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Understanding the experiences of people with Acquired Brain Injury and their interactions with outside services

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Abstract

Previous research has focused on Acquired Brain Injury (ABI) regarding the cognitive, behavioural, psychological and social effects, and the outcomes and implications this has had in different areas of people's lives. However, there has been limited research exploring the existing relationship between individuals with ABI and community service providers.

Therefore, the current study's objective was to understand the experiences that those with ABI have had of community services and to recognise the extent to which they believed that these services understand their difficulties and needs. An interpretative phenomenological approach was used to allow the participants to reflect on the areas in which they believed were most important to their subjective experiences as a person with ABI, family member related to someone with ABI, or as a professional who had interacted with people with ABI in their role. Eight participants were recruited (two professionals, two individuals with ABI and four family members of individuals with ABI) and took part in semi-structured interviews. Five super-ordinate themes were identified following analysis of the transcripts 1) Hidden disabilities, 2) Knowledge and understanding, 3) Impact of ABI, 4) Access to services, and 5) Safeguarding. Several sub-themes within each superordinate theme were also identified. The findings from the study were consistent with previous research literature, and identified areas that could be improved.

Introduction

Background

Understanding Acquired Brain Injury (ABI) and its effects has become increasingly important as more people are affected by it. In the UK between 2013-2014, there were 348,934 hospital admissions for ABI (10% increase since 2005-2006), showing an increase in the number of people sustaining a brain injury each year (Headway, 2015).

Acquired Brain Injuries (ABI) are caused by damage to the brain from a traumatic cause (for example road traffic accidents, falls and other external forces) or non-traumatic cause (such as stroke or infections), all of which occurs after birth (Headway, 2015). The symptoms of ABI vary in severity and may include physical disabilities, such as difficulties in speech, movement (dyspraxia), seizures, sensory difficulties, headaches, fatigue and incontinence (Haywood, 2010; Marshall, Teasell, Bayona & Bayley, 2007; Youngson & Alderman, 1994). However, those who recover physically may acquire longstanding non-physical invisible symptoms. For instance, cognitive effects may result in deficits of attention/memory, visuospatial skills and executive functions (King & Tyerman, 2003; Konrad et al, 2011). Psychological and behavioural effects of ABI include depression, increased aggression, impulsivity, emotional instability and deficits in self-control (Arciniegas & Wortzel, 2014; Kelly, Brown, Todd & Kremer, 2008). These effects of ABI, can be detrimental to interpersonal relationships, housing situations, employment and education, as well as increase the likelihood of illicit behaviours among those with ABI (Braine, 2011; Hawley, Ward, Magnay & Mychalkiw, 2004; Materne, Lundqvist & Strandberg, 2017; Olson-madden, Brenner, Corrigan, Emrick & Britton, 2012). The difficulties that people with ABI face means that integrating them back into the community can be challenging. Thus, outside services such as social or mental health services, focus on catering to the long term needs of those with ABI (Cierone, Mott, Azulay, & Friel, 2004). However, research uncovering the experiences that individuals with ABI have with these services is limited.

Difficulties that those with ABI may encounter

Several studies have acknowledged the existing barriers that those with ABI face between their employers and other outside services when resuming work, (Gilworth, Eyres, Carey, Bhakta & Tennant, 2008; Hofgren, Esbjornsson & Sunnerhagen, 2010; Liaset & Loras, 2016; Materne, Lundqvist & Strandberg, 2017). For example, Hofgren et al (2010) found that there is limited flexibility shown to those with ABI and from their employers or colleagues. Additionally, there is a lack of understanding towards the consequences of ABI within the workplace. Outside services often do not provide enough motivation and guidance for those with ABI to return to work (Liaset & Loras, 2016). These external factors, coupled with the ongoing invisible symptoms that those with ABI sometimes face, can decrease their self-esteem and elicit feelings of loss of control, further hindering their psychological and emotional recovery (Gilworth et al, 2008).

The difficulties experienced by those with ABI in relation to their employment, are similar to those individuals who attempt to resume their academic studies after suffering an ABI. Hawley, Ward, Magnay and Mychalkiw (2004) found that behavioural problems and difficulties with work in schools were not addressed with the majority of schools failing to acknowledge ABI as the cause. This results in the individuals not

getting the help and the support they need (Hawley et al, 2004). Research investigating the effects that ABI can have on education and employment, suggests that there are fundamental issues with the provision of information between other services and those with ABI, thus making it difficult to ensure that those with ABI have a smooth transition when returning to work and/or academic study (Hawley et al, 2004; Materne, Lundqvist & Strandberg, 2017).

Beyond the challenges of returning to employment and/or academic study, individuals with ABI who experience psychological distress or difficulties in communicating may find the maintenance of interpersonal relationships challenging (Bay, Hagerty, Williams, Kirsch & Gillespie, 2002; Shorland & Douglas, 2010). This can result in those with ABI having low involvement with others within a social context, thus increasing the likelihood of poor psychosocial functioning and isolation (Bay, Blow and Yan, 2012). The consequences of ABI are not exclusive to the individual, but also have an impact on family members. A substantial body of work has addressed the effects that ABI has on the caregivers (majority of whom are family members). Such effects include: difficulties in coping and adapting, concerns for the future, increased loneliness and a higher risk of depression (Braine, 2011; Cannuscio et al, 2002; Godfrey et al, 2003; Marsh, Kersel, Havil & Sleight, 1998). These studies indicate the high-level of burden and stress among the carers, and emphasises the way that ABI has impacted the individual themselves (Wade, Taylor, Drotar, Stancin, Yeates & Minich, 2002) thus showing the importance of outside support for family members when caring for those with ABI (Rivera, Elliot, Berry & Grant, 2008; Wade, Carey & Wolfe, 2006).

The breakdown of interpersonal relationships and family difficulties following ABI can cause social isolation and feelings of loneliness, increasing the vulnerability of those with ABI (Rook, 1984). Hwang et al, (2008) reported a high prevalence of individuals with ABI among those who are homeless, leading to poorer health outcomes such as substance abuse. Olson-Madden et al (2012) found that characteristics such as disinhibition, impulsivity, and impaired executive function that can arise from ABI can contribute to the risk-taking behaviour of substance abuse. The high likelihood of a proportion of people with ABI experiencing these situations highlights the importance of proactive services that can rehabilitate or prevent those from getting into vulnerable situations (Hwang et al, 2008). However, ensuring that vulnerable people with ABI participate in rehabilitation can prove difficult if they refuse, particularly if they are incorrectly deemed as having the emotional and mental capacity to make decisions concerning their care. The effects of ABI are dynamic: therefore, someone who is discharged with the capacity to make decisions may not have that same capacity in the long term (Trachsel, Hermann & Biller-Andorno, 2014; Triebel et al, 2012). Invisible symptoms including deficits in executive function, verbal reasoning and working memory significantly impair the ability to understand, reason and appreciate the details of treatment (Dreer, DeVivo, Novack, Krywanski & Marson, 2008). The research done on the vulnerability of those with ABI and possible impairments regarding their capacity to make decisions shows the importance of safeguarding those individuals who may find themselves in vulnerable situations (Douglas, Bigby, Knox, & Browning, 2015).

The substantial research showing the long-term effects and difficulties following ABI, emphasises the importance of long term rehabilitation with outside services to successfully integrate those with ABI back into the community (Salter, Foley, Jutai,

Bayley & Teasell, 2008). Following discharge from hospital, care is focused on improving the physical needs and, eventually improving the psychosocial difficulties that those with ABI face, such as returning to employment and education, renewing social relationships and reducing vulnerability as much as possible. However, studies have shown that there is a substantial proportion of people with ABI following hospital discharge who have unmet needs to facilitate this progression (Bay, Sikorskii & Gao, 2009; Cicerone, Mott, Azulay & Friel, 2004; Stalder-Luthy, Messerli-Burgy, Hofer, Frischknecht, Znoj & Barth, 2013).

For example, Cicerone, Mott, Azulay and Friel (2004) addressed the concern that those with severe ABI are typically deemed unsuitable for long term rehabilitation in community or facility based programs, despite the potential benefits. Here Cicerone et al (2004) reviewed the outcomes of participating in long term rehabilitation programs, measuring changes in the functional status for those who would not normally be accepted. The findings showed a significant improvement in the participants' motor and cognitive assessments and an increase in their capacity to be admitted into community living (85.6% of participants) thus, showing improvement in their functional status. The results illustrate the danger of excluding people who have differences in severity of ABI from long term rehabilitation services.

Further research has shown the benefits of psychological interventions in reducing the negative impact that ABI can have on mental health. For example, Stalder-luthy et al (2013) conducted a meta-analysis of research investigating the effectiveness of psychological interventions in reducing depressive symptoms following ABI. The findings showed a significant reduction in depressive symptoms experienced from those with ABI compared to controls. The positive outcome highlights the necessity for more long term psychological rehabilitation to be implemented, to further support the adjustment of those with ABI in the absence of mental health issues.

Much research has addressed the difficulties that those with ABI have, concerning their cognitive, behavioural, psychological, and emotional outcome, and the subsequent effects in their lives (Braine, 2011; Hawley et al, 2004; Materne, Lundqvist & Strandberg, 2017; Olson-madden, Brenner, Corrigan, Emrick & Britton, 2012). To address this, a proportion of outside services exists that work towards getting those with ABI and their families the best possible long-term community support (Turner-Stokes, Nair, Sedki, Disler, & Wade, 2005). The services that interact with ABI include: social services, financial advisers, probation services, disability employment advisers, job centres, housing officers, learning support advisers, home care services, solicitors, GP's, drug rehabilitation, mental health services, occupational health and general hospital services (Turner-Stokes, Nair, Sedki, Disler, & Wade, 2005). However, there is limited research investigating the interactions between people with ABI and these outside services.

This current study used the interpretative phenomenological analysis (IPA) approach to further understand the experiences that those with ABI and their family members have with external services. IPA focuses on the participant's personal life experiences and their reflection on factors that they consider to be most important regarding their experience (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008). The implication is that the data collected is a rich detailed account about the participant's major life experience that could not be obtained using quantitative methods. Exploring the

service users' and professionals' subjective experience can potentially provide outside services with a better understanding of the daily and long term difficulties that those with ABI encounter (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008). Therefore, the current study used IPA to allow the professionals, family members, and those with ABI to openly reflect on their lived experiences. Particular focus was placed on the extent to which to those with ABI and their family members believe that outside services understand their difficulties and needs, as well as the difficulties that professionals who interact with them encounter in supporting clients. This can provide vital information to allow the services to adjust the way in which they interact with individuals to accommodate to their true needs.

Method

Design

A semi- structured telephone interview and Interpretative Phenomenological Analysis (IPA) was used to explore the experiences that people with ABI, family members and professionals have with outside services.

Participants

Eight participants (4 females, 4 males, aged 31-79 years) took part in the study. The participants were recruited using an opportunity sample by the advertisement of services who were contacted (Headway UK and Somerset, and Respite service in Somerset). A separate online survey study was conducted prior to this interview study and some of the participants consented to take part in this study through the survey. The participants were all individual cases unrelated and unknown to each other, with one living in America and giving an account based of their experience there and seven of the participants giving an account based on their residency in England. All the participants fitted the criteria of being over the age of eighteen and either a family member of a person with ABI (4 participants), having ABI (2 participants) or a professional who has interacted with people with ABI in their role (2 participants). None of the participants withdrew from taking part in the study before, during or after the interview.

Materials

The participants completed an online survey in their own time following the hyperlink sent to them (<https://www.surveymonkey.co.uk/r/8FS6MJG>). The survey included an information sheet page giving a brief introduction to the aims of the study, general instructions and the participants' rights in taking part (see Appendix A). The participants consented to take part in the interview by continuing to take part in the survey and left their email address at the end of the survey (see Appendix B). For the participants who did not consent to the telephone interview through the survey, an information sheet (see Appendix C) and consent form (see Appendix D) were developed for them to sign and return prior to the interview. During the interview, a schedule (see Appendix E) was used for the interviewer which contained sixteen questions to structure the interview. The questions used covered areas of; social services, employment and education, crime and probation, family dynamics, effectiveness of treatment, relationships between professionals and people with ABI, life changes after brain injury and positive versus negatives experiences. After the interview the participants were sent a debrief sheet (see Appendix F) going over the aims of the research, contact information for further enquires and helpline services.

Procedure

At the end of the online survey, the participants had an option to take part in a follow-up interview. For those who consented, arrangements were made for the time and date of the interview in hourly slots. At the start of the telephone interview, the participants were re-briefed about the main objective of the study, their right to withdraw, and the participants verbally consented to audio recordings. The participants were given the chance to ask any questions relating to the procedure. Following this, depending on each of the participant's response, several questions from the interview schedule were used to guide the interview. However, the semi-structured interview design allowed the participants to discuss other areas of their experience outside of the schedule. At the end of the interview, a summary consisting of the main points of the interview were reported back to the participants allowing them to add on points and any questions that they had were answered. After the interview, the participants were sent a debrief sheet including contact information for further enquires and helpline services.

Data analysis

The interviews lasted between 25 minutes – 1 hour, and the audio recording of each one were transcribed verbatim. Non-verbal cues such as laughter were included in the transcription in brackets and long pauses were symbolised as ellipse.

The audio-recordings of each transcript were listened back and re-read several times to ensure that the participants were the focus of the analysis (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008). During this stage, exploratory comments were made in the right side of the table. This consisted of descriptive comments about key words, phrases or explanations that the participant used. Linguistic comments were also noted such as laughter or repetition and more conceptual interrogative comments were made (see example in Appendix G) (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008).

The exploratory notes were then used to identify emergent themes in the left column. The emergent themes were then put into chronological order in a separate table (see example in Appendix H) and moved around to form clusters of related themes ((Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008)). Superordinate themes emerged either by renaming a cluster of themes (abstraction), making an emergent theme the superordinate theme (subsumption), through contextualisation or by the frequency that the emergent theme had appeared (numeration) (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008).

This was done for all eight interviews followed by a cross analysis, where the superordinate themes and clusters were grouped with similar superordinate themes in and across all the interview transcripts, developed into master themes (see table 1 below). The superordinate themes identified were 1) Hidden Disabilities, 2) Knowledge and understanding, 3) Impact of 4) Access to service, and 5) Safeguarding.

Table 1: The superordinate themes and subthemes developed from analysis, and examples of transcription which supports it.

| Superordinate themes | Subthemes | Example of extract related to this |
|-----------------------------|--|--|
| Hidden disability | - | <i>Int 4 p. 46 "if you met him now you wouldn't think there was a problem and it's just this is where the so called professionals have kind of not urm not kind of seen what was there I've seen it urm my friends have seen it my family have seen"</i> |
| Knowledge and Understanding | Information Provision | <i>Int 8 p.55 "like in my case it didn't start until ten days after, to contact them because I had no idea, I, my family had no idea, I just started acting very bizarre. If they'd been some kind of explanation of what could happen, like psychologically, what can change in case you did have a brain injury"</i> |
| | Training and awareness | <i>Int 7 p.19 & 30"and the police are the urm, are dealing with each situation without the information or the training " - "would be it would be training, it would be training to identify"</i> |
| | Empathy | <i>Int 5 p.58 "the education department are probably going to take her to court again for previous lack of attendance will be taken into account and she probably will have to do a few days in prison" - "it was presented at court but it wasn't deemed sufficient reason for his well, since that time terrible record of school attendance."</i> |
| Impact of ABI | Cognitive & behavioural and psychological & social effects | <i>Int 8 p.40 " I was laughing, giggling making jokes during the funeral service" – "urm I lost my libido and then became like, I became a sex addict, I didn't know I just had, I just had sex with anybody strangers it was crazy."</i> |
| | Family as carers | <i>Int 1 p.81-83 "when it comes to (name) personal care, I do that between me and my mum" – "and because we're both mothers, I think it makes it easier, when it comes to going out and doing activities, my younger brother (name) tends to do a lot more of that because they have, they're close, they have good fun with each other, urm but when it comes to hospital appointments my dad mainly goes."</i> |
| | Family burden | <i>Int 4 p.58 "you do don't you, you go through horrendous times with it. I've actually felt quite suicidal at times. And I don't think people know that I really have."</i> |
| | Grieving old identity | <i>Int 1 p.75 "She's still grieving losing the son that she knew and raised and trying to get to know this whole new person who has different memories and a different voice and</i> |

| | | |
|--------------------|----------------------------------|---|
| | | <i>a different sense of humour.”</i> |
| Access to services | Medical care | <i>Int 1 p.95 “everyone seems to focus on getting the person active again, getting them moving, getting there, there arms working, there legs walking, no one seems to focus on the cognitive health of the person who’s had the accident, or speech and language, as long as he is up and walking and everything you can see is in the right order, mm, that’s how it feels”</i> |
| | Community integration | <i>Int 6, p.11 “but after that it was largely up to myself to kind of arrange to go back into society and urm, find my own way, and the services that I found were not...not... sufficient in in long term rehabilitation.”</i> |
| | Specialist care | <i>In 3, p.32 “they might do a program for a sh short period of time but urm the specialist services that was available were quite generic services, urm it’s limited, it’s when I say limited I mean none.”</i> |
| | Interdisciplinary care | <i>p.122 “she’d been working with the school with the boy who actually attempted suicide the whole time, and they still couldn’t get him into CAHMS so what became evident was that you know getting a young person...therapeutic help...feels nigh on impossible.”</i> |
| | Staffing and organisation issues | <i>Int 7 p.20 “they’re set out to manage people through...through meetings, where people aren’t actually in the meetings, so it’s like a professionals meeting, which I think is ridiculous, urm or they don’t actually go to the address, and they don’t actually leave their offices – but their organisation just isn’t set up for that frontline delivery.”</i> |
| | Carer & family inclusion | <i>Int 6 p.37 “one of the resources that I found that was really lacking in my care was that, I got a a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury, and lots of things like that and urm I didn’t feel that...the immediate sort of medical services drew on that support they almost tended to exclude my family members from.”</i> |
| Safeguarding | Capacity | <i>Int 3 p.84 “for that information to be urm to sink in and then what we get is the the after effect of that conversation understood or been taken literally or do you see what I mean, so on the space of it, it makes it seem quite, they respond quite normally or or seem whatever is normal and respond appropriately and what we see afterwards is something completely different”</i> |

| | | |
|--|---------------|--|
| | Vulnerability | <i>Int5 p.122 "he started smoking weed and it was helping him that stuff sleep" " and it you know when we tried to talk to him about it he said, it's the only thing that makes him feel better, and I mean it broke my heart one time he said the weed is the only friend I got, he sees it as his only support."</i> |
|--|---------------|--|

Results and discussion

The analysis of the eight semi-structured interviews revealed five superordinate themes that were present throughout, with sub-themes identified within each superordinate theme. One of the superordinate themes 'Hidden disabilities' had aspects that were relevant and connected to the other themes. The remaining themes that emerged were 'Knowledge and Understanding of ABI' (subthemes: information provision, training and awareness, and empathy), 'Impact of ABI' (subthemes: cognitive, behavioural, psychological and social effects, family as carers, family as burden, and grieving of old identity), 'Access to services' (subthemes: medical care, community integration, specialist care, interdisciplinary care, staff and organisational issues and carer and family inclusion) and 'Safeguarding' (subthemes: capacity and vulnerability).

Transcription notation

Transcription from the interviews is present in quotations with ellipsis (...) used to represent pauses, dashes (-) in between quotations show the text omitted if irrelevant. To protect the participant's identity, names of people, hospitals and locations are omitted to allow for confidentiality. Instead, the participants are referred to by their interview number.

Theme 1: Hidden disabilities

The major theme of hidden disabilities illustrated all the participant's difficulties and consequences of the non-physical invisible side of ABI, and how this has shaped much of their experiences. The participants who were professionals explained how the hidden disabilities of ABI acted as a barrier in providing appropriate support due to difficulties in identifying and knowing the severity of ABI. The family members and individuals with ABI revealed the frustration they had towards the professionals and the public who stereotyped their disability. In the following extract, participant 4 describes the extent to which her husband hid his symptoms of ABI from the healthcare professionals.

Int 4 p.46 "If you met him now you wouldn't think there was a problem and it's just this is where the so-called professionals have kind of not, um not kind of seen, what was there, I've seen it um my friends have seen it, my family have seen it because when he has gone to these professionals he has kind of made a supreme effort um not to display it but he is increasingly now displaying more of the actual symptoms of a front temporal dementia."

Participant 4 alongside other participants interviewed revealed how apparent the effects of ABI were to themselves, but were not accepted by society. This indicates an issue regarding the preconceived ideas that society including professionals have on what ABI should present like (Linden & Boylan, 2010; Redpath & Linden, 2004). It wasn't until participant 4's husband displayed "actual symptoms" of ABI that the professionals were willing to do a full assessment. The description of "actual symptoms" further shows that unless the symptoms conform to the norms and

validates the public and professionals preconceived idea of ABI, the symptoms the husband has does not exist (Linden & Boylan, 2010; Redpath & Linden, 2004). This attitude towards ABI is detrimental for the person to get the support that they need from outside services (Linden & Boylan, 2010; Redpath & Linden, 2004). For example, participant 8 and 5 (Int 5, p.294; Int 8, p.142; see example in Appendix I) described their struggle with resuming work and getting the long-term support following hospital discharge due to the hidden symptoms not being recognised as ABI. The findings from this study are consistent with previous research which found that those with ABI whose hidden symptoms and subsequent support were overlooked, were increasingly frustrated and did not trust the healthcare professionals compared to those who displayed typical symptoms of ABI (Clements, 1997; Landau & Hisseett, 2008; Langlois, Rutland-Brown & Wald, 2006).

Theme 2: Knowledge and understanding of ABI

Despite the growing number of people diagnosed with ABI (Headway, 2015), all the participants revealed their concerns towards the insufficient knowledge and understanding that the professionals within community support services had towards the needs of those with ABI and their families. Most of the participants reflected on their experience of being discharged from hospital, without being signposted to resources that can increase their own knowledge about ABI. The participants described being unprepared, confused and not being able to appreciate what it means to have ABI. This is demonstrated in participant 8's interview in the following extract.

Int 8, p.10 "just instructed me to lie in a dark room. And I was confused like I had a fog, I'm a single mum of a, urm he was seven at the time, and I couldn't hear, I couldn't see, I was falling when I walked"

Int 8 p.55 "like in my case it didn't start until ten days after, to contact them because I had no idea, I, my family had no idea, I just started acting very bizarre. If they'd been some kind of explanation of what could happen, like psychologically, what can change in case you did have a brain injury"

Another participant who was a professional acknowledged that services do not provide enough information to those effected by ABI. Instead, individuals are often discharged from hospitals without a follow up explaining the services that they can contact for support (Int 3, p.64; see appendix I). Due to the gap in their knowledge of ABI participant 1 described how her mother was heavily reliant on the internet for answers, showing the desperation people have in trying to understand ABI (, Int 1, p.125; see Appendix I). Without having the means to learn more about ABI families will lack awareness about the deficits. Morris (2001) found that with the provision of written information to carers and those with ABI led to a decrease in psychological distress compared to controls without helpful information. This is due to the level of self-awareness that those with ABI have about the functional consequences of their own deficits (Fleming & Strong, 1995). Without that self-awareness, family members and those with ABI will be unable to set themselves realistic goals for long term recovery (Flashman & McAllister, 2002; Fleming & Strong, 1995). The findings from the current study, and past research, suggest that there is a need to make the provision of information about the prognosis of ABI to those affected an essential part of the discharge process to reduce uncertainty and psychological distress.

However, the subtheme of information provision is not an issue exclusive to the carers and individuals with ABI, but also problematic between different services. For example, participant 7 who was a police inspector revealed the difficulty of not having information sharing resources between services such as General Practices about the

person with ABI that they were interacting with (Int 7, p.14-16; see Appendix I). The inability to recognise and consider that someone has ABI raises some concerns in the training of professionals outside of the health care system. In the following extract, participant 7 explains the lack of training officers have had to identify the possibility that someone has an ABI. Participant 6's explained the consequences of interacting with someone who does not have the training to consider his disability:

Int 7 p.19 & 30 "and the police are the urm, are dealing with each situation without the information or the training " - "would be it would be training, it would be training to identify"

Int 6, p.33 & 34 "didn't see the, take into account I may be disabled or give me a chance to get my crutch out the car, they kind of treated me like I'm a criminal" – "They weren't initially aware, it was quite interesting cause it, as soon as they did become more aware, as I told them, they acted differently towards me and they understood that I was disabled" – "it was quite a psychological impact I think"

The consequences of not having the knowledge and understanding due to the lack of training, may have led to the mistreatment and negative psychological effect of participant 6. Once police officers knew that he had an ABI, their demeanour changed and they showed more understanding. Many of the participants also perceived there to be a lack of empathy among the professionals towards their circumstance. For example, some of the participants experienced being labelled as difficult and accused of malingering from the professionals. Participant 4 described a situation where a healthcare professionals told her that she was wasting their time and needed to move on with her life (Int 4, p.206; see Appendix I). Participant 5 reflected on her grandson's poor attendance in school due to the chronic headaches he had from the ABI. She felt that the school did little to acknowledge his ABI and lacked empathy when they decided to prosecute his mother.

Int 5 p.58 "the education department are probably going to take her to court again for previous lack of attendance will be taken into account and she probably will have to do a few days in prison" - "it was presented at court but it wasn't deemed sufficient reason for his well, since that time terrible record of school attendance."

The education department's role in the mother's prosecution (participant 5) demonstrates the poor knowledge they have about the complications and effects ABI can have on a child. Farmer and Johnson-Gerard (1997) found that teachers and other school staff had more misconceptions about ABI in factors that affect recovery, memory, new learning, behaviour and continued development, compared to rehabilitation professionals. As discussed in the introduction, other studies (Hawley, Ward, Magnay & Mychalkiw, 2004; Linden, Braiden & Miller, 2013) have showed the inability for schools to acknowledge ABI as the cause of difficulties with engagement in academic study. The lack of empathy shown from diverse types of professionals further highlights the lack of knowledge and understanding that they have of ABI and indicates the need for additional training to increase their knowledge.

Theme 3: Impact of ABI

The theme of knowledge and understanding of ABI drew upon the participants being unprepared, and their experience with professionals who were unable to relate to them due to their insufficient knowledge of ABI. The impact of ABI delves into the ways in which ABI directly affected people's lives. The subtheme of cognitive, behavioural, psychological and social effects of ABI reveals the participants experience of the changes that occurred following the aftermath of being diagnosed with ABI. However, the interviews illustrated how ABI can have diverse effects on different people. For

example, participant 8 experienced mainly cognitive and behavioural changes, whilst participant 5 also experienced psychological and social difficulties.

Int 8 p.40 " I was laughing, giggling making jokes during the funeral service" – "urm I lost my libido and then became like, I became a sex addict, I didn't know I just had, I just had sex with anybody strangers it was crazy."

Int 5 p.80 "but it's clear he is desperately unhappy, he talks about taking his own life." – p.94 "he hasn't been able to maintain many close friendships"

The impact of ABI shown in interview 8 and 5 is consistent with a large amount of research that outlines the cognitive, behavioural, psychological, and social effects of ABI as discussed in the introduction (Arciniegas & Wortzel, 2014; Braine, 2011; Kelly, Brown, Tood & Kremer, 2008; King & Tyerman, 2003; Konrad et al, 2011). However, similarly to the participants' experience of the hidden disability of ABI, some of the participants shared their frustrations towards the public and outside services stereotyping the effects of ABI. For example, participant 6 experienced major physical symptoms of ABI with minor cognitive effects. He described the impact of the professionals' constant negative input, stating what he would not be able to do (Int 6, p.139; see Appendix I).

The diagnosis of ABI also had an impact among family members who transitioned to the role of carers due to their relative's inability to live and manage independently. The findings of this study brought up the subtheme of family carers. In interview 1, the participant described the new responsibilities the family had towards her brother and how they adapted to this.

Int 1 p.73 "urm my mum was expected to to case manage like she was supposed to know what she was doing and she's only just floundering above like trying to suss it out for herself"

Int 1 p.81-83 "when it comes to (name) personal care, I do that between me and my mum" – "and because we're both mothers, I think it makes it easier, when it comes to going out and doing activities, my younger brother (name) tends to do a lot more of that because they have, they're close, they have good fun with each other, urm but when it comes to hospital appointments my dad mainly goes."

Participant 1's account shows the variety of responsibilities and adjustments families must make to be able to care for those with ABI. However, the mother's expectations to take on the role as a case manager without the specialised knowledge of ABI become a burden. Participant 1 later goes on to describe the negative psychosocial effects this had on her mother. Family burden is also common in those who do not have other members to help with the different roles (Braine, 2011). In the following extract, participants 4 and 5 reflect on the burden they had whilst caring for someone with ABI.

Int 4 p.58 "you do don't you, you go through horrendous times with it. I've actually felt quite suicidal at times. And I don't think people know that I really have."

Int 5 p.66-68 "until eventually the situation became very intolerable" – "cause my daughter at this point struggled to cope"

The participants revealed the extent to which caring for someone with ABI can have a detrimental impact on their psychological well-being. This is evidenced by participant 4's interview who described the suicidal thoughts she experienced when managing the dynamic effects of her husband's ABI whilst being an advocate for him. These findings are consistent with previous studies that investigated the changes within the family following ABI. Degeneffer (2001) found that the family difficulties following ABI

does not decrease or resolve with time due to the constant care families provide to their relatives. Braine (2011) also reported difficulties among family carers when it comes to coping and adapting which increased feelings of loneliness and psychological distress. These findings suggest that more support for family caregivers is needed from outside services as well as therapeutic support to monitor the family members own well-being (Rivera, Elliot, Berry & Grant, 2008).

Some of the participants experienced a sense of loss and grief when reflecting on the changes in the person's identity. This is illustrated from participant 1's concerns about her mother's grief. This is also shown from a wife's perspective reflecting on her husband's identity in the following extract.

Int 1 p.75 "She's still grieving losing the son that she knew and raised and trying to get to know this whole new person who has different memories and a different voice and a different sense of humour."

Int 4 p.36 "his personality was totally changed and urm he adopted this, urm very bizarre inappropriate sense of humour, not to the way he was"

In interview 1, the participant described her mother's grief of her brother as an ongoing issue which worsened the less busy she was with his care, she then goes on to propose that her mother has depression. The feelings of grief and change in identity were also recognised by the participants who were professionals as a common experience people with ABI and their families will go through (Int 3, p.175; see Appendix I). Collings (2008) described that the parental grief following a change in identity in the aftermath of ABI can occur when parents begin to reflect upon the loss of a normal development and future they expected their child to have. The grief that parents or others can have towards the change in identity is different from the stages of bereavement people will normally experience as the person still exists (Bruce and Schultz, 2001). It may be beneficial to provide continuous long-term support for family members who must adjust to the changed future, instead of only providing support during the time of diagnosis (Collings, 2008). ABI is dynamic and requires long-term rehabilitation thus support given to family members to help them cope with the grief should reflect this (Collings, 2008).

Theme 4: Access to services

The participant's difficulties getting the right access to services was a major theme. All the participants commented on the positive experience and efficiency of the physical and medical treatment they were given. However, the participants reported on there being too much focus on this side of the person's care and not enough on other aspects. Participant 1 described the amount of energy put into to the physical rehabilitation of her brother, whilst participant 6 highlighted the contrast between the short term medical care to long-term rehabilitation.

Int 1 p.95 "everyone seems to focus on getting the person active again, getting them moving, getting there, there arms working, there legs walking, no one seems to focus on the cognitive health of the person who's had the accident, or speech and language, as long as he is up and walking and everything you can see is in the right order, mm, that's how it feels"

Int 6 p. 45 "my rehabilitation and that was kind of... I still felt a bit was more with my medical needs rather than, long term you know chance"

This links to issues discussed in the first theme of hidden disabilities as the healthcare professionals did little to attend to the hidden symptoms of ABI. The participants felt that if the same effort that was put into the medical care was put on other aspects their

ABI the experience would have been more positive for them (Int 3, p.49; See Appendix I). The lack of adequate care towards the cognitive, psychological and social aspects of ABI, can make attempts to integrate into the community difficult (Cicerone, Mott, Azulay and Friel, 2004)). The participants who attempted to re-integrate found that there was a lack of services that assisted them towards this goal. Participant 6 and 8 reflected on this experience.

Int 6, p.11 "but after that it was largely up to myself to kind of arrange to go back into society and urm, find my own way, and the services that I found were not...not... sufficient in in long term rehabilitation."

Int 8, p.36-38 "urrrm they closed my case saying look she's rehabilitated, she can work shortly after that, very shortly after that I lost my job." – "not getting any support from services and I was written off by people that I used to manage."

The lack of support that these participants received when becoming part of the community, particularly for participant 8, demonstrates that there are unmet needs in assisting those with ABI to achieve their long-term goals of employment, academic study and achievements. The findings from this were consistent with previous research discussed in the introduction which found that there is a limited amount of services that provides those with ABI with the motivation and guidance to do so (Hofgren, Esbjornsson & Sunnerhagen, 2010; Liaset & Loras, 2016). The benefits of community integration following ABI were demonstrated by participant 6 when he independently made the choice to return to university.

Int 6 p.13 "yeah I really really really enjoyed that because it was getting back out into kind of...normality is the better word and, made a lot more friends and it was just...that's what a person my age was in mid-twenties would do, so again because a long time sort of during the formal rehabilitation and stuff, urm, don't really...almost didn't much, and that kind of caused me to feel down as a disabled person to have something after suffering from brain injury, should have to do something where you can just be an ordinary person."

This was clearly a positive experience for participant 6 and contributed to the positive perception of himself by achieving what his old self would have done before having an ABI. Being able to feel 'normal' and building social relationships was beneficial for his self-esteem and self-confidence. Gilsworth, Eyres, Carey, Bhakta and Tennant (2008) found that those who were not able to successfully integrate back into the community through employment and other means had decreased self-esteem and feelings of loss of control which prevented a positive psychological and emotional recovery. This was consistent with participant 8 shown in the extract above, which exposed a gap in outside services not offering enough support to facilitate successful community integration following ABI.

All the participants expressed difficulties in accessing specialist ABI services. Participant 2 had difficulties in finding care homes that could manage the severity of his daughter's ABI. In the extract, participant 3, who was a professional, acknowledged the limited amount of specialist services available for individuals with ABI.

In 3, p.32 "they might do a program for a sh short period of time but urm the specialist services that was available were quite generic services, urm it's limited, it's when I say limited I mean none."

Participant 3's acknowledgement of the limited amount of specialised services available suggests that there is some awareness among the professionals about the demand for specialised services that needs to be addressed.

An important aspect of specialised services is having a strong interdisciplinary care team (Arbreu, Zhang, Seale, Primeau & Jones, 2002). This is something that was of concern to the participants who experienced difficulties in contacting the right professionals and criticised the low level of interaction that the professionals have with themselves. This is demonstrated from participant 5.

Int 5 p.94 "Urm it sounds awful but even after a point you do begin to start feel the services aren't going to help you anyway, you know this sort of imagination that there's all this talk about this you know mental health doing this that and the other but what we can't seem to see is we haven't been able to contact these places for years and access any of it."

p.122 "we hoped he'd get into CAHMS but at social services meetings one of the workers was saying that – she'd been working with the school with the boy who actually attempted suicide the whole time, and they still couldn't get him into CAHMS so what became evident was that you know getting a young person...therapeutic help...feels nigh on impossible."

Not having access to the services participant 5 believed her grandson needed resulted in her not being able to trust the service providers, harming the relationship. Recurring events like this led to the pessimistic attitude of participant 5 about the success of future support. The constant let down of specialist support from certain members of the interdisciplinary team led to learned helplessness for some of the participants (Int 5, p.334 & 372; see Appendix I) (Maier & Seligman, 1976). The participants felt as if they were constantly failing to improve their situation without the support they needed from professionals and came to accept that it was never going to change, in some cases, discussed later in theme 5, leading to anti-social behaviour (see safeguarding).

All the participants commented on the staff and organisation issues. Participant 2 reflected on the beneficial opportunities that his daughter missed out on (Int 2, p.64; see Appendix I), whilst participant 3 discussed issues out of the professionals' control (Int 3, p.65; see Appendix I). Other issues discussed were staff being overworked which made it difficult for them to give their full attention to patients. All the professional participants were concerned about the way in which the system of outside services is setup and the subsequent professionals' day to day routines.

Int 7 p.20 "they're set out to manage people through...through meetings, where people aren't actually in the meetings, so it's like a professionals meeting, which I think is ridiculous, urm or they don't actually go to the address, and they don't actually leave their offices – but their organisation just isn't set up for that frontline delivery."

Getting the information from these participants regarding difficulties with staff, suggested that organisations do not interact enough with service users in their environment, which makes it difficult for them to truly understand their needs. The way in which service users must contact outside services when in need of support was described as not friendly for those with ABI but easier for the professionals (Int 7 p.84; see Appendix I). This alongside the inconsistency of staff (having multiple social workers) can contribute to difficulties in long term recovery (Int 5, p.76 & 116; see Appendix I).

The final subtheme for access to services was carer & family inclusion support. This revealed issues that the participants experienced concerning the available support for family members' well-being, and support for their care role. Family members also felt that they were excluded from the care plan of their relative. Many participants felt as if the knowledge of what the person with ABI was like pre-injury and their opinions about their rehabilitation were not appreciated and considered.

Int 1 p.95 "and she backed out of it and I went why and she said well it's group therapy, said that's all it is its group therapy its people stood around talking said it'll be like top trumps and she painted all of these negative connotations towards this group and I genuinely think there should be a service that offers some sort of even if it's just CBT-but it doesn't seem to be."

Int 6 p.37 "one of the resources that I found that was really lacking in my care was that, I got a very close family and my family members, knew an awful lot about my personality, and about my interests before the injury, and lots of things like that and urm I didn't feel that...the immediate sort of medical services drew on that support they almost tended to exclude my family members from rehabilitation or meetings and things like that and I think that, they really could have really learnt a lot about the way that my interest have formed, and the way that I was involved in my family to a greater degree."

Laroi (2003) proposed that it is highly important to involve family members in the rehabilitation process of the relative with ABI. Doing so provides the opportunity for them to express their concerns and provide valuable input that professionals may not have considered without knowing the person with ABI beforehand. As discussed in the theme of knowledge and understanding this is also the opportunity to educate family members and have good insight into the changes that they can expect to happen to their relative. This research along with the current findings emphasise the importance of a holistic health care approach, to ensure that the person with ABI is not treated by the symptoms that they are experiencing but as a whole person which includes their family (Kreutzer, Kolakowsky-Hayner, Demm & Meade, 2002)

Theme 5: Safeguarding

The final major theme was safeguarding issues around those with ABI. This included the subtheme of capacity which was the extent to which someone with ABI can mentally and emotionally make their own decisions about their rehabilitation (Trachsel, Hermann & Biller-Andorno, 2014). In the extract participant 3 described the safeguarding issues that come up when those with ABI may not have the capacity to comprehend topics discussed regarding their treatments and the misconception professionals have about the choices people with ABI have made.

Int 3 p.84 "for that information to be urm to sink in and then what we get is the the after effect of that conversation understood or been taken literally or do you see what I mean, so on the space of it, it makes it seem quite, they respond quite normally or or seem whatever is normal and respond appropriately and what we see afterwards is something completely different"

Int 3 p.63 "there needs to be an approach where have a multidisciplinary meeting and discuss you know, you know best interest and things like that but ultimately that person has capacity and they chose they're say they're choosing to live like that, well nobody would actually choose to live like that"

This illustrates the tendency to overlook whether or not someone has the mental and emotional capacity to discuss the implications and options they have following ABI. This is often a critical point in their recovery in ensuring that their long-term care needs will be catered for (Trachsel, Hermann & Biller-Andorno, 2014). If a patient with ABI appears to have capacity when they do not, they may make choices which are not in their best interests due to a lack of understanding of their own condition and impairments (Trachsel, Hermann & Biller-Andorno, 2014; Triebel et al, 2012). This further highlights the importance of having an advocate who will represent the person's best interest, to ensure that safeguarding steps are met. (Douglas, Bigby, Knox, & Browning, 2015).

The vulnerability that some people with ABI show further highlights the importance of

safeguarding. Participant 5 discussed her grandson's drug use, whilst participant 7 addressed how anti-social behaviour can occur following ABI.

Int5 p.122 "he started smoking weed and it was helping him that stuff sleep" "and it you know when we tried to talk to him about it he said, it's the only thing that makes him feel better, and I mean it broke my heart one time he said the weed is the only friend I got, he sees it as his only support."

Int7 p.26 "they tend to urm, be isolated in the community, urm, and they're more likely to, attract people who may have other motives by befriending them, urm, around sort of...using their house...as somewhere to stay if they may be homeless or... exploiting them financially...urm some form of exploitation"

Previous research (Hwang et al, 2008) has addressed the increased vulnerability that those with ABI can have leading to problems such as homelessness and substance misuse. This issue was acknowledged by both of the professionals, some of the family members and individuals with ABI. Participant 5's account of her grandson's use of marijuana demonstrates the implication of being isolated and the failure of reintegrating back into the community through academic study as discussed in theme four.

Conclusion

The purpose of this study was to gain an in-depth understanding into the experience that people with ABI have and the extent to which family members, individuals with ABI and professionals believe that community services understand their difficulties and needs. The main findings of the study revealed key areas that the participants believed to be important in understanding the service users' experiences and what they felt the service providers commonly overlooked, from initial diagnosis to the long-term recovery following ABI.

Langlois, Rutland-Brown and Wald (2006) found that there was a high tendency among professionals to overlook invisible symptoms of brain injury, and subsequently overlook the support needs of those with ABI, causing mistrust from ABI survivors towards professionals. This was consistent with the findings of the current study. The participants were frustrated with the professional's reluctance to acknowledge the hidden symptoms of their ABI and provide care for this. This harmed the relationship between the person with ABI and the professionals. Linden and Boylan (2010) found that implications include issues when those with ABI attempt to reintegrate into the community. This may be due to individuals with ABI leaving with a lack of self-awareness about their deficits which can make it difficult to plan realistic long-term goals in rehabilitation (Flashman & McAllister, 2002; Fleming & Strong, 1995).

The study also revealed concerns regarding the family members, people with ABI and some of the professional's lack of knowledge and understanding about the complications of ABI. These findings were supported by previous research (Morris, 2001), thus suggesting that the provision of appropriate information to all of those affected by ABI should be made a compulsory part of the discharge process, to reduce uncertainty and psychological distress (Morris, 2001; Fleming & Strong, 1995).

The findings also illustrated a lack of training when identifying and responding to people with ABI, particularly among professionals outside of the healthcare system. This resulted in the mistreatment and labelling of participants, mainly due to professionals lacking in empathy. The lack of training is further supported by previous

research such as, Farmer & Johnson-Gerard (1997) who found substantial misconceptions about the implications of ABI among teachers. To tackle this misconception, more training should be implemented among professionals outside of the healthcare system such as education departments and probation services.

The impact of ABI also highlighted feelings of frustration among participants who received constant negative feedback from professionals regarding their future. This suggests the need for professionals to provide more positive rehabilitation to motivate those with ABI to get as close to the level of function they were before the ABI (Cicerone, Mott, Azulay & Friel, 2004).

Previous research such as Degeneffer (2001) and Braine (2011) highlighted the difficulties that family members experienced as carers. Collings (2008) found that grieving the old identity of someone with ABI is a long-term process that families experience. The current study validated this showing the psychological effect such as depression and suicidal thoughts participants experienced as carers. These findings indicate the necessity for a variety of long-term support for caregivers. Having a variety of options will allow families to be supported in a way that fits their own needs.

The positive aspect of the participants' experiences is the efficiency and effectiveness of the medical care provided. However, the findings showed that the attention, interdisciplinary care, and communication the participants experienced with the medical side of ABI was lacking for the cognitive, social and psychological side of ABI. Further research should focus on the differences between medical and other rehabilitation care to identify why and what makes the difference in efficiency. This can be used to apply existing methods that work to an area that is needed such as psychological care.

The participants experienced limited access to outside community services. This included criticisms in the way that organisations were set up. For example, the professionals limited interactions in the community with ABI service users. These factors were seen to further damage the relationship between the service users and providers as those with ABI lost faith in the system. The participants also reflected on the tendency to exclude family members when drafting care plans, which often minimised the support network of the individual with ABI. This was also recognised by Laroi (2003) who highlighted the importance of involving family members in the rehabilitation process to provide further support to the relative and increase their knowledge. Kreutzer, Kolakowsky-Hayner, Demm and Meade (2002) suggested that a more holistic health care approach to the person with an ABI is necessary to avoid the treatment of the person being solely focused on the symptoms and disability.

The importance of safeguarding those who do not have the capacity to make decisions and who are highly vulnerable was identified in the current study. This is supported by Hwang et al (2008) who found a high prevalence of homelessness among those with ABI which led to outcomes such as substance abuse. This behaviour can also occur under symptoms of disinhibition, impulsivity or impaired executive function (Olson-Madden, et al, 2012). Therefore, appropriate safeguarding measures should be put in place for those likely to fall in this category through means such as regularly reviewing the vulnerability and capacity of those with ABI in their community.

The data from the participants also revealed that there is need for a professional to be involved in the care of the family members and individuals with ABI in the long-term to provide stability. Having to get to know multiple different people in the short-term did not allow strong positive relationships to be built. Assigning a professional such as liaising officer to each case to oversee the interdisciplinary care around the families and people with ABI, may provide that stability and ensure that those with ABI have access to services that are vital to their rehabilitation.

The findings of the study revealed issues in the relationship between those with ABI and outside community services with the data showing more difficulties that families and individuals with ABI encounter. The professional accounts validated much of what the family members and individuals with ABI discussed, but they also touched on issues about funding and overworked staff. Although, there was a mixture of participants including a professional within the healthcare system and another outside the healthcare system, not recruiting a wider variety of professionals who frequently interact with this population (for example case managers and social workers) was a disadvantage to the study. Future research should include a wider variety of professionals who are, or should be, frequently involved in the care of people with ABI and their family members. Doing so would allow a more holistic well balanced interpretation, to add to the important findings in this study.

To conclude, this study has highlighted difficulties individuals with ABI and their families experience when interacting with community services. Furthermore, the study has identified key areas for improvement in community service provision. To ensure the long-term rehabilitation needs of those with ABI, and their families, are met, professionals working within community services need better training about the long-term impact of ABI and there needs to be greater access to services, with particular focus on interdisciplinary, specialist teams offering tailored care.

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Appendices can be seen in Supplementary files in the list of Article Tools showing to the right-hand side of the main window.