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Whose outcome is it anyway? Outcome and Brain Injury Case Management

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Outcome and brain injury case management

Whose outcome is it anyway? Outcome and Brain Injury Case Management.

Abstract

Context: The Acquired Brain Injury (ABI) literature highlights various factors that can prevent successful community rehabilitation and hinder good long-term outcomes. Brain injury case management is a service model with the potential to overcome these barriers within rehabilitation and longer-term care and support, but there is minimal research surrounding the effectiveness of case management in ABI.

Objectives: This study aims to gain a better understanding of outcomes in brain injury case management and what facilitates good outcomes when working with clients.

Methods: Using a mixed qualitative approach using both conventional content analysis and thematic analysis, 28 Brain Injury Case Managers completed an online qualitative questionnaire about what constitutes a good outcome in brain injury case management. Of these, five took part in a follow-up interview.

Findings: The analysis identified four themes related to brain injury case management outcomes; 1) A client-centred approach to outcome, 2) the role of the Brain Injury Case Manager, 3) Monitoring outcome in case management, and 4) Issues of funding.

Limitations: Response rate to the survey and interviews was low due to recruiting during the COVID-19 pandemic. The study only included Brain Injury case managers and future studies should consider including clients and family members perspectives.

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Implications: This study identified that brain injury case management is a holistic approach to rehabilitation and case coordination that requires further attention. Appropriate holistic measures of quality of life and outcome need to be developed to support the evidence-base for case management.

Introduction

Acquired Brain Injury (ABI) is an injury to the brain that occurs during or after birth. The causes of ABI can be traumatic (Traumatic brain injury (TBI); road traffic accident, assault, a fall, or nontraumatic; stroke, infections of the brain, hypoxia etc; Mass *et al.*, 2017). Acquired brain injury is an international phenomenon, placing significant pressures on countries' health and long-term (social) care services (Dewan *et al.*, 2018, Peeters *et al.*, 2015). Models of long-term support for people with ABI and their families are not as evidence based as some other areas of rehabilitation. In particular, it is not clear how to conceptualise and measure outcomes in this area. Case management is one model of support used in this context. This paper focusses upon the UK experience of case management to explore the issues around outcomes, the contribution of case managers to agreeing and achieving these, and how to measure them.

Acquired Brain Injury and Rehabilitation services in the UK

Since 2005/2006, there has been a 10% increase of ABI hospital admissions in the UK, equating to 945 admissions per day and one every 90 seconds (Headway UK, 2018). The annual cost of ABI, considering premature death, hospital stays, health and social care, as well as the loss of employment, is around £15 billion, around 10% of the NHS budget per year (United Brain Injury Forum, 2018). ABI is reported to be

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the leading disability in under forty-year-olds in the UK (Fleminger and Ponsford, 2005). Men experiencing increased social deprivation (poor social and economic environments) are most vulnerable to experiencing an ABI (Headway UK, 2018; Dunn, Henry and Beard, 2003).

More people are surviving ABI due to technological and medical advances and, therefore, contributing to the increasing prevalence of ABI survivors in society (Hutchinson *et al*, 2016). However, a common misconception of ABI is that impairments are inclined to be physical (Dunn *et al*, 2003; Higham and Phelps, 2019). Although ABI survivors can experience mobility issues, impaired speech, and fatigue (Whiteneck *et al*, 2016), it is the diverse range of chronic hidden disabilities incurred that are problematic and often long term. Cognitive difficulties can include memory (Mathias and Mansfield, 2005) and attention deficits (Rohling *et al*, 2009), as well as behavioural and emotional changes associated with executive dysfunction (Wood and Worthington, 2017; Hart *et al*, 2005). These can inhibit an ABI survivor from living an independent life and, therefore, require long-term support and/or rehabilitation.

Research identifies the psychosocial consequences of residual functional impairments in ABI survivors to be the most debilitating (Holloway and Tasker, 2019). The loss of employment and subsequent financial safety net, reduced quality of, or the breakdown in, relationships, mental ill-health and substantial social difficulties are associated with poorer long-term outcomes of ABI (Friedland and Potts, 2014; Fleminger, 2008; Williams *et al*, 2020). These are often characterised by substance abuse, homelessness, social isolation, a presence in the criminal justice system or suicidality

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(Adshead, Norman and Holloway, 2019; Woolhouse, McKinlay and Grace, 2018; Norman, 2016; McMillan *et al*, 2015; Degeneffe and Bursnall, 2015).

The World Health Organisation (WHO) defines rehabilitation as: “*a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.*” (WHO, 2020). The aim of rehabilitation is to improve functional outcomes by restoration, compensation and adaptation. In doing so, individuals affected by brain injury work with others to meet meaningful and personal goals. Reintegration into the community, undertaking roles that are considered important, and playing a part within a family and community are often most valued (Clark-Wilson, Giles and Baxter, 2014). Rehabilitation interventions have demonstrated success at recovering a client's function, specific to discipline and usually targeting the expected internal deficits of ABI (cognitive, behavioural and emotional changes) (Malec, 2005), or may be more holistic and functional in nature (Clark-Wilson *et al*, 2014). A rehabilitation team may consist of an Occupational Therapist, Physiotherapist, Speech and Language Therapist and Psychologist, as well as other allied health professionals and support staff. The rehabilitation team, via a process of goal setting and measurement, can monitor and measure progress (Malec, 2009; Evans, 2012). An evidence-base supports their effectiveness of these services at influencing a positive outcome following ABI (National Institute for Health and Clinical Excellence, 2019; Turner-Stokes, 2008; Van Heugten, Gregorio and Wade, 2012). External factors relating to personal characteristics, family dynamics and the home environment, which may not be the main focus of traditional rehabilitation services, pervade the ABI literature and are reported to influence outcomes in ABI (Ponsford, 2013; Whiteneck, Gerhart and Cusick, 2004).

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The quality of long-term care, rehabilitation and support services following an ABI are fragmented in comparison to acute care (Piccenna *et al*, 2016). Research suggests that clinical and social care systems are not designed for the complexity and prevalence of an ABI (Degeneffe and Bursnall, 2015; Degeneffe, Green and Jones, 2016; Holloway, 2014; Odumuyiwa *et al*, 2019). As non-ABI generic services suffer from decreased resource allocation resulting from budget cuts (Gray and Barford, 2018), the consequential time constraints and lack of comprehensive understanding of the survivor mean that these services have a propensity to overlook the hidden disabilities associated with ABI, instead focusing on physical impairments (Holloway, 2014; Odumuyiwa *et al*, 2019; Holloway and Fyson, 2016). Failure to accurately identify executive dysfunction, coupled with loss of insight, can prevent survivor engagement in rehabilitation and support tasks, leading to poorer outcomes (Medley and Powell, 2010).

Although the body of research detailing the barriers to a good outcome in ABI is relatively recent, the deficits in services have been longstanding (Social Service Inspectorate, 1996; British Association of Brain Injury Case Managers, 2020), with the United Kingdom (UK) Department of Health (DH, 2005) (now Department of Health and Social Care (DHSC)) acknowledging that the long-term care needs of those with ABI do not "fit" within pre-existing services in the UK NHS or Social Services (SS) (British Society of Rehabilitation Medicine, 2003). Instead, the DH proposed a clinical model of case management to provide quality care and control costs to bridge the gaps in services (DH, 2005; Clark-Wilson and Holloway, 2015).

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The British Association of Brain Injury and Complex Case Management (BABICM) define this case management role as "*...a collaborative process, which assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's health and wellbeing, education and/or occupational needs, using communication and available resources to promote quality, cost-effective and safe outcomes*". Brain Injury Case Managers (BICMs) should have a health or social care professional qualification and experience working with ABI (BABICM, 2020). Recent research has indicated the effectiveness of case management in overcoming the barriers to a good outcome in ABI (Simpson *et al*, 2018).

Despite this, in the UK, the utilisation of the clinical model of case management in the long-term care of ABI clients is poor, with most BICMs only working with ABI clients funded because of litigated cases. While exceptions to this do exist, such as the 'Neuro navigators' service (Kings Health Partners, 2018) that provide similar case management models within a National Health Service (NHS) context, a BICM is an unlikely provision within statutory health and social care service because of funding constraints, and the considerable strain services have been placed under in supporting the UK population (Clark-Wilson and Holloway, 2015). Overall, brain injury case management does not have a strong evidence-base compared to the standard rehabilitation services recommended by NICE (2019).

Furthermore, there is limited research on appropriate outcome measures that could be employed by BICM (Lannin *et al*, 2014). While specific rehabilitation specialists may routinely employ outcome-specific measures, case managers often struggle to find effective outcome measures that assess global functioning more specifically. One

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of the ultimate goals of case management is to improve overall quality of life for the person with ABI, but such measures tend to be poor at identifying aspects of day-to-day functioning that are important to clients and can miss key symptomology (Norman *et al*, 2021). This is problematic in terms of measuring outcomes for clients, but also makes it difficult to provide an evidence-base for the effectiveness of BICMs. Better understanding and attaining evidence of effectiveness in case management could improve the likelihood of this service becoming part of statutory service provision and hopefully enable more individuals with ABI to achieve good long-term outcomes.

The literature surrounding BICM is relatively scarce, particularly from a UK perspective, and therefore little is known about its effectiveness or a definitive understanding of what the role should entail (Lukersmith, Millington and Salvador-Carulla, 2016). However, the work of Lukersmith *et al* (2016) highlights the need for an integrative approach to case management across services that is key to the model of case management used within brain injury. The review also identified the key role brain injury case management can play in supporting statutory services. With this lack of clarity around BICM in mind, this study sought to gain a better understanding of outcomes in brain injury case management and what facilitates good outcomes when working with clients.

Method

Participants

Ethical approval was obtained through the Faculty Research Ethics Committee of the [University name]. All data were anonymised with unique identifiers used in both stages of the study. All participants gave full informed consent to participate.

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BICMs registered with BABICM (510 individuals) were sent details of the study via email and through the BABICM online newsletter. Twenty-eight participants (27 female, Mage = 47.6 years) responded to the invitation and took part in an online survey, a response rate of 5.5%. Participants had between 1 year and over 20 years of experience working in brain injury case management, with a range of different BABICM registration levels from practitioner to advanced practitioner (see table 1). The average number of clients the BICMs currently had varied from fewer than 6 through to over 50. These figures may in places represent individuals who offer supervision to other case managers and may have included supervisee caseloads as well as their own as 50 represents a very high caseload. BICMS came from a range of professional backgrounds, with the most common being Occupational Therapy.

INSERT Table 1 here

Of the original 28 participants in the questionnaire study, 12 agreed to take part in a follow-up interview stage. Due to the COVID-19 global pandemic, and the increased workload experienced by the BICMs at this crucial time, only five telephone interviews were conducted.

Design & Procedure:

This study used a sequentially phased exploratory research design, appropriate for developing a complete and rich understanding of a topic on which there is very limited previous literature. Triangulation was employed through a survey questionnaire and interviews with a sample of respondents to explore in more detail issues from the survey and, thereby, enhance the validity and reliability of the findings (Carter *et al*, 2014; Hsieh and Shannon, 2005).

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The initial phase of data collection employed an online survey, provided on the survey platform *Joint Information Systems Committee (JISC)*. The questionnaire asked for demographic and professional practitioner information, alongside open-ended questions focused on the use of outcome measures and perceptions of outcomes in brain injury case management. Example questions of the latter included; '*what do you consider to be a good outcome?*', '*what would you expect a good outcome measure to capture?*' and '*What do you know about outcome measures in acquired brain injury?*'.

The practitioner information questions were analysed using descriptive statistics, and the qualitative questions were analysed using Conventional Content Analysis (CCA; Hsieh and Shannon, 2005). At the end of the questionnaire, the BICMs were invited to provide an email address to participate in the second phase of the data collection, a semi-structured telephone interview. The latter consisted of seven questions (appendix A) designed to elicit elaboration on targeted responses from the survey data. Example questions included; 'What factors enable a good outcome?', 'What particular client characteristics are associated with good outcomes?' 'How does the case manager change an outcome?' The telephone interviews, which lasted between 20 minutes to one hour, were audio-recorded and later transcribed verbatim.

Data Analysis:

Questionnaire

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Due to limited literature regarding brain injury case management and outcomes, CCA was employed as it allowed the opportunity to explore the data for topics frequently discussed or described with enough depth and passion to warrant inclusion (Hsieh and Shannon, 2005). Conducting CCA in this way gathers information directly from the participants' responses without imposing pre-defined categories (Hsieh and Shannon, 2005). The process of analysis consisted of reading and re-reading the data while making exploratory comments that would later be derived into codes that represent key concepts in the data. Next, the codes were grouped into meaningful clusters that identified the main themes captured in the questionnaire data. Validation of the CCA was confirmed by another project team member. The data used at this stage of the analysis process was used to create a framework for analysing the interviews conducted in the second stage of the study. CCA is a method used for creating qualitatively rich data from limited open-ended responses and is also appropriate when researchers wish to quantify themes from open-ended questionnaire data (Vaismoraldi et al, 2013). The analysis was led by one of the research team and then checked with others in the team.

Interview:

The semi-structured telephone interviews were analysed using both a deductive and inductive thematic approach (Braun and Clarke 2006). Thematic analysis is more appropriate for use with detailed interview responses and where researchers are not wishing to quantify findings (Vaismoraldi et al, 2016; Vaismoraldi et al, 2013). Initially, a deductive framework was applied to the interview data to identify the pre-defined themes created in the first stage of the data analysis process. This was constructed based on the analysis of the questionnaire data. An inductive thematic analysis

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followed to identify new themes not previously captured by the CCA. The process of analysis was similar to the CCA and involved reading the transcripts and making exploratory notes that were later derived into codes (Braun and Clarke, 2006). These codes were then grouped into meaningful clusters that identified the main themes. Applying an inductive approach to the data led to several iterations of sub-themes and defined a further five sub-themes overall. For example, *Family is Supportive* was an initial sub-theme under *Client Centred Approach to outcome*. However, continual review of the data highlighted the prevalence and importance that the participants placed on the association between the level of support received by the ABI survivors family and their ability to support the ABI survivor to reach their own positive outcome. Inductive analysis was particularly useful to establish and define the root issues of *Capturing Outcomes in Case Management*. The survey data demonstrated a clear dissatisfaction with the current case management systems that measure outcome, however the interview data generated three additional sub-themes that provided richer detail about of what these issues were, how these outcome measures could be improved and how to accurately measure the effectiveness of case management in achieving good outcomes. These analyses were conducted by one member of the research team and checked with others in the team. Quotations used below from the interviews are labelled according to the participant reference number, e.g. P1.

Results

The thematic analysis identified four main themes: a client-centred approach to outcome; the role of the BICM; monitoring outcome in brain injury case management; and funding. This section will describe each theme, though it should be noted that

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there are interactions between themes. The themes and their accompanying subthemes are presented in the thematic map (see Figure 1 below).

INSERT TABLE 2 HERE

INSERT FIGURE 1 HERE

Theme 1: Client-centred approach to outcome: Over three-quarters of the BICMs participating in the online survey responded with *"the client"* when asked the question *"Who, in your experience, determines what a good outcome is?"*. The BICMs explained that *"there's certainly not one size fits all..."*, as one responded expressed *it*, in terms of what a good client outcome might look like because of the variability of impairment experienced by the client and the interaction with their context. The participants discussed that adopting a client-led approach to their work ensured outcomes reflected the client's agenda rather than the BICM's. The experiences of the participants highlighted that their role facilitated tailoring of support to the individual client and family needs, to improve engagement in rehabilitation and to achieve a higher quality of life for the client. It is important to note here that while outcomes are primarily client-led, the participants identified that there was often tension between what the client wanted and what was in their best interests. Additionally, research into the impact of acquired brain injury upon family members has identified significant levels of stress and burden upon relatives. Families need time and respite from providing care, especially as the burden of care increases. The BICM is engaged to focus on outcomes for the individual, however these need to be considered in the context of their family system. This can lead to competing outcomes where there is discordance for many reasons. The BICM and their relationship with the person and

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their family provides a unique opportunity for clarification and consistency (Clark-Wilson & Holloway, 2020).

"we really [...] we're not being directive, we're not saying "well these are my goals". (P2)

"it becomes a lot more challenging to reach those higher-level outcomes if you've got somebody with severe cognitive problems it's just not going to happen". (P3)

"my outcomes are about erm...enabling the client to be as independent as possible...have the support that they need so [...] that we can facilitate them to participate in [...] life as much as possible." (P3)

"As a case manager, a 'good' outcome is where a client is kept safe and feels as though they have some control and/or some level of independence in their lives." (P5)

The BICMs discussed that fulfilling the client's needs was beneficial to the client's progression but recognised that needs varied across time and between individuals. The types of client requirements met by the BICM included specific ABI-related needs, such as implementing care and support scaffolding (a structure of support that exists around the client to enable daily living), assistive equipment and adjusting education pathways. A key element identified was the holistic way BICMs met clients' wider needs which promoted wellbeing through enabling attendance at typical health screens, addressing health concerns, and addressing housing issues.

"I mean we've got one of our clients we've had for I don't know 15 years or something [...] because he just needed ongoing support after his case settled and [...] we are providing that support". (P3)

"so for that particularly-particular family a really good outcome has been that we have been able to get her into a specialist school that is now meeting her needs". (P1)

"the outcome was that they actually put triple glazing on the kind of bit of the flat that didn't have it which included his bedroom and his living room [...] so now he's getting a good night's sleep and he feels more comfortable". (P3)

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The participants reported that families *"feel supported"* when included in decisions about the care and rehabilitation of their family member. The BICM role enabled implementation of a support 'scaffold' that somewhat alleviated family burden and facilitated the maintenance of family relationships with the client. Throughout the discussion, it became apparent that the BICMs provided support to families experiencing ambiguous loss (the feeling of bereavement without the death of a person; Boss, 1999) and grief often associated with ABI. The inclusion of family is an important part of case management but can lead to difficulties when the wishes of the client are at odds with the wishes of family members. In such cases, it is the role of the case manager to ensure that the direction for rehabilitation reflects the client's voice but also takes into account the impact on family and what is in the best interest of the client.

"the relationships do suffer so you know a good outcome may be [...] managing to get the support in [...] to enable someone to maintain their relationship with their partner". (P3)

"you know I've got one psychologist that I've approached recently [...] the fiancé of my client is so anxious she's experiencing post-traumatic symptoms [...] having heard of her fiancé's accident". (P3)

"the case manager is in a good position to see the bigger picture and can make a difference by ensuring professionals are working cohesively and in the best interests of the client and their families...If a case manager is influencing good outcomes for the client, this will be evidenced by clients reaching their goals (both objectively and subjectively), families having faith in the process, trust from deputy regarding clinical decisions, cohesive care plan and good communication between MDT. Also risks will be managed and minimised and clients will remain as safe as possible". (P4)

Participants also explained that their role in supporting the family, enables them to provide rehabilitation practice and meet the emotional needs of the client within the context of the family. BICMs discussed this to be beneficial to the client's engagement, thus progressing the rehabilitative gains of the client. In contrast, one participant

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identified that clients without family support are likely to be vulnerable to deterioration or stagnation of their recovery.

"family support can make a huge difference in terms of outcome [...] so if you've got a...family member who is able to support the client in the rehabilitation and then carry over [...] any strategies that have been put in place by the therapist you know throughout the day while the therapists aren't there that can make such a difference in terms of the outcomes". (P3)

"I think for those people who haven't got any family and are very isolated ...it's much harder to engage them...I think where you've got more supportive families you can really see the difference it makes". (P1)

BICMs stated that good outcomes are associated with clients that are *"willing to engage in therapy"*. The participants reported *"trying to mirror what [the client] is already engaging in"* to encourage client engagement in activities that are influential to their recovery, remaining faithful to the client-centred approach of brain injury case management. Participants explained that their role enabled them to identify and address barriers to engagement such as poor mental health and inappropriate environments.

"so that could be a physio [...] goal it could be an OT goal but [...] in the first place you've got to find the right key to open the door to engage the client". (P2)

"psychological status would really affect outcome [...] lacking motivation because they're feeling low in mood [...] we would be looking at trying to address the depression and see if we could put somebody on antidepressants or you know to lift their mood which would then enable them to hopefully engage more". (P3)

The experiences of the BICMs in this study defined a good outcome for the client as an improved quality of life, rich in activities associated with social participation. The participants explained that the extent of the impairment experienced by the client considerably contributed to the variability of what constituted a good quality of life.

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“by December we had the team in place and now it’s working like a dream and now they’re going to take him on holiday”. (P2)

“so, some of my clients would be really severe brain injuries who would be perhaps or would have been classed as minimally aware or perhaps still are [...] a good outcome might be getting them out of hospital and getting them a good care package to enable them to have a reasonable quality of life taking into account their injuries”. (P3)

“you know helping them to reengage in leisure activities um...also good outcomes might be around relationships particularly”. (P3)

Understanding the underlying issues of brain injury allows BICM's to work with clients to create client-focused goals. For clients, who have reduced insight into deficits resulting from brain injury, good negotiating skills and a positive therapeutic rapport is essential to establish realistic life goals and manage the tensions in this process. BICM's can then develop a case formulation, which considers the means in which clients achieve goals towards the outcomes they seek. The data did reveal times when there was potential conflict for case managers when aiming to be client centred. These included times when clients and family members may differ in their desire for certain goals to be achieved, instances where clients may have been lacking mental capacity to make certain informed decisions, or where there is a discrepancy between a therapist and client goal.

“Sometimes there can be a discrepancy between [...] a therapist goal compared to [...] the client’s goal. This can be due to the client’s lack of insight, lack of understanding of the steps required to achieve their goals, or their capacity to be able understand the information provided” (P9).

“A family that is supportive and has a good understanding of the client and their needs can help the client to achieve positive outcomes. They need to be a family that is supportive but not overly protective. they need to respect the client and allow them to make decisions for themselves where they have the capacity to do so” (P13)

“Barriers to good outcomes can be mental health difficulties; level of engagement; financial limitations, lack of client insight, lack of adjustment to acquired injury, unrealistic expectations of family members” (P11)

Commented [A1]: One quote deleted here for brevity

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Theme 2: The role of the Case Manager to achieve a good outcome: building on the previous theme of a person-centred approach, participants consistently discussed the activities of their role as to aid a flexible overview of the client, underpinned by the BICMs experience with ABI. The participants explain that continuous assessment and readjustment of a client's overall progress is integral to influencing a good outcome based on what is desired and realistic to the client. Clinically, continuous assessment is always required to ensure any changes to the client's condition, needs, environment, or treatment are noted as this will impact on their desired outcomes. Participants also highlighted the complexities of case management and that many factors that may influence outcome were not within the ability of case managers to control. Goal setting and working towards a client's desired outcomes is an ongoing process which may often be influenced and affected by an individual's insight into the impact of their own condition and their residual metacognitive abilities (Gracey et al., 2009). The BICM process is, in reality, iterative and subject to change as the intervention proceeds (Clark-Wilson and Holloway, 2015). Prioritisation of efforts and goals is by necessity a joint and shared effort, the role is relationship based (Lukersmith et al., 2016).

"you're having to re-reassess and maybe prioritise [...] re-prioritise outcomes or sort of simplify them to what's actually achievable because for some people it might be keeping them safe". (P1)

"we've got a feedback form and a survey gismo form with questions that I've set with support of the team [...] so we get an idea of what's happened in the sessions and that's sort of tweaked [rehabilitation goals] and reviewed depending on where we're seeing progress". (P1)

"I think the difficulty for case managers in terms of outcome is that there are so many things [...] that are beyond our control". (P3)

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Participants commented that their role included the coordination, implementation and maintenance of an appropriate support system tailored to each client's needs. Individuals post ABI who often struggle with impairments to their executive skills are identified as more able to perform regular and unvarying activities of daily living than instrumental activities of daily living that require "online" thinking, idea generation, problem solving, decision making and planning (Giles et al., 2019). The concept of the support an individual requires is therefore considerably broader than in standard care services and is sometimes referred to as "scaffolding" around an individual; supporting that person to act rather than acting on their behalf (Vygotsky, 1978). All BICMs indicated "getting in a good team" to be associated with a good outcome in brain injury case management. The participants inferred the team to include all those with direct or indirect contact with the client such as support workers, family, therapists, solicitors, the deputy, etc. The role of the BICM facilitates team cohesion by encouraging a good therapeutic relationship between those in direct contact with the client, clarity and punctual sharing information regarding the client, and a consistent approach delivered by all involved with supporting the client. This was supported by the participants who highlighted that the absence of team cohesion was associated with poorer outcomes for the client. Often the support scaffold requires a team of people working closely with the BICM, as in the following quotations:

"so at the beginning of case management ...there's nobody involved with the client apart from the solicitor [...] so I have to build up a team [...] to work with that person um...and that can vary hugely depending on what the needs of client are". (P3)

"[recruitment of rehabilitation staff] that's a lengthy usually three-month process sort of from beginning to end and we have much more control when we write the care plans". (P2)

"I think another thing apart from the good rapport is [...] communicating regularly with the therapists and making sure that they're keeping on track". (P3)

Commented [A2]: I don't think you need this many quotations - just perhaps 2 that best illustrate the point you are making,

Commented [A3R2]: Some removed and these seem to summarise the role best

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BICMs are also required to liaise with an array of generic services (social care services, benefits agencies, housing departments, physical and mental health organisations etc) and associated professionals, to enable them to continue to hold an accurate overview reflective of the client's recovery progress. BICMs may also interact with these services to advocate for the client to ensure their needs are being met.

The BICMs described their role at times to be, as one participant commented, "*very much an advocacy role*" facilitated by their previous knowledge and experiences with ABI clients and their contexts. The participants explained that the primary cause for advocacy surrounded access to non-ABI specialised statutory services, as one BICM stated, "*that [...] aren't designed to [...] accommodate [...] those more complex cases where actually the need is probably higher*". BICMs also recount being an advocate for the client, to the client and their family, when attempting to meet the client's needs effectively and/or to protect client's wellbeing, both of which are associated with a good outcome.

The complexity of brain injury presentation often results in people falling between gaps in health and social care systems. People with brain injury can be failed as a result of lack of understanding and communication between services. The advocacy role of the BICM in providing a holistic overview and communication of need can improve outcomes. The outcome may be beyond the BICM's control, however, e.g funding, existence of provision, access to specialist services etc., and this creates difficulty in deriving an outcome measure reflective of the BICM's intervention.

Additionally, as noted above, tensions may arise between clients and their families when setting realistic goals, especially if clients lack insight into their condition. Listening and understanding perspectives, motivational interviewing, and good negotiating skills, can develop positive ways forwards, which consider the wishes of

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all respective parties, the capabilities and capacities of clients, and the anxieties and fears that present themselves in this situation.

“there’s that thing of arguing the case a bit as well [...] when some of the statutory services get wind of the fact that there’s a litigation case that potentially there’s funds already put in place then they’ll say “well you don’t need us because you’ve already got this support” um... when actually my view is if they’re entitled to something then [...] regardless of the sort of finances they should be able to receive that”. (P1)

“what I think of as a good outcome for her is the fact that I’ve managed to get her taking a contraceptive depo regularly [...] [s] she’s got ideas about wanting to get pregnant and start a family which actually...in the context of her brain injury... could be pretty [...] disastrous”. (P1)

All participants reported the therapeutic relationship (a strong relationship built of mutual trust, respect and positive regard infused with empathic listening on the part of the professional (Rogers, 1957)) to be necessary to establish a comprehensive understanding of the client and their needs. The BICMs also explain that the therapeutic relationship elicits trust between themselves, the client, and the client's family which can overcome feelings of uncertainty on the part of client and family members that occur due to a lack of understanding of brain injury and its impact and the likely success of long-term rehabilitation. Subsequent discussion suggested that BICMs value the therapeutic relationship because of the benefits it affords to the role in progressing the client's recovery.

“because I had that relationship with mum she was able to say “yeah ok I trust your judgement and agree with you” and actually it has been the right thing”. (P1)

“not going to be able to even look at outcomes until you’ve established some sort of rapport or a relationship where you can um... have those discussions”. (P1)

“I don’t know how that’s going to affect my relationship and I’m not sure who’s going to deliver the news I hope it’s the deputy rather than me [...] because that will sully things”. (P2)

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Theme 3: Monitoring outcome in case management: The majority of BICMs, including the survey participants, agreed that outcome measures that "*demonstrate the client's progression*" (survey respondent 11) in ABI are essential but "*capturing those subjective...elements*" (P2's direct comment) of brain injury case management is "*really difficult to measure*" (P3's direct comment). The participants further discussed how the multi-dimensional impact of ABI, clients' access to funding and variability in client-led outcomes can further complicate attempts to measure the effectiveness of brain injury case management.

"I can see that in certain situations that specific outcome measures are needed [...] and maybe as a case manager you do have that broader overview [...] I mean you're looking at things like quality of life aren't you [...] how do you measure those?". (P1)

"I mean that's the thing...having scope for that there's a lot of areas to think about [...] and what's important for one client isn't for another and... that sort of variability". (P1)

Throughout the discussions, two of the BICMs used the terms "goal" and "outcomes" interchangeably suggesting ambiguity surrounds their use in brain injury case management practice. Clinicians use outcome measures to obtain detailed scales of objective change. Goals are the measure of change that clients have chosen for themselves. Goals and outcome measures can be used separately or interchangeably as a way to evaluate progress or not of an intervention. Some participants report using "goals" to evaluate the short-term progress of the client as well as the BICMs employers evaluating their performance based on goals achieved.

"what I'm going to do in my future practice is to take the goals with me and say "right where are we up to?" and use it as a working document for each case management meeting". (P2)

"so that we can analyse the results and sort of look at in terms of outcomes how many goals we've managed to achieve in the last six months". (P3)

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The BICMs report an intense dissatisfaction with current outcome measures used in ABI case management as most focus on rehabilitation and do not measure other aspects of a case manager's role. An example of this is the Functional Independence Measure (FIM) / Functional Assessment Measure (FAM), a global measure of disability (Tuner-Stokes and Siegert, 2013) commonly used within NHS inpatient and rehabilitation settings. Subsequent discussions established the core reasons to be 1) global outcome measures are too generic and simplistic to account for variable factors that can influence the recovery of an ABI client and 2) current measures do not assimilate well with the breadth and subjective effects of the tasks completed by the BICM to meet client needs, which contribute toward an outcome in ABI.

Overall, case managers identified working on a range of client goals across a range of different domains and that the long-term outcomes of these goals were not appropriately supported by current quantifiable outcome measures that tend to be focused within specific domains (e.g. physiotherapy, speech and language etc). One BICM explained that some ABI outcome measures (e.g. the FIM/FAM for assessing functional processes or measures of goal attainment) are incompatible with the collaborative, client-led approach to outcome that brain injury case management adheres to.

"most measures are overly simplistic and better for inpatient and basic functional processes (FIM/FAM) and not for the complexity [of] community living post ABI". (Survey 2)

"from that point of view it was a very useful document [goal attainment scale] but I [...] would have been extremely wary showing that with a client whereas with this document [goal attainment scale] at [BICM company] I'm perfectly happy to share it and even if they haven't achieved their goal". (P2)

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To overcome their dissatisfaction with the current outcome measures used in brain injury case management, the participants determined case management to be *"more about [...] tracking progress"* (P5's direct comment) to flexibly inform a holistic perspective of the client's wellbeing and recovery in terms of outcome. The BICMs explained that qualitative feedback forms tailored to each client and completed by family members, observations by the BICM, and the collation of information from reports provided by the standard rehabilitation services, enabled monitoring of progress. The participants reported their respective employing companies to be searching and trialling alternative measures that can reflect the prime target of BICM; the holistic, individualised, external factors that enable good outcome for the client. Outcome measures, which allow for an evaluation of clients' and family progress and adjustments over time, with the understanding of the positive therapeutic and case management interventions (or barriers), could facilitate patterns of knowledge and learning for all in the field of brain injury and case management. Case Management companies want to seek the most effective solutions and promote good practice towards cost-effective outcomes.

"so the recovery star [an outcome measure that asks clients to rate their functioning in multiple domains, e.g. financial, wellbeing, health etc (Triangle, 2019) looks at various aspects of the clients lives their housing, their relationships, their daily activities, ability to manage money...We have recently started to look at recovery star as a possible outcome measure". (P3)

"they've [team of case managers] devised this neuro-functional outcome scale that we've [been] using it on some of our clients for the research [...] I can see that it'd be useful as a thorough [...] overview of the clients and that say if you were to repeat it [...] it would be a more obvious documentation [...] of progress maybe". (P1)

The participants commented that it is *"really hard to look at purely the case management"* (P4's direct comment) to establish the effectiveness of the BICM

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contribution to an ABI client's outcome as the BICMS are "*not the actual ones that are doing the actual rehab*". Case management is about the coordination of the rehabilitation that takes place for a client and ensuring that the structure around the client is appropriate to support their needs. Therefore, case managers are influencing a process that is not entirely within their control. This makes it particularly difficult to use simple outcome measures with case management. However, the participants explained that an appropriate measure of case management in ABI is welcomed as it would provide an evidence-base for the effectiveness of case management that could negate the "*risk that [the] role will be reduced in the future*" (S10) as well as to reassure their practice as BICM.

"so much of it [BICM work] is very individualised and very subjective I think it's that it would be quite reassuring I suppose to [...] to be able to capture that in a...yeah in a more evidence-based way I suppose". (P1)

"I think the difficulty for case managers in terms of outcome is that there are so many things [...] that are beyond our control". (P3)

Theme 4: Funding: Although BICMs acknowledge funding to be an integral factor underpinning a good outcome for an ABI client, it is, as one case manager stated, "*not what [BICMs] consider a good outcome*". However, the participants explained that funding enables the BICM to access resources, equipment, particular skillsets, care packages, and housing options to fulfil the client's needs effectively; all of which is associated with a good outcome in ABI. The clients of the BICMs included in this study had obtained funding as a result of litigated cases. The participants commented that clients with poorer outcomes were often those with limited funding and only statutory service involvement which significantly restricted the role of a BICM and their

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rehabilitative options. Additionally, the participants frequently referred to liaising with deputies and solicitors to access funding which demonstrates a multi-layered system to manage funds appropriately to meet the client's needs indefinitely.

“if the client has quite severe injuries or there's concerns about them managing their money [...] there's a financial deputy [...] and often in those incidences there is a case manager involved to oversee the rehab to help the deputy to manage the money”. (P3)

“for me as the case manager the actual money that's gained by the settlement isn't my outcome [...] it's somebody else's outcome that enables me to put my rehabilitation in place to enable me to get my outcomes I guess”. (P3)

Discussion

The aim of this study was to gain a better understanding of what a good outcome in brain injury case management and what facilitates good outcomes when working with clients. The results indicate that the client generally determines what a good outcome in brain injury case management ought to be, and hence, the importance for case management being client-focused and case managers developing therapeutic rapport and working alliances with clients and family members, as well as with members of the multidisciplinary team. The client-focused nature of the work is complex as the data indicates that case managers must negotiate the needs of clients, family members, and to a certain extent funders and employers, when shaping rehabilitation. Ultimately, client-focused care was discussed by participants in relation to providing rehabilitation that was in the client's best interests wherever possible.

A fundamental part of achieving a good outcome relied on establishing a strong therapeutic relationship as this can furnish the BICM with a comprehensive understanding of the client to meet their emotional and practical needs efficiently

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(Simpson *et al.*, 2018). Therefore, the knowledge of the client held by the BICM can be a more reliable detection of hidden disabilities that are notoriously difficult to formally assess but importantly, are associated with poorer client outcomes (Clark-Wilson *et al.*, 2014; Holloway, 2014; Odumuyiwa *et al.*, 2019; Holloway and Fyson, 2016; George and Gilbert, 2005; Manchester, Priestley and Jackson, 2004). Knowledge and understanding of the clients and their needs is instrumental in achieving good outcomes, and for identifying when a client's wishes are/not met.

There is an inherent tension when endeavouring to provide client centred approaches to individuals with an ABI who may lack mental capacity to make decisions regarding their own welfare, treatment and support (Owen *et al.*, 2017). This is perhaps less the case for people with profound and enduring impairments to cognition that wholly preclude involvement in decision making. It is most certainly the case, however, for those who are able to physically function but to do so with impaired decision making skills, impaired executive functioning, impaired cognition and metacognition, difficult to manage behaviours and who may pose a risk to themselves or others by their actions or inactions (Wood and Worthington, 2017). The BICM is dutybound to follow relevant laws and guidance whilst endeavouring to ensure the client voice is central, risks are managed and identified goals are worked towards.

The study established that one of the core activities provided by BICMs is emotional and practical support to families as well as clients, which subsequently improved client engagement. Bodies of research exploring the negative impact of ABI on families recommend treating the family and the client as a single unit to alleviate stressors

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(Odumuyiwa *et al*, 2019), and is demonstrated to enable family's active participation in supporting the client through rehabilitation (Hartman-Maeir *et al*, 2007).

The findings suggest that there is a need to encapsulate the holistic approach to supporting those with ABI and their families to gain a more accurate indicator of the effectiveness of brain injury case management. The BICMs in this research reported actively seeking alternative measures for assessing outcomes that are more specific to case management following ABI. This is often difficult because current outcome measures are too specific to highlight these more holistic processes. The participants in this study state monitoring the overall progress of clients to be a more appropriate measure of the holistic and variable aspects the brain injury case management targets. There is a, though, we would assert, a need to encapsulate this in a more evidence-based manner.

Additionally, the BICMs described feeling dissatisfied by current measures of outcome in brain injury case management, originally used to measure internal factors of the client in direct rehabilitation services (for example, speech and language therapy or physiotherapy). However, this study has established that BICMs also target restoration of external factors surrounding the client to influence outcomes, such as family relations. Existing global outcome measures are not sensitive to the targets of case management, nor useful to establish the effectiveness of case management in ABI outcome (Simpson *et al*, 2018; Lannin *et al*, 2014). Hence, 70% of the participants in the online survey stated a preference for a brain injury case management specific outcome measure. Such a measure would need to help understand the client in the context of their family and lifestyle they had before the brain injury, to evaluate

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underlying deficits and the level of functioning of the client within context. The measure ought to include progress over time in client-centred goals. BICM would also benefit from measures of family functioning before and after injury, and over time.

A BICM-specific measure could be complemented by other specific, specialist clinical tools (from all relevant disciplines), to understand all underlying deficits and how these could impact on rehabilitation. This could assist in liaison with other rehabilitation professionals.

In terms of better understanding the contribution of BICMs to achieving clients' outcomes, participants in this study identified that improved quality of life was an overall 'good outcome' for clients, characterised as consisting of a richness of psychosocial factors which aligns with rehabilitation services (Malec, 2005; Huebner *et al*, 2003; Clark-Wilson, 2006). The BICMs reported that fulfilling the client's holistic needs enabled client engagement in rehabilitation and ultimately improved participation in their communities.

The experiences recounted in this study demonstrate how the activities and specialist knowledge attached to the role of BICM, helps to overcome the variability of context and impairments between ABI clients. BICMs use their extensive knowledge of the client, family and of brain injury to identify gaps in support and match client needs to relevant available resources or service provisions (Odumuyiwa *et al*, 2019; BABICM, 2020; Simpson *et al*, 2018). Therefore, one aspect of the effectiveness of case management is implied by the BICMs ability to overcome the barriers to accessing service provisions that family members and clients can experience (Degeneffe *et al*, 2016; Greenwood *et al*, 2016; O'Callaghan, McAllister and Wilson, 2012).

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The participants highlighted funding to be a critical element that enables the delivery of quality brain injury case management. The case management process with integrative interdisciplinary working around a client is expensive and requires extensive financial input to sustain. Yet these are crucial to ensuring the process is client-centred. BICMs discussed that in the cases when financial settlements cannot meet the client's needs, this leads to a reliance on statutory services, which subsequently influences poorer outcomes. Unfortunately, this is supported by the wider literature that demonstrates restricted budgets in statutory systems to be partially responsible for reduced quality of, and access to, service provision (Degeneffe and Bursnall, 2015; Degeneffe *et al* 2016; Gray and Barford, 2018).

Limitations

It must be noted that participation in the online survey and subsequent telephone interview was low leading to small samples of respondents. Unfortunately, the time allocated for phone telephone interviews was disrupted by the current Covid-19 global pandemic, with many of the BICMs that had initially expressed an interest in taking part being unable to do so due to the resulting increased workload. Despite this, the telephone interviews conducted were with BICMs with a variety of experience of brain injury case management (3-20+ years) providing a richly detailed account to aid in understanding outcome in case management. This allowed for a sufficiently detailed thematic analysis to be conducted. Future research would benefit from the inclusion of families, clients, and financial deputies to gain a wider picture of how outcomes are established in brain injury case management.

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Future research:

Alongside the process of developing outcome measures in case management, there is also a need to develop a more robust measure of quality of life for clients of ABI. Current quality of life measures do not adequately detect the range of biopsychosocial difficulties that people with ABI experience (Dijkers, 2004) and are often not focused on symptoms and difficulties that are important to clients and their families (Norman *et al*, 2021). Creation of a more sensitive measure that can be used at multiple time points to record reliably changes over time in the areas noted above would help to demonstrate the role the brain injury case management can play in bolstering quality of life.

The current had identified that effective case management requires working closely across professional groups, but also in close communication with family members to ensure the client's needs are met, particularly when there may be issues of mental capacity. This approach is fundamentally client-centred but does not always entail prioritising the client's wishes. This nuanced approach to client-centred work needs further investigation in future studies.

Conclusion

There is a need to better understand the place of case management in supporting people with ABI and their families, and particularly understanding the complex issues of outcomes, how they can be best conceived and measured, and what interventions help to achieve them. This study has highlighted that a good outcome in brain injury case management is one that is client-centred and determined either by the client or in conjunction with the client, and where appropriate, their family to achieve improved quality of life. The role of the BICM is to target the external factors that are influential

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contributors to a client's outcome. By supporting the family, facilitating access to quality services and providing justification for funding, BICMs help meet the client's needs that enable them to successfully re-establish their lives. Potentially the best way to encapsulate the effectiveness of this is by monitoring the holistic progress of the client through holistic work with clients and family members. However, as yet, a suitable measurement tool is not available. Changes to monitoring outcome in brain injury case management are essential to strengthen an evidence-base, to ensure that more clients can achieve their desired outcome.

Declaration of interest

The authors report no conflicts of interest

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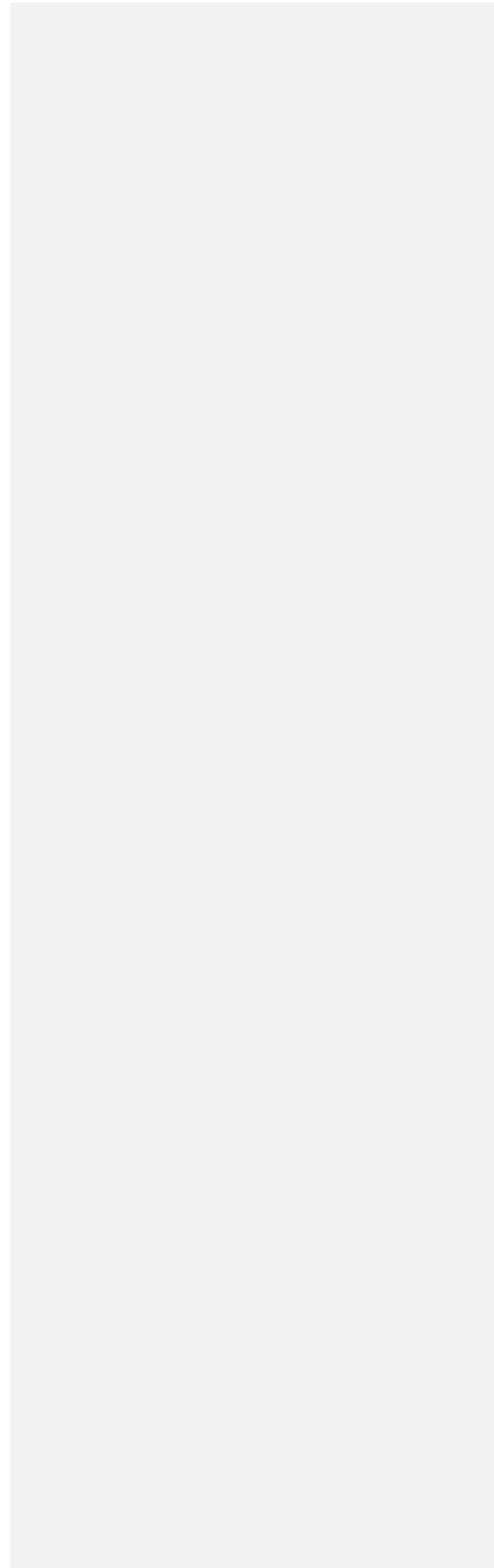
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Table 1: Characteristics of participants

Participant Characteristics	Number of participants
Case Management experience (in years):	
< 1 year	1
1-3 years	1
3-5 years	2
6-10 years	7
11-15 years	5
16-20 Years	4
>20 years	8
Number of current clients:	
1-5	10
6-10	11
11-15	2
16-20	2
21-30	1
31-40	0
41-50	0
Over 50	2
Type of registration with BABICM:	
Practitioner	2
Registered practitioner	11
Advanced Registered practitioner	15
Professional background:	
Occupational therapist	12
Social worker	4
Psychologist	1
Nurse	6
Physiotherapist	3
Special education & family keyworker	1
Counsellor	1

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Table 2: Table of Themes

Theme	Subtheme
1. A Client-centred approach to outcome (88)*	a) Client needs are met (49) b) Family are supported and supportive (36) c) Client engagement (29) d) Quality of life (10)
2. The Brain Injury Case Manager role (97)	a) Coordinate (63) b) Advocate (29) c) The therapeutic relationship (54) d) Facilitate team cohesion (70)
3. Capturing outcome in case management (20)	a) Goals=outcome confusion (7) b) Dissatisfaction with current measures (18) c) Holistic progress (43) d) Evidence of case management (19)
4. Funding (36)	

*Numbers in brackets represent number of times the theme was identified in the telephone interview data