the Microsoft Teams function as per university policy and stored on a secure server. The Teams transcription function was enabled only for the researcher facilitating the focus groups and interviews and was used to facilitate verbatim transcription of the focus groups and interviews. It was important to carefully consider the balance between naturalised and denaturalised transcription (Oliver et al., 2005) to ensure sufficient detail was captured in the transcriptions to enable the discourse analysis. The automatically developed transcripts were then revised alongside the recordings to ensure these were accurately verbatim, and to facilitate the researcher to become familiar with the data. Transcription commenced one week following the focus groups and interviews as participants were provided this time frame to withdraw from the research.

Analysis

Transcripts were read and re-read for initial familiarisation with the data. A diary was completed throughout the research and analysis process to record the process and support

reflexivity (Mauthner & Doucet, 2003). Whilst the analysis was completed individually, supervision was used to discuss the analysis and consider the constructions of the discursive object in the text, the wider discourses, and the implications of these.

Multiple recommended processes for conducting a discourse analysis based on Foucauldian principles were considered. Willig's (2008) six stages of discourse analysis formed the basis for this project, as outlined below.

1. Initially, the transcripts were read multiple times to highlight all references to the discursive object of family needs in the context of an ABI and consider how these are constructed. Both implicit and explicit references to the discursive object were considered, as well as considering occasions where the discursive object was *not* mentioned.
2. Following this, the different constructions of the discursive object were carefully considered. The identified constructions of the discursive object in the analytic text were situated within the context of wider discourses.
3. The next stage of analysis focused on identifying the discursive function of these different constructions. For example, the possible purpose of different constructions was considered, including possible benefits of these. These were also examined in relation to different constructions in surrounding discourses.
4. It was important to appraise the *subject positions* offered by the different discourses considered in the above stages. Attention was paid to how different constructions may enable participants to take different positions.
5. Analysis additionally considered how these subject positions may enable certain possibilities for practice.
6. The final stage of the analysis was to consider the different experiences that may be enabled through the constructions and subject positions. The analysis is only able to

comment on the possible subject experiences that may be enabled through these discursive constructions, rather than on whether participants were themselves having these subjective experiences.

Ethical Issues

This research received a favourable ethical opinion from the University of Surrey ethics committee (appendix E) and abided by the BPS and HCPC research ethics standards (2021; 2016). Focus group rules were discussed prior to commencing discussion. These included the importance of confidentiality, requesting participants not share and identifiable information about others during the focus group, and requesting participants maintain confidentiality for anything shared by other members of the group.

It was acknowledged that focus groups could include discussion of sensitive material and could possibly lead to the psychological distress of participants. In accordance with guidelines of governing bodies (HCPC, 2016; Oates, 2021), participants were offered to contact the researcher should they wish to seek support for any emotional distress raised by discussions and were able to discuss possible support options.

Participants provided informed consent prior to their participation in the research. They were given one week following the focus groups to withdraw their consent to participate should they wish to, at which point their data would have been removed from the analytic text. Following this time period, the data was transcribed, and participants were assigned pseudonyms during the transcription process to maintain their anonymity and confidentiality.

Findings

Four main discourses were identified in the transcripts that informed participants' constructions of the needs of families. These have been titled evidence-based theoretical constructs, models, and strategies; taking a relational approach; beyond diagnosis; and

consumerism. Each participant drew on multiple discourses throughout their participation in the focus group or individual interview. Therefore, whilst the four discourses are discussed separately, they collectively represent participants' narratives throughout their participation. Each of these discourses are summarised and discussed below; both in how they appear in the data obtained during this research, and in how they are situated in wider literature.

Evidence-Based Theoretical Constructs, Models, and Strategies

Participants drew on model and guidelines-based discourses in their constructions of the needs of families following an ABI. Coming from this perspective, healthcare professionals may draw on guidelines, theories, theoretical constructs, and strategies to inform treatment or support that is offered to individuals and families that are using services. Equipped with these concrete, tangible, evidence-based ideas, professionals may be viewed as experts in a position to understand the needs of families and prescribe what may be the most appropriate interventions or support.

One way in which models informed how participants were conceptualising the needs of families was through their understanding and application of theories and theoretical constructs. For example, some participants referred to theories or concepts that speak to what families may be navigating in responding to the ABI. ABI was conceptualised by one participant as both the family and individual having *“been through a trauma”* (participant 8, line 2265). In the aftermath of this event, families were understood to be navigating this trauma, and need support and space to do so. Drawing on theories of ambiguous loss, participants described the needs of families in their experience of grief; *there's the ambiguous loss as well, with families experience where, yeah, that person is changed, but they're still there, which is a really hard thing* (participant 4, line 413-414). The role of professionals was described to include *“helping families with the- their own emotional adjustments to what has been an absolutely, you know, life changing experience for the person, but also the family”*

(participant 9, lines 2497-2499). This quote highlights one conceptualisation of the some of the experiences families may be navigating in the aftermath of an ABI. Considering ABI and its effects as a lifechanging psychological trauma offers participants another lens through which they might formulate their needs.

Another way in which participants drew explicitly on models in their constructions of the needs of families was through citing models or strategies families may benefit from following an ABI. Some participants referenced models they might share with families to help a family understand what they may be experiencing; *“I talk about the iceberg and we often see the tip of the iceberg. There's a lot hidden underneath and I think that a lot of professionals don't appreciate the volume of what's beneath the surface in particularly the invisible presentation of deficits and difficulties”* (participant 3, lines 404-407); *“It's the Y-shaped model of identity integration where people kind of rotate between, OK, I'll move towards the person I think that I need, you know, I'm going to be but I want to go back to the person I am”* (participant 3, lines, 523-525). Additionally, participants described families as benefiting from certain techniques. For example, the provision of information and psychoeducation was raised many times; *“giving them more information really for them to understand what the journey might look like for them and their relative”* (participant 1, lines 73-75). Different participants spoke of a number of different techniques they may draw upon when working with families, highlighting the need to draw on evidence-based strategies in their work; *“There are other kind of techniques that I use that are quite easy to learn and you know, I do think are helpful for clinicians to use or at least have in mind when they're meeting with families”* (participant 7, lines 2132-2134). This discursive construction enables participants to draw on their knowledge of the evidence-base in determining suitable support for families. It is also important to acknowledge the expert power (French & Raven, 1959)

given to professionals through the evidence-base, and how an evidence-base can act to validate these approaches.

Participants drew on the evidence-base in their constructions of the needs of families through concepts, theories, models, and strategies. This method of constructing needs through offering evidence-based support is well trodden in healthcare services. Rycroft-Malone and colleagues (2004) discuss how research evidence, particularly evidence that explores efficacy, has received heavy focus in UK healthcare. There is an element of non-decision-making power (Lukes, 2005) in a context where ideas that can be researched and have been evidenced are more highly valued. This prioritisation can also create a context where professionals may have increased expert power (French & Raven, 1959), as they may hold the knowledge of the evidence-base, and be trained in skills to implement this. As such, adopting this discourse can help professionals feel enabled to know how to support an individual or family.

Participants additionally acknowledged the role of implementing interventions based on formulation. One participant described *“I can’t just pull an intervention off a shelf”* (participant 8, line 2427). This quote demonstrates a level of discursive certainty (*“I can’t”*), asserting this as common knowledge. Evidence-based discourses placing professionals in a position of expert (French & Raven, 1959) and decision-making power (Lukes, 2005) may enable professionals to speak with increased certainty or confidence. It was acknowledged that individual and family factors need to be taken into consideration when determining how to support them; *“different families need different things depending on their own individual factors as well”* (participant 12, line 3556).

The use of formulation may be beneficial for clinicians in conceptualising individual needs and offering an explanation for why identical approaches may not be equally effective or helpful for different families who have experienced an ABI. Formulation is linked to

evidence-based discourses and as such participants are able to continue to draw on the evidence-base in explaining individual differences through this approach.

Whilst it is acknowledged that there are limited guidelines available for clinicians with regards to working with families following an ABI, professional guidance can enable clinicians to practice in a way that is informed by verified evidence-based research. *“I think number one is I think if you look at, uh, obviously the ABI strategy that's just out is very good. I mean that gives everybody a baseline to start working from.”* (participant 11, lines 3420-3421). The reference to specific documentation to guide clinical practice could act to offer more guidance to clinical decision making. However, the tentative language used by the participant when discussing the strategy, and lack of depth about why this is “very good” may reflect the general lack of specific guidance documentation to support clinical decision making in this area. In the context of evidence-based health services and clinical practice, drawing on concrete constructs evidenced in research may also act to validate clinical work. Where specific guidelines are lacking, clinicians may draw on knowledge incorporated in existing guidance and evidence, such as in relation to working with ABIs in individuals or working with families in other capacities.

Clinical guidelines and policies are an important tool within evidence-based practices. These can support professionals and services to ensure they are working in line with the evidence-base, and as such to improve the quality of care for service users (Veenstra et al., 2017). This may be an important benefit for participants drawing on guidelines to describe the needs of families after an ABI.

It is also important to note that evidence-based discourses have received some criticism when relied upon heavily to the extent that other possible mechanisms for change are ignored. Based on reviews of literature available at the time, Lambert and colleagues suggested that multiple factors that can influence change. Techniques and models were one

element of this, but it was acknowledged that other factors including extra therapeutic change, expectancy, and factors common across therapeutic approaches were also important (Lambert, Shapiro & Bergin, 1986).

Taking a relational approach

Participants spoke about the importance of soft skills and being human when working with families after ABI. In these discussions, clinicians can be seen to be drawing on wider discourses that speak to the importance of the relational practices in physical and mental health care. It is important to note that whilst these discourses are also evidence-based, as those in the previous section, they were generally discussed separately by participants, and thus are represented as a separate discourse in this paper.

Situated within wider discourses of the importance of therapeutic relationships, participants spoke to aspects of clinical practice that facilitate rapport. The key importance of listening to the story of families was highlighted by several participants; *“They [clinicians] need to not hear, but actually listen. I think listening is imperative.”* (participant 10, lines 2987-2988). Another key role of clinicians from the relational perspective identified was normalising the experiences of families. *“There's a huge benefit of that, yeah, normalization that then, yeah, they're not weird or unusual or or selfish for for what they're experiencing”* (participant 4, lines 80-82). In addition to the above, an important part of developing the therapeutic relationship was noted to be acknowledging and validating a families experience, enabling them to feel heard and contained. One participant stated; *“sometimes families just need to actually just have it acknowledged kind of what on earth has happened and how difficult things are and and that, you know, things will get better, but they just need up that validation and that acknowledgement as as a first step.”* (participant 7, lines 1925-1927). These quotes demonstrate how participants drew out elements of practice that facilitate a relational approach.

Constructing the needs of families after ABI relationally enables participants to draw on evidence that speaks to the benefit of relational approaches in supporting individuals and families. Developing therapeutic connections as highlighted by participants in this research is an important element of fostering engagement between individuals and services (Kayes et al., 2021). This can in turn facilitate neurorehabilitation work. Connecting with others and feeling held has important benefits following traumatic experiences, such as a family member experiencing an ABI. Patient-professional relationships are additionally valued in the delivery of high-quality care (Veenstra et al., 2017). This highlights how incorporating and drawing on multiple discourses can enhance the ability to understand and support the needs of families.

Within this wider discourse, the importance of certain relational qualities that professionals possess was highlighted. One participant stated, *“the feedback that I get is that families respond best to therapists, team members, case managers, who who they who are human, who they feel they can relate to”* (participant 2, lines 695-697). The importance of coming alongside families was noted, with one participant describing the need to *“be with that that person be with that family and be with those families’ experiences”* (participant 7, lines 1931-1932). These qualities may support the development of therapeutic relationships between families and clinicians or services.

Focusing on a relational approach enables participants to take on more of a human subject position. This is something that has emerged as valuable to family members of individuals who have survived an ABI (Holloway & Ellis-Hill, 2022; Holloway & Tasker, 2019). The humanisation framework describes eight humanising dimensions (Todres, Galvin & Holloway, 2009). Hollis and Ellis-Hill consider this framework in the context of families that include individuals who have survived an ABI (2022). They explore several ways in which these families may be dehumanised and argue that adopting this lens can draw out

some of the hidden experiences that families may have. The involvement of professionals possessing the qualities highlighted in the humanisation framework can help form therapeutic relationships, which in turn facilitate engagement with services (Holloway & Ellis-Hill, 2022). As such, prioritising being human, approachable, and empathetic when working with families may serve to promote helpful outcomes and positive feedback from families.

Drawing on discourses around the importance of soft skills and a relational approach, it was acknowledged that family members may have needs that may differ from the needs of the ABI survivor. A key role of clinicians working with families may be to offer a space for family members to consider and express their own needs in relation to the ABI and its impact. One participant spoke of the importance of family members having *“a confidential, with limits, obviously, but kind of, you know, a a safe space to to consider what their what their worst fears are and what their you know, what their hopes are”* (participant 5, lines 1123-1125). The participant additionally highlighted the need for families to have *“that space to really talk about what they're worried about without worrying about the patients that are being there and hearing that”* (participant 5, lines 1121-1122).

Taking a relational approach to connecting with families may also support clinicians to recognise the needs of different members of the family. This is important as evidence speaks to the risks of carer burden affecting members of an individual's system who may take on new caring responsibilities following an ABI (Knight et al., 1998). Offering support to families in this way may help promote their wellbeing and create capacity for families to care for their loved ones.

A concept that has emerged in previous research is that of the “expert companion”, which describes clinicians who are both human and relationally focused, as well as knowledgeable about the condition and able to use and share expert knowledge with families (Holloway & Ellis-Hill, 2022). Considering families' needs from this discourse allows

clinicians to connect with families and privilege relational ideas alongside other discourses. In this way, clinicians are bringing together multiple aspects that are evidenced to be important in therapeutic outcomes (Lambert et al., 1986). This highlights the need to consider the different discourses that may be emerging, and how these may sit alongside one another or interact with one another.

Beyond diagnosis

Participants constructed the discursive object by considering the needs of families beyond the ABI. These conceptualisations can be situated within wider discourses that speak to considering a person and their identity beyond the medical diagnosis they have been given. To enhance understanding of individuals and families, it is also valuable to recognise their identities that are pre-existing and existing alongside the medical condition.

One way in which participants spoke to the importance of seeing families beyond the medical need that brought them to services was in their acknowledgement that different families may have different needs. Participants spoke of having an *“individualised approach”* (participant 2, line 127) and *“being flexible to different needs”* (participant 12, line 3705). Viewing families as individuals and considering the needs of families in this light was acknowledged as being important. One participant spoke of the importance of not making assumptions about individual families; *“I just take take each family as they come, and just you know, try not to make assumptions about what I'm going to see before I see it, and then when I meet them kind of work out what their needs are as as a family, you know, because every family is different.”* (participant 7, lines 2056-2059). Another participant highlighted getting to know the individual family and their values as beneficial in order to consider how they may view goals and needs following the ABI; *“it's trying to understand you know their values, the meaning underneath that idea they have, um and the, you know, the goals they have”* (participant 4, lines 519-521).

The examples from the data above demonstrate participants considering the identities families may hold. Individual and family history and culture can contribute towards identity formation, and influence how self-identity may emerge in relation to a medical diagnosis (Karnilowicz et al., 2011). Individuals and families may often hold multiple identities, and different elements of self-identities can emerge in different contexts. Recognising and working with these can also be important in empowering families (Karnilowicz, 2011). As such, this discourse highlights how expert power (French & Raven, 1959) that may be located in healthcare services, service providers, and clinicians, can be shared with service users; professionals may be experts by training, but families are experts in their own experiences.

Participants also spoke about getting to know individual families as they operated before the event of ABI. One participant explained this includes *“being curious and exploring, you know, the ways families um operate in their own culture and you know, being sensitive and and you know um moving in that direction, rather than your own direction”* (participant 4, lines 610-613). Importance was given to getting to know a family’s pre-existing relationships and working to understand the needs of the family following an ABI in the context of their story prior to ABI. The family story prior to the ABI will impact how the family navigate the time following the ABI. For instance, one participant stated, *“I think those situations are the situations where we’re seeing where families perhaps are less involved or wanting to be less involved and that’s been because there’s been issues in the relationship beforehand”* (participant 6, lines 1626-1628).

There are many experiences that individuals and families may need to navigate after there has been an ABI (Butera-Prinzi et al., 2016; Whiffin et al., 2021). Discourses that consider individuals and families beyond the acquisition of a brain injury additionally acknowledged the significance of what families may have been navigating prior to this event. This may include experiences, life stages or general family dynamics that have often

developed over multiple generations (McGoldrick et al., 2014). Constructing the needs of families in this light may facilitate a broader formulation of needs and offer one possible explanation for some of the differences that are observed in the presenting needs of different families.

The needs of families from this discursive perspective also highlighted needing to consider how family relationships and values can be supportive through and beyond the rehabilitation process. The experience of a significant life event in the family can place pressures on relationships; *“it [ABI] also has traumatized the family as well because their family dynamics have changed” (participant 10, lines 2977-2978)*. It is important to consider how family relationships may be protected and fostered at these times, as one clinician described their role as *“advocating for them to safeguard their relationships with their loved one” (participant 8, lines 2218-2219)*. This participant positioned themselves as an advocate for families, which may imply a certain power or ability to influence relationships in families they are supporting. Participants also highlighted the value to encouraging families to remember and draw on what they mutually found important as a family prior to the ABI; *“I think the nice thing that family has value is being able to do things together they would have, which are more normalizing [...] I think they want some level of normality, which is not so clinical” (participant 6, lines 1764-1765, 1770-1771)*.

Emphasising relationships between family members is highlighted as important following the event of an ABI. Family functioning around ABIs correlates with, and has predictive value for, both positive and negative outcomes for carers and families; with better functioning associated with positive family outcomes, and poorer functioning associated with increased burden (Baker et al., 2017). As such, considering how family relationships may be protected during a difficult time follows as a priority for clinicians working in this context.

Consumerism

From this discursive perspective, the needs of families following an ABI were constructed in the context of what services are available and accessible, and in the workings of the wider national healthcare systems. These conceptualisations of the needs of families are situated within a wider consumerist framework, which draw more on a business model approach to setting up and providing healthcare services.

It is important to consider how this discourse views the relationship between the service provider and the service user. The values and priorities of those creating and providing a service may differ from those using a service. Healthcare can be organised primarily around the convenience of professionals and experts. Alternatively, a consumerist approach would suggest service users' perspectives be prioritised in decisions made about service development (Tritter et al., 2010). In this context, the roles of professionals in services may also include supporting service users with their priorities and hopes.

Within this context, participants viewed their role to include supporting families to understand services. For example, one participant explained that *"it's often my first encounter with families, and then I'm explaining about kind of what community rehab might look like in an inpatient setting"* (participant 6, lines 1350-1351). Going beyond understanding services, participants also voiced their role to include supporting families to navigate services and processes after an ABI, for example *"financial support, respite, organized kind of services to give that person [carer/family member] to break"* (participant 3, line 380).

An additional role that some participants described themselves as having was trying to integrate families into the care team around the ABI. One participant stated; *"We're all this team together, including the client, including the family and the MDT"* (participant 1, lines 644-645). However, one participant also described how families may not feel welcomed to be with their family member in the aftermath of the ABI as *"hospital services are literally built*

that that don't accommodate for families, and almost impractically say you're not part of this process.” (participant 3, lines 445-447).

Services are often developed, and commissioning agreed, based on treating the service user, and as such decisions are made on policies and procedures, as well as physical aspects of service building construction, with this in mind. More consumerist approaches to healthcare place value on the views of service users, developing care around their needs (Tritter et al., 2010). Often the evidence-base and funding focus on the patients (i.e. the individual who has experienced the ABI). In this way, family members or others in the wider system may not be a primary consideration of service development. However, involving family members can support rehabilitation after an ABI (Choustikova et al., 2020; Foster et al., 2012). Practices that implicitly exclude family members are an example of the dehumanising practices that can occur within services (Holloway & Ellis-Hall, 2022). As such this also links to the discourse of taking a relational approach and highlights the relevance of clinicians adopting humanising approaches when working with individuals and families (Todres et al., 2009). The tensions of neuro-rehabilitative services appealing for funding and convincing commissioners of the need for this are documented (Duarte et al., 2010). Therefore, it follows that obtaining the additional funding to structure services around the needs of the family as well as the survivor of ABI can be challenging. However, clinicians focusing on how they can support families to become more involved and part of the team around the survivor of ABI when appropriate may have important implications for service users and families in terms of both outcomes and satisfaction.

In this consumerist framework several challenges were discussed, which participants described navigating in their roles. One such challenge surrounds the lack of funding for certain services. One participant described; *“And sometimes the other difficulties, obviously statutory services not having enough funding. That's a huge problem, really, really big*

problem.” (participant 11, lines 3401-3402). This participant highlights the scope of this, using multiple different words to emphasize the extent of the challenge (“*huge*”, “*really big*”). This was noted to impact on clinicians’ facility to work with family members as “*families don't get supported unless we make an active an active decision to support them*” (participant 7, lines 1970-1971). This demonstrates how clinicians may be in a position of power over service users. The use of “*active decision*” can be linked to Lukes’ (2005) decision-making power, though it is also relevant to also consider that non-decision-making power is likely an influence through the wider context that existing services are situated in (i.e., the lack of services provision for families of ABI survivors).

Consumerist discourses around healthcare services have highlighted the location of accountability for challenges. With many stakeholders in service development, it is important to consider how service users, clinical professionals and the manager or leadership team may share accountability (Rober, 2017). As such, challenges may be considered by all parties, and all have a role in highlighting gaps and considering how these may be addressed.

Viewing health services through a consumerist lens draws focus to the boundaries of services that may limit the support individual services, and the professionals working in them, are able to offer. Participants described needing to consider “*the needs of the family member versus the needs of the family member in the context of the patient*” (participant 9, lines 2831-2832). This is important as services are often set up to be focused on the ABI survivor, which can challenge clinicians’ capacity to support family members or the wider system; “*I don't think anyone needs convincing that families are important but but services are under such pressure that that's often not the the primary thing that that we're encouraged to do or that fits into our job plan*” (participant 12, lines 3602-3604). In this quote, the participant positions themselves as beholden to their service context and indicates the

decision-making and non-decision-making (Lukes, 2005) power that services may hold over the clinicians working within them.

Participants acknowledged a number of challenges they encounter in their work with families following ABIs. By drawing on the consumerist discourse of healthcare services, many of these challenges have been attributed to the larger collection of healthcare organisations national or locally, as opposed to individual services. This may function to enable clinicians and services to focus more on the support and provision they are able to offer, and to highlight the gaps in support for families.

Discussion

This study aimed to answer the research question of; How do clinicians with experience working in neuro-rehabilitation services construct the needs of families of survivors of ABI? Foucauldian Discourse Analysis was the analytic method adopted to answer this question (Willig, 2008). This method was used to explore how the different discourses participants used to describe the needs of families could be situated in wider contexts, and how these wider discourses supported clinicians' constructions of families' needs, as well as how power was viewed through these lenses.

From the analysis, four main discourses emerged within which the discursive constructions of participants could be situated. As was described throughout the findings, each of the summarised discursive constructions that emerged in the analytic text is observable within the wider literature. Equally, certain discourses can be seen in existing literature focusing on ABI. This research offers insight into how these discourses may be brought together in how clinicians in this project described the needs of families, and their work with families. As such, whilst described separately, the multiple wider contexts taken into account in this research can be viewed as complementary to one another.

Participants drew on evidence-based theoretical constructs, models, and strategies in their descriptions of family needs through theories, strategies, and published documents. These discourses may act to highlight the importance and value of evidence-based knowledge in supporting the provision of high-quality care (Veenstra et al., 2017). This model is represented in the literature about ABIs. Theories describe some of the common themes in what families may be navigating following an ABI (Butera-Prinzi et al., 2016; Whiffin et al., 2021). Whilst the evidence on interventions for families in this context is limited, the existing evidence does appear to suggest that interventions can have positive outcomes for families (Butera-Prinzi et al., 2010).

Alongside these constructions, participants additionally highlighted the value of relational discourses in constructing the needs of families. Relational approaches are recognised to be important in clinical care (Veenstra et al., 2017). In the literature base focusing on ABIs, several projects have explored with families what they deemed valuable in their experiences of healthcare services following the ABI. Themes emerging from multiple projects highlight relational elements to clinical practice (Bamm et al., 2015; Choustikova et al., 2020; Holloway & Ellis-Hall, 2022; Holloway & Tasker, 2019).

Another discourse that emerged from the analytic text was going beyond the diagnosis. This included considering individual families and their identities in and beyond the context of the medical needs (Karnilowicz, 2011). This discourse also acknowledges that families will have been navigating their lives prior to the ABI, and these contexts will continue to hold significance for the family (McGoldrick et al., 2014). The experiences and journeys differ between families following an ABI (Butera-Prinzi et al., 2016), and differences between families may account for some of this heterogeneity. Family functioning following a ABI, is seen to impact the outcomes for families (Sander et al., 2002; Vangel et

al., 2011). The broader family identity is therefore an important element to consider in developing an understanding the family needs in a specific context.

Finally, a consumerist discursive perspective was considered. This perspective includes integrating stakeholder perspectives in what services may need to consider in their offerings (Tritter et al., 2010), as well as the accountability of services and stakeholders (Rober, 2017). A growing body of qualitative evidence is considering the views of family members after an ABI, making them participants in research to hear their perspectives (Choustikova et al., 2019; Fisher et al., 2020; Holloway et al., 2019). Under a consumerist lens, capturing more stakeholder views is important. It can be challenging trying to navigate service development for ABIs (Duarte et al., 2018), and the consumerist discourse offers an insight into some of these challenges.

Collectively, these discourses offer an interpretation of how participants described the needs of families following a family member surviving an ABI. This highlights the multiple influences on clinicians when working in this context, and the different discourses that may be collectively contributing to the constructions of family needs. Whilst these discourses can be described distinctively from one another, it is important to recognise their influences together in participants' descriptions of their work. The needs of families can be complex and multi-faceted in nature, and as such it is beneficial to consider multiple factors alongside one another (Lambert et al., 1986), rather than to focus on one explanation or influence to the deficit of another.

It is important to recognise that certain discourses may be privileged in the context of English neurorehabilitation services, as well as in the training professionals receive to work in these services. This research is able to provide analysis of the participants who took part, which is done via a Foucauldian discourse approach. However, participant's individual and collective contexts will inform their professional identities and inform what they say.

Additionally, certain discourses may be more endorsed in the wider evidence-base, for example, where increased funding for new research may be assigned, or where training programs may adopt particular approaches. It is important to acknowledge that these biases may exist, and the influence they may have on research projects such as this one.

One limitation of this research is that it focused solely on the clinicians working in neurorehabilitation settings and did not include the perspectives of other stakeholders in the analytic text generated. This is important given that families living with an ABI often need to interface with services that are not specific to survivors of an ABI. Service users and families were consulted as part of the design process of this research to ensure that their views helped form the research question and methods used to generate analytic text (i.e. the topic guide). The benefit of focusing on clinicians is that this research was able to offer insights into the discourses these participants drew on in their neurorehabilitation work, and the implications this has on clinical practice, which in turn also affects service users and family members. These understandings highlighted some of the complexities of working with families following a ABI, and how clinicians may be drawing on a variety of ideas, drawing these together throughout their practice. Having a more informed understanding of this may support future developments in clinical practice in this field.

The possible limitations of the analytic method need to be considered, and findings be understood in this context. A question raised about Foucauldian Discourse Analysis is to what extent subjective experiences can be theorised or understood based on discourses (Willig, 2008). It is important that the analysis and findings using this method be tentative in nature, exploring the wider discourses being drawn on and considering the possible consequences of these for speakers and their practice. However, this is not to say that all speakers will draw on the same discourses, or that any singular piece of research is able to capture all possible discourses that may be relevant. This research method and writeup is by

its nature itself a discursive construction. Continuing to be reflexive throughout the research process is therefore important (Mouthner & Doucet, 2003). Reflexivity throughout the research process is key in supporting awareness of this and is a key component of Foucauldian Discourse Analysis. One of the important benefits of adopting a Foucauldian Discourse Analysis is the insight that can be offered, beyond summarising the analytic text, into exploring discourses in more depth, situating these in context and considering the roles of power.

In terms of the implications for future research, this research used a Foucauldian Discourse Analysis method to consider how clinicians constructed the needs of families following an ABI. Using the same method of analysis, it may be interesting to consider how family members describe their needs following the ABI of a family member. Looking at whether family members draw on similar or different discourses when describing needs may be important. The possible gap in the needs of families being met has been established in previous research (Choustikova et al., 2020; Fisher et al., 2020; Holloway et al., 2019) and this may be an interesting way to examine this idea.

Considering the implications for possible practice and policy, it is valuable if clinicians can be reflexive with regards to what may be influencing their clinical practice. Reflexivity may include appraising how the evidence that forms a knowledge base is produced, and how it is used in practice (Malterud, 2002). There can be biases in the production of knowledge (i.e., how research is conducted), and in how clinicians draw upon knowledge in practice. Being mindful of the wider discourses that clinicians may be drawing on in neurorehabilitation practice may support this reflexivity.

Additionally, whilst the lack of clinical guidelines for working with families following an ABI is acknowledged (Foster et al., 2012), the findings of research such as this project may offer important considerations in the development of clinical practices. The

project speaks to how the participants currently practice and how they consider the needs of families in after a ABI. As families and ABIs are idiosyncratic, it may be beneficial to draw on the knowledge that professionals working with this population have gained to consider the challenges, as well as how families could be supported. Future research and developments in this area may wish to consider developing guidelines for working with families following a brain injury. It would also be important to consider how other stakeholders, such as ABI survivors and family members could be represented in this.

Conclusion

This research considered the discourses clinicians drew on in evaluating the needs of families after an ABI and describing how they worked with families in this context. A Foucauldian Discourse Analysis enabled the analysis to elaborate on the perspectives participants offered, as well as situating these in wider discourses that may emerge, and considering the role of power. A key learning from this research surrounds how the four discourses that were observed in this research can be seen to collectively inform clinicians' ideas of the needs of families following an ABI, and through this inform clinical practices.

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Appendix A. Research advertisement



ARE YOU WORKING WITH FAMILIES FOLLOWING AN ACQUIRED BRAIN INJURY?

We are looking for **clinicians** with experience of **working with families** following a family member experiencing an **Acquired Brain Injury**.

We are interested in finding out *how clinicians construct the needs families of survivors of Acquired Brain Injury*.

Taking part will involve joining an **online focus group** along with other clinicians to discuss your experience. The focus group will run for about **60-90 minutes**.

We hope this can inform clinical practice, allowing services to better respond to the needs of families/individuals following ABI.

For more information, or to express your interest in being involved, please contact Maria Butler on

This study has been given a Favourable Ethical Opinion by the University Ethics Committee

Thank you!

Appendix B. Participant Information sheet

PARTICIPANT INFORMATION SHEET

Title of Study: Examining how clinicians construct the needs of families following an Acquired Brain Injury (ABI)

University of Surrey Ref: FHMS 21-22 014 EGA

PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

Section: Taking Part

Invitation Paragraph

We would like to invite you to participate in this research project on clinician perspectives of working with families following an Acquired Brain Injury. Being part of this study is voluntary, choosing not to take part will not disadvantage you in any way. If you want to be part of the study, we ask that you read the information below carefully to understand why the research is being done and what your participation will involve. If you have any questions, you can contact us using the contact details at the end of this information sheet.

What is the purpose of the study?

This project aims to explore how clinicians engage with and conceptualise the needs of families following an ABI. To do this, the project aims to answer the research question; How do clinicians with experience working in neuro-rehabilitation services construct the needs of families of survivors of Acquired Brain Injury? This will involve semi-structured focus groups and interviews with clinicians with experience working in neuro-rehabilitation services.

Who is responsible for this study?

This study is the responsibility of Maria Butler (Trainee Clinical Psychologist) and supervisors Freddie Byrne and Thorsten Barnhofer at the University of Surrey and involves collaborators at La Trobe University/Bouverie Institute in Australia who have kindly shared their project materials following their similar research.

Why have I been invited to take part?

You are invited to participate in this study because we value your opinion and expert knowledge as a professional working with experience working with families following an Acquired Brain Injury. To be eligible to take part in this study you must be over the age of eighteen, speak English, and have professional experience (either current, or past experience over one year) working in neurorehabilitation (either NHS, third sector or private sector, supporting rehabilitation after a neurological impairment).

Do I have to take part?

Participation is voluntary and you do not have to take part. We will describe the study in this information sheet and will give you one week to read this, so you can decide whether you wish to take part in this study. Please contact us if there is anything that is not clear, or if you have any questions, or if you would like more information.

What will happen to me if I decide to take part?

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate. You will be given a copy of this consent form to keep. The personal contact details you have provided to receive this information sheet will be used for further contact about the research and for no other purpose. These will not be kept after this study is completed.

You will be given a brief questionnaire with demographic questions, and we will arrange a time to complete the focus group or interview. These will be conducted remotely (you will be sent access information) and will be 1.5 hours in length. These will be recorded to enable verbatim transcription and anonymised for data analysis. Recordings will be stored securely on a recording device; transcripts will be stored on a secure university server. Recordings will not be used or made available for any other purpose than the research project and will be destroyed at the end of the study.

What happens if I do not want to take part or if I change my mind?

You are free to withdraw all data you have provided up to one week after the focus group or interview, without giving a reason. Following this time, as the interview will be transcribed and fully anonymised, it will not be possible to remove the information you have provided. We will delete all personal identifying information provided by you.

What are the possible benefits in taking part?

The information we will get from the study will contribute towards building research in this area. Any results may offer perspectives that may support services to better respond to the needs of individuals and family members.

Are there any potential risks involved?

With any study there are (1) risks we know about, (2) risks we don't know about and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

A possible disadvantage to taking part in the study is that sharing your experience may cause some discomfort or upset. You may ask for a break from the interview or withdraw from it at any time. Information on sources of support will be provided. It is possible that other members of the focus group may express different views. In order to reduce any potential risks, the researchers will discuss ground rules with the group, and intervene should this be required.

Will my participation be kept confidential?

All the information that we collect about you during the research will be kept strictly confidential and only accessed by either members of the research team or responsible members of the University for auditing and/or monitoring purposes. You will not be able to be identified in any ensuing reports or publications.

The nature of focus groups means that discussions will be expected to be confidential within the group. Although the researchers will safeguard the confidentiality of the discussion to the best of our ability, the nature of focus groups prevents the researcher from guaranteeing that other members of the group will do so. The researcher will discuss confidentiality and privacy at the beginning and end of the focus groups and outline expectations of confidentiality.

Will my data be shared or used in future research studies?

Your information may be subject to review for monitoring and audit purposes, by individuals from the University of Surrey and/or regulators who will treat your data in confidence.

What will happen to the results of the study?

We will produce a final report summarising the main findings. This research may be published in peer reviewed scientific journals and present them at conferences. Any published findings or quotations will use pseudonyms and will maintain your confidentiality and anonymity. You will not be personally identified in any reports or publications.

You can contact the study team to find out the results of the research.

Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion.

Section: Your personal data

What is personal data?

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name, contact details, age, and professional role, which is regarded as 'personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

Who is handling my personal data?

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. We will not share any of your personal details with the collaborating universities on this project, and any research data will only be shared once this has been fully anonymised beforehand, so that you are no longer identifiable.

What will happen to my personal data?

As a publicly funded organisation, we have to ensure that when we use **identifiable personal** information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the **public interest** and special category data is processed on an additional condition necessary for **research purposes**. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for **ten** years after the study has finished after which time any identifiers will be removed from the aggregated research data.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you decide to withdraw from the study, we may not be able to withdraw your data. We will keep and use the minimum amount of personally identifiable information about you that we have already obtained in order to complete the study.

If you wish to make a complaint about how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter (dataprotection@surrey.ac.uk). If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO) (<https://ico.org.uk/>).

You can find out more about how we use your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting dataprotection@surrey.ac.uk.

Section: Further information

What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)

Research and Innovation Services

University of Surrey

Senate House, Guildford, Surrey, GU2 7XH

Phone: +44 (0)1483 689110

Email: rigo@surrey.ac.uk

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study then you should follow the instructions given above.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Maria Butler

Trainee Clinical Psychologist

Email:

Supervised by: Dr Freddie Byrne and Professor Thorsten Barnhofer.

Thank you for reading this information sheet and for considering taking part in this research.

Appendix C. Consent form

INFORMED CONSENT FORM

Thank you for considering taking part in this research.

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Examining how clinicians construct the needs of families following an Acquired Brain Injury (ABI)

University of Surrey Ref: FHMS 21-22 014 EGA

The person asking for your consent must explain the project to you before you agree to take part. If you have any questions about the Information Sheet or their explanation, please ask the researcher before you make your decision. You will be given a copy of this Consent Form and the Information Sheet to keep and refer to at any time.

By **initialling** each box, you are consenting to this part of the study. Any un-initialled boxes will mean that you DO NOT agree to that part of the study and this may mean you are ineligible for the study.

Taking part in the study		
	Statement	Please <u>initial</u> each box
1	I confirm that I have read and understood the information sheet dated [1.0, 19/10/2021] for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time during the study without giving any reason. Furthermore, I understand that data already collected can only be withdrawn up to one month after the focus group or interview.	
3	I understand that information I provide may be subject to review by responsible individuals from the University of Surrey and/or regulators for monitoring and audit purposes.	
4	I understand that information I provide will be used in various anonymised outputs, including reports, publications, or presentations.	
5	I understand that my personal data, including this consent form, which link me to the research data, will be kept securely in accordance with data protection guidelines, and only be accessible to the immediate research team or responsible persons at the University.	
6	I understand any personal contact details collected about me, such as my phone number and address, will not be shared beyond the study team.	
7	I agree to take part in this study.	

8	I understand that my anonymity cannot be guaranteed in the focus groups, but participants will be asked to keep the discussions confidential, and the research team will keep any information collected confidential.	
9	I agree to keep the discussions in the focus groups confidential.	
10	I consent to my audio recording/video recording to be used for the purposes stated in the information sheet.	

Signatures		
Name of Participant	Signature	Date
Name of Researcher	Signature	Date

Appendix D. Topic guide for focus group and interviews

Focus Group / Interview Guide

How do clinicians with experience working in neuro-rehabilitation services construct the needs families of survivors of Acquired Brain Injury?

Introduction

- Welcome and thank you for participation. Facilitator introduction. Review aims of the focus group / interview.
 - This project aims to explore how clinicians engage with and understand the needs of families. To do this, the project aims to answer the research question; *How do clinicians with experience working in neuro-rehabilitation services construct the needs families of survivors of Acquired Brain Injury?*
- Consent
 - Review consent form key points – voluntary participation, recording of the focus group / interview, one month after today to withdraw consent
- Logistics
 - Duration 1.5 hours, free to ensure own comforts met. If leaving the virtual room, please let facilitators know if you are alright/require support.
- Ground rules
 - Everyone will have an opportunity to speak and only one person talks at a time
 - It is important for us to hear everyone's ideas and opinions
 - There are no right or wrong answers to questions
 - Turn off or silence mobile phones
 - Confidentiality expected to be upheld by all participants.
 - Technology – welcome people to stay off mute unless excess background noise, in which case mute unless speaking.
- Any questions?
- Introductions to each participant (name, role).

Questions (and prompts)

1. What do families need after ABI?
 - a. *(e.g. psychoeducation/information, support navigating tasks).*
2. What skills do clinicians need to support families following an ABI?
 - a. *What is helpful in working with family members following an ABI?*
 - b. *What is unhelpful in working with family members following an ABI?*
3. What are the challenges in working with family members following an ABI?
 - a. *My understanding is that working with families after ABI can stir up difficult emotions in us as practitioners. What strategies are helpful for clinicians to manage themselves and to remain calm and present?*
 - b. *What gaps to supporting families do you identify in the system/services?*
 - c. *How can clinicians best support families to balance maintaining hope with realistic expectations?*
4. How do you consider the diverse needs of families/family members into your work with them?

- a. Are there any challenges that working with diversity brings?*
 - b. If so, how can we mitigate these?*
- 5. What do you think families would say about what was helpful or less helpful?
 - a. (e.g. distressing changes, hope, new roles, narratives)*
- 6. What would you say are the key messages for clinicians when working with families/people with ABI?
- 7. Is there anything else that anyone would like to raise or discuss today?

That concludes today's interview / focus group. Thank you for participating and sharing your perspectives. Should any of today's discussion have provoked distress, please feel free contact the researcher via email, and they can signpost you to support services. The researcher will monitor for next half an hour to respond promptly.

Appendix E. Favourable ethical opinion

RESEARCH & INNOVATION SERVICES
SURREY.AC.UK/RIS



Research Integrity & Governance
Office (RIGO)
4th floor Senate House
Guildford
Surrey GU2 7XH UK

T: +44 (0)1483 68 9103/2051

ethics@surrey.ac.uk
www.surrey.ac.uk

Maria Butler
Psychology
Faculty of Health and Medical Sciences

06 December 2021

Dear Maria,

EGA ref: FHMS 21-22 014 EGA

Project Title: Examining how clinicians construct the needs of families following an Acquired Brain Injury (ABI)

On behalf of the University Ethics Committee (UEC), I am pleased to confirm a 'Favourable Ethical Opinion' (FEO) for the above research on the basis of the submitted protocol and final supporting documentation listed in the table below.

Date of confirmation of ethical opinion: 6th December 2021

Please note that you must provide RIGO with the permission letter or email from the networks and/or closed groups, before the research commences.

This opinion is given on the understanding that you will comply with the relevant University policies, ethical and professional standards and any applicable regulatory requirements, and have completed all mandatory training provided by the University of Surrey.

Please follow guidelines below and note that all research activity must comply with current University guidance regarding the Covid19 pandemic:

<https://www.surrey.ac.uk/coronavirus/researchers/research-university-ethics-committee-approval>

If you wish to make any changes to the Protocol for this project, now or later, other than those permitted in the guidance provided in the above link, you must submit a Notification of Amendment form before any changes can be implemented. Please refer to the Guidance on Amendments which can be found on the Research Integrity and Governance Office webpages. Please note that the governance approval of this project is only valid until the study end date provided on your final EGA form listed below.

Please be aware that the Committee must be notified if the following incidents and events occur:

- Protocol deviation e.g. changes in recruitment methods, consent method, poster advertisements, study design or study materials such as questionnaires;
- Study extension for recruiting participants and/or data collection;



- Serious adverse events (SAEs) (e.g. life-threatening such as self-harm) or adverse events (AE) (e.g. an unexpected reaction such as skin irritation) that may potentially impact the research participants or your data integrity. This should include any unexpected event not related to the study, events related to the study and death of a participant related or unrelated to the study and;
- The study is terminated earlier than expected with reasons.

You should do this by contacting ethics@surrey.ac.uk. Please be advised that the Ethics Committee and/or RIGO audit research projects to ensure that researchers are abiding by the University requirements and guidelines.

This 'Favourable Ethical Opinion' is valid only for the duration of the project. The study end date will be the date of the last visit of the participant or the completion of any data collection as stated on the EGA form listed below.

If you have any query regarding your project, please contact RIGO at ethics@surrey.ac.uk

The final list of documents reviewed by the Committee is as follows:

Document	Version	Date
SAGE ID 801367-801358-84945064	N/A	19 October 2021
EGA	V1.0	19 October 2021
Protocol	V1.2	12 November 2021
Consent form	V1.1	18 November 2021
PIS	V1.1	18 November 2021
Clinician Advert	V1.1	03 December 2021
Focus Group – Interview guide	V1.0	19 October 2021

Yours sincerely



Dr Kevin Wells
Chair of the University Ethics Committee
RIGO: MT

Copy to Thorsten Barnhofer



Appendix F: Example initial analysis: Discourses and quotes

Construction: Services and Systems Wider discourse: Consumerism		
Ppt Number	Text	Notes
9	“The tricky thing is when we have those sort of conversations to families, it is with the premise of how that then relates to the support of the index person and so like I said, there's a bit of a grey line as to. Where that overlap comes between the. Just the needs of the family member versus the needs of the family member in the context of the patient. So it's all gonna be sort of related to them being unwell or in hospital.”	Family needs in the context of the primary patient
5	“But for us here there is that line of kind of, you know, say for example if you start doing some, you know work with some do every week and it becomes apparent that pre-existing issues are the main focus of that then for us that would be the point where we have that conversation where we think we need more than what we're able to give them. (...) it's very difficult actually to say what the remit is of family work”	References to service context / limitations of scope of care
6	“And also kind of having having the respect and expertise amongst my wider MDT, so I in my service it's it's neuropsychology led, so I'm the clinical lead for the service, but ensuring that my speech and language therapy colleague and my occupational therapy colleague, for example, we're all singing from the same hymn sheet and we've all got each other's backs. And that when we are presenting information to families, whether that be a review report or a discharge reports or meeting with them to talk about significant concerns or something. That we're all making sure that we have that same fundamental grounding in our in our understanding and our assessment.”	MDT approach to care
7	“It's like, you know, often the answers are there the solutions are there, and it's not for, like, a random clinician who's known this family for five minutes to suggest things that just aren't they these things are there families just need a bit of confidence. In. Knowing that they know.”	Integrating the survivor's family into care planning
3	“A huge range of different sort of modalities supporting somebody and then some areas, you know, UM. It's just absent, you know, one particular discipline might be completely absent. And so I think within our services, there was often a lot of positive feedback about kind of feeling that they were. um their needs are being met in, in, in all spheres.”	Holistic care
6	“Forms are are horrible. They're really, they're really thick. They're really wordy, you know, and and families will often come to me and say, I I don't understand what this means or I don't understand that. And, you know, my team are very good in in helping families and completing those forms”	Practicalities and logistics

Construction: Knowledge Base (Theory, Strategy, Techniques)		
Wider discourse: Evidence-Based Theoretical Constructs, Models, and Strategies		
Ppt Number	Quote	Notes
3	“there's a real, real difference in flavor of the work between things like stroke and kind of acute work and and then, yeah, much more long term and how families respond to both of those situations as fascinating to to go between them.”	Changes over time
5	“I think some people, some families will really need um you know, concrete, UM, direct interventions like psychoeducation. (...) sort of say that we're like sounding board a lot. So we might be like a sounding board for families in terms of things like how are they sleeping, how are they eating, how are they looking after themselves? Umm in general. So you might get into the realms of things like sleep hygiene and with a family member”	Reference to a theory or strategy (explicit or content)
11	“I just think there needs to be a little bit more diversity in the way that we support people and having a rich mix of people because there are people who are coming from walks of lives who their lived experience can actually be utilized in a way that can be beneficial”	Experts by experience, drawing on lived experience
8	“I think keeping open lines of communication is really important and and being very honest about where we are and what our expectations are and and from the off being very honest about how severe brain injury is (...) I get that we all have to maintain hope to a certain degree, but we also have to have some kind of realistic expectations alongside it.”	Information provision, offering honest prognosis
Construction: Soft skills		
Wider discourse: Taking a Relational Approach		
Ppt Number	Quote	Notes
10	“I think more than anything they need that, that compassionate understanding (...) I think listening is imperative. I think it's important because sometimes the clinicians, because they have a plethora of knowledge they've studied, there's one part to, to supporting people which definitely the level of academia somebody has goes to support and the understanding of that from a, from a scientific factor. But to actually listen to the people and the families to understand”	Offering a safe space, showing compassion and empathy
2	“Therapist, team members, case managers, who Who they who are human, who they feel they can relate to. So it's just again that we've we've talked about a lot, haven't way about being attuned and changing your accent or whatever you need to do to restore that really to to develop that really therapeutic relationship with that. Yeah, yeah, the that's underpinned by sort of empathy and and and humanist approach really.”	Forming an alliance/rapport, connecting with families

3	“being a a safe space for someone to explore some of the most difficult questions around brain injury like you know who who is this person going to be now you know and is it OK for me to be sad about the fact that I've lost that person, or you know, I'm I supposed to act as if it's going to be OK”	Family needs for separate spaces
<hr/>		
Construction: Individual Families in and beyond Brain Injury		
Wider discourse: Beyond Diagnosis		
Ppt Number	Quote	Notes
4	“I guess it's that attunement (...) going with what's helpful for that person rather than yeah ideas you had about what's going to be helpful, or maybe what was helpful for the last person. And kind of you know, withholding that present moment. (...) sensing whether to go forward with something or whether to hold back with something as well. Uhm, whether what you're going to say or do is going to be helpful for that, for that person or. or not really. So it's, I don't know. It's kind of like a. Like a dance, really. But they the dance is going to be different with each person.”	Individualised, person centred and flexible
7	“I would say that's really important is that families know what they need. They just don't. Often families know what they need. They just don't realize it. So often families have the answers and and actually they just need a bit of help in finding the answers.”	Empowering families
5	“Ask them about their loved one and not just the the you know the the information regarding cognition and what they're noticing, but also about them as a person and what's important to them and how they think we can support them because they'll be an awful lot of information within that which in turn supports the family because they feel like they can leave the ward and walk away, and that their loved one is safe and, you know, sort of heard and looked after”	Learning about individual family values and relationships

Part C: Summary of clinical practice and assessments

This part is not available due to confidentiality and access is not possible. The table below summarises the clinical experience and assessments undertaken.

YEAR 1	
PLACEMENT	
Working Age Adults: Assessment and Treatment Service <i>November 2020 – September 2021</i>	
ASSESSMENTS	
WAIS	WAIS Interpretation and Administration
Practice Report of Clinical Activity	Assessment and formulation: Cognitive Behaviour Therapy with a female in her early thirties presenting with Obsessive Compulsive Disorder.
Report of Clinical Activity N=1	Assessment, Formulation and Intervention: Cognitive Behaviour Therapy with a female in her early thirties presenting with Obsessive Compulsive Disorder.
Service-Related Project	An investigation into the efficacy of digital groups through a comparison between online STEPPS group provision and face to face STEPPS group provision.

YEAR II	
PLACEMENT	
Adults in Later Life (Neuropsychology Pathway) Split Placement: Dementia Assessment Service & Neuropsychology Service <i>October 2021 – March 2022</i>	
Children, Young People & Families: Child Development Centre & Child and Adolescent Mental Health Service <i>April 2022 – September 2022</i>	
ASSESSMENTS	
Report of Clinical Activity – Formal Assessment	Neuropsychological assessment of a Romanian 32-year-old woman reporting mood and cognitive difficulties.
Presentation of Clinical Activity	A Systemically Informed Reformulation and Proposed Intervention with Jack, a Pre-Adolescent being Assessed for an Autism Spectrum Disorder.

YEAR III	
PLACEMENT	
Specialist Placement: Paediatric Psychology Service <i>October 2022 – March 2023</i>	

YEAR III	
Learning Disabilities (Split Placement): Assessment and Treatment Unit & Community Learning Disabilities Team	
<i>April 2023 – September 2023</i>	
ASSESSMENTS	
Application of Systemic Ideas to a Clinical Scenario	Systemic theory applied to the assessment, working formulation and planned intervention for an adolescent boy referred to the service and his family.
Report of Clinical Activity	Assessment, Formulation and Intervention for a family referred to the Paediatric Psychology Service for support with Enuresis and Encopresis.