



RESEARCH

The Experiences of Relatives of People with Acquired Brain Injury (ABI) of the Condition and Associated Social and Health Care Services

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Context: ABI can arise from many causes and is a significant issue for long-term care. Developments in health care have meant that many more people with ABI are living longer, some with complex needs arising from their brain injury. The consequences of injury are generally long-term, even lifelong. Family members of people with ABI are significant to their rehabilitation, support and care, and research has identified many of the challenges they face.

Objective: This paper reports work to survey the views of family members of people with ABI to ascertain their experience of the condition and their views and experience of related health and social care services.

Method: An online survey was distributed via ABI networks to family members of individuals affected by ABI. One hundred ten respondents ranked the difficulties met by their relative living with an ABI and rated the services they had encountered. A series of open questions enabled respondents to provide greater detail regarding their experience and knowledge.

Findings: The key findings are that relationships between the injured and non-injured parties change, alterations to roles and responsibilities are difficult and mediated via unending and complex grief. Relatives reported poor levels of involvement in decisions regarding the provision of social and health care services, a failure to be given good, accurate information in a timely fashion and the need to 'fight' for virtually any service provided. Service provision, particularly post-hospital discharge, was very regularly criticized for being either entirely absent, unaware of the impact of brain injury, failing to take account of actual functioning and/or structured in ways that are not concomitant with the needs of the injured person or the relative. Lack of knowledge of the impact of ABI by non-specialist staff and services is particularly highlighted as a barrier to progress and an added burden for relatives to contend with. Social work in particular was commented upon most negatively, most often for a failure to understand the condition and needs. Valued services and professionals are noted to be humane, knowledgeable about ABI, aware of the impact ABI has on the non-injured relative and able to act as a single 'one-stop' focal point for service provision.

Limitations: As a self-selecting cohort of respondents to an online survey the work is not necessarily generalisable to the population as a whole. The findings, however, provide important considerations for improving social and health care services for people with ABI and the key relatives involved in supporting them.

Implications: Commissioners and providers of social and health care services ought to work more closely with family members of people living with ABI. Services and individual practitioners need to be more knowledgeable about the likely functional outcomes of ABI, in particular the impact of invisible impairments to cognition and executive functioning. Relatives identify the benefit of good quality, accurate information and of a knowledgeable single point of contact across time and setting. Knowledge of ABI, of neurorehabilitation and of the impact of ABI upon family members by social workers is noted to be poor and attention to this may help with people's rehabilitation and to prevent unnecessary additional carer burden.

Keywords: acquired brain injury; family; carers; social work; case management; neurorehabilitation; executive impairment

Introduction

Acquired Brain Injury (ABI) is a significant issue for long-term care. Data collected in the UK suggest that, on average, 445 people are admitted to hospital with a head

injury every day (Headway, 2015b). Many of these injuries caused in, for example, road traffic accidents, assaults, falls and sporting injuries are generally minor, but a significant proportion can cause traumatic damage to the brain. The vast majority (95%) of admissions to hospital with head injury present with a normal or relatively unaltered state of consciousness, and 0.2% of admissions will result in death during the acute phase of admission (NICE,

2014). In addition, ABI can arise from some diseases, such as encephalitis and meningitis, as well as from incidents of anoxia (shortage of oxygen, overdose, cardiac arrest, etc.), haemorrhage and other non-trauma caused conditions.

Survival rates for people with serious brain injury have increased as a consequence of improvements to paramedicine, neurosurgery, neuro-imaging and intensive care treatment; for example, the development of artificial ventilating systems has improved mortality rates (Powell, 1997; Fins, 2015; Klemen and Grmec, 2006). Despite these improvements, ABI is still noted to be the commonest cause of death or disability in those aged 1–40 years (NICE, 2014). People affected by ABI are disproportionately represented in prison populations, homelessness services, domestic violence and suicide statistics (Williams et al., 2010; Oddy et al., 2012; Simpson and Tate, 2007; Alston et al., 2012). Brain injury in childhood, even mild injury, is noted to have significant impact in terms of lifetime mental health service use, substance use and incarceration for acts of violence (Sariaslan et al., 2016; McKinlay, 2014).

The impact of ABI varies considerably for people depending on the location and extent of injury. Potential changes to physical and sensory abilities, cognition, executive functioning, behaviour and personality can be the consequences of ABI (Ponsford, 2013). As a long-term condition, this impact is felt over many years, potentially for a lifetime (Masel and DeWitt, 2010). Recent increases in rates of injury amongst females in England and Wales (Headway, 2015b) indicate that men are now 1.6 times more likely to be injured than women. Children and those aged 75+ are age groups noted to have increased incidence of ABI (Trefan et al., 2016; Thompson et al., 2006). Older people generally have worse outcomes from ABI (Merzo et al., 2016). Some younger people with ABI suffer significant consequences across their lifespans (Sariaslan et al., 2016).

Despite it being a long-term condition for many, there are few longitudinal studies (particularly over 10 years post injury) of the impact of ABI. There are significant issues with researching this group, the more severely injured, including that many are more likely to be 'lost to follow-up' for researchers (Dan Hoofien, 2001; Langley et al., 2010).

Results of research into rates of return to work following ABI vary according to methodology. A systematic review of such research identified that 40% of subjects were able to return to employment within a two-year period following injury, albeit sometimes at a lower level of responsibility and/or for fewer hours than pre-injury (van Velzen et al., 2009). This figure is replicated in other work that includes those with moderate and severe injuries (Friedland and Potts, 2014). Ability to return to (and maintain) employment is noted to be a function of behaviour, cognitive/functional abilities and communication abilities and style (Brooks et al., 1987; Meulenbroek and Turkstra, 2016), which may all be altered as a result of ABI.

Brain injury challenges simplistic notions of care provision which focus upon single issues and compensation and support for physical impairment (Clark-Wilson et al., 2014). Also, potential service users with ABI who lack insight into their difficulties and who demonstrate complex to manage behaviours challenge concepts of

self-directed care (Holloway and Fyson, 2016). Family members are potentially less 'carers' and instead are more 'managers' post-injury in instances when the main impact of the condition is executive, behavioural and cognitive in nature (Knox et al., 2015). For those with more significant brain injuries, an investment in specialist neuro-rehabilitation is noted to potentially reduce costs of long-term care (Worthington et al., 2006; Oddy and Da Silva Ramos, 2013). Difficulties with loss of insight and poorer executive functioning are identified as being associated with higher case management costs (Clark-Wilson et al., 2016).

Family members of people affected by ABI have long been recognised as being significantly impacted upon by the injury to their relative (Romano, 1974). Research points to the difficulties experienced by family, such as changes in the abilities of the person affected with ABI, potential changes in their personality and behaviour, reduced social contact and community integration, as well as difficult role and relationship changes, e.g. from partners/equals to providers of care/support (Anderson et al., 2012; Bishop, 2006; Nabors et al., 2002; Degeneffe, 2001; Blake, 2014). This takes place in the context of unending grief and ambiguous losses which shape relatives' experiences (Kreutzer et al., 2016; Giovannetti et al., 2015). The relationship with and experience of formal long-term/social care of these family carers has relevance for providers of services. Hence, this paper reports work to seek the views, experiences and knowledge of family members affected by ABI in relation to not just the condition itself but also the services encountered as a consequence.

Methods

An online survey was created in 2014 ('live' for three months), targeted at the relatives of people living with an ABI using *Survey Monkey*, with a confidential link for distribution. The national brain injury charity Headway, the Child Brain Injury Trust, the United Kingdom Acquired Brain Injury Forum, the Brain Injury Rehabilitation Trust, the Brain Injury Social Work Group and the British Association of Brain Injury Case Managers distributed the link to potential respondents and publicised the survey. The survey, then, potentially recruited family members from across the UK.

The survey contained a number of demographic questions and a series of Likert scales examining how they rated the importance of regularly encountered ABI-related issues. Respondents were asked to rate their view of the relative difficulties experienced by the person with ABI they were reporting on, from 0 (relative has no issues within this domain) to 10 (relative has extreme difficulty). The rating scales were split into different domains that reflect the commonly experienced difficulties after brain injury drawn from the existing literature; these were titled executive, behavioural, emotional, physical, sensory, cognitive and insight difficulties. An explanation of each domain was provided to support the judgement of the respondent in rating the difficulties experienced.

In addition, six open-ended questions were asked, allowing for free narrative by respondents to expand on their own experiences, including identifying areas of difficulty not listed in the closed questions. Respondents also had the

opportunity to note what services they had encountered related to their relative's ABI and to rate them. Additional space was provided for respondents to comment upon what 'worked' and what did not from these experiences.

Responses to the free-text questions were thematically analysed by each question. To enable respondents' comments to be contextualised and anonymised through the remaining part of this article, a key (see **Figure 1**) has been created consisting of the relationship with and the living arrangements of the injured party and number of years since injury. Hence, in the discussions below, the code U6, for example, would refer to a person with a brain injury who lives in a residential/rehabilitation setting, having been injured between 6 and 10 years.

Individual professionals are referred to by their job titles and no names of towns and cities or services have been used. Ethical approval for the study was granted by the University of Sussex.

Limitations of the Study

Despite promoting the survey widely through many networks and seeking a large and diverse sample of respondents, it needs to be borne in mind that respondents to online surveys will, by their nature, be self-selecting and, hence, may not be representative. Similarly, 110 responses for a condition that affects many hundreds of thousands of people is a limitation when considering the generalisability of the findings. Despite these caveats, the survey provides rich insights in to the perspective of family and carers of a significant group of people who are living with brain injury.

Findings

One hundred ten surveys were completed fully enough to be considered for analysis. The completed surveys were analysed quantitatively and qualitatively. Not every respondent answered yes/no for the rating scales (a 'do not know' option was also available), hence frequency of report is not 110 for each scale.

Respondents to the survey were overwhelmingly female (85%), ranging in age from 18 to 75+ years old. Sixty-five per cent of respondents were aged 45+; 74.5% of respondents were either parents (34.5%) or partners (40%) of the injured party, the rest made up primarily by siblings or adult children of the injured person. 77% of the people living with ABI reported upon were male. Nearly 90% of the cohort described by respondents were

of working age at the time of injury. 70% of the group had a traumatically caused brain injury – road traffic accidents account for just over 50% of the respondent cohort, in line with other research into cause of injury (UKABIF, 2016).

More than a third of this cohort reported over ten years' experience post-ABI with nearly 15% of individuals living in non-community settings such as specialist long-term neurorehabilitation units. UK census results into household composition indicate that fewer than 12% of people of working age live alone whereas 32.7% of this cohort, who live in the community, do not live with friends or family, living either alone or with support workers (ONS, 2011). With a paid employment rate of only 10%, it would suggest that the cohort in this study are more severely injured than in some other research relating to ABI and employment and that use of long-term care services and/or need for long-term carer support is more likely to be required.

Respondent rating of difficulties as a consequence of the ABI

Respondents median scores of difficulties (out of ten) rated more severely the 'invisible' consequences of the ABI, such as cognitive (8/10) and executive (7/10) impairments, than the more visible physical impairments (3/10). In particular, cognitive difficulties were noted by over 96% of the respondents. This was rated as the issue that creates the most difficulty for the person with the ABI. Sixty-six per cent of respondents said that cognitive, executive, emotional and/or behavioural difficulties were compounded by reduced insight on the part of the person suffering the ABI. Previous research has shown that insight difficulties are associated with increased use of case management time, greater difficulty for family members and difficulties engaging the brain-injured party with rehabilitation (Bach and David, 2006; Clark-Wilson et al., 2016; Medley and Powell, 2010). Non-parametric Spearman's Rho Correlations (non-parametric test) were performed between insight and each of the domains. All measures, with the exception of the physical scale, showed significant correlations with reduced insight. It is of note that physical impairment is not correlated with such difficulties. Invisibility of impairment and the injured party's lack of insight makes the relative's support role and tasks more taxing. Understanding the nature of the difficulty, the underpinning reasoning for post-injury changes, is not

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|----------------------|---|
| Living arrangements: | T = Live together U = Lives in a unit/residential/rehabilitation setting A = Lives in own accommodation, with or without paid support |
| Years since injury: | 02 = 2–5 years post injury 06 = 6–10 years post injury 10 = 10+ years post injury |

Figure 1: Key to identify respondent details.

therefore obvious, and loss of insight reduces or removes the injured person's capacity for accurate self-analysis to support this.

Although only 56% of respondents ($n = 62$) reported physical difficulties to be an issue for the relative with ABI, it should be noted that 22 reported very high levels of physical impairment (15 reporting 10/10 and 7 reporting 9/10). Advances in neurosurgical procedures would appear to be increasing the possibility of some very severely injured people surviving but without necessarily improving quality of life-related outcomes (Garvin et al., 2015).

A social consequence of ABI, loss of friendships, was noted to have occurred for 77% of individuals with an ABI but, also, for nearly half of the respondents too. Friendship post-ABI is noted to be an under-researched field and one that is problematic for the injured party (Salas et al., 2016). Spearman's Rho correlations were performed between the number of respondents' friendships (loss of) and the different domains. It was observed that increased loss of insight and behavioural difficulties were strongly correlated with loss of friendships by the respondent (correlation is significant at the 0.01 level, 2-tailed).

These results would indicate that, for this cohort, there is a significant relationship between increased difficulties with behavioural control and loss of insight by the injured party, and the friendships of the non-injured relative. This statistical relationship is not seen between the ratings of the injured party's physical impairment and the reported respondent's friendships. Again, from the perspective of the relatives responding to this survey, it is the invisible deficits and difficulties that appear to be having a greater impact upon the respondent than the visible, physical disability.

Respondents were asked to rate out of 10, with 10 being highest, the quality of the service received by the brain-injured party. **Table 1** presents the ratings of respondents, with the highest-rated service first. Frequency of report in the table varies as not all individuals access every service.

Once an individual's risk of imminent death had been averted, a range of (potential) support services becomes available depending upon clinical need, local provision and navigating the system. As can be seen from **Table 1**, the highest-rated services are those that may be characterised as life-saving (hospital) and those specialising in brain injury. Such services frequently work across settings and have a focus on restoration of functioning. It is notable that the highest-rated services also have the lowest standard deviation scores, indicating that people are more likely to consistently rate them highly.

Whilst it would be unwise to infer too much from data generated from an online survey of self-selected participants, the difference in rating for brain injury case managers versus social workers is stark and would appear not to have been previously investigated.

Responses to the six open-ended questions

Q1: How has your relationship been affected by the brain injury?

Ninety-seven survey respondents provided responses to this question. Perhaps surprisingly, three people replied to this question identifying *only* positive changes to their relationship with their relative living with ABI, for example:

It has brought us closer as we now appreciate how short life is. (Child U2)

Table 1: Respondent rating of the services received by the brain-injured party as a consequence of the brain injury. Ranked by highest rated service to lowest.

| | Frequency of report | Percentage reporting using this service | Mean quality score | Std. Deviation |
|---|---------------------|---|--------------------|----------------|
| Brain Injury Case Manager | 44 | 40% | 7.6364 | 2.08082 |
| Hospital (A&E/ITU) | 93 | 84.50% | 7.0215 | 2.40912 |
| Neuropsychologist or Psychologist | 66 | 60% | 6.8485 | 2.10671 |
| Support service such as Headway or Child Brain Injury Trust | 75 | 68.20% | 6.8 | 2.371 |
| Physiotherapist | 69 | 62.70% | 6.6667 | 2.10508 |
| Occupational Therapist | 69 | 62.70% | 6.2464 | 2.24529 |
| Neuropsychiatrist or Psychiatrist | 46 | 41.80% | 5.8696 | 2.23715 |
| Counsellor | 33 | 30% | 5.8485 | 2.51398 |
| Day Centre | 27 | 24.50% | 5.4815 | 2.7227 |
| Inpatient rehabilitation (NHS or other provider) | 76 | 69.10% | 5.3947 | 2.98476 |
| Speech and Language Therapist | 51 | 46.40% | 5.3529 | 2.4562 |
| Home care or support work services | 64 | 58.20% | 5.1875 | 2.52527 |
| Social Worker/Social services | 59 | 53.60% | 4.5254 | 2.89087 |

None of these three respondents, however, lives with the injured relative, all of whom had suffered their injuries more recently and were described as very physically impaired but with few behavioural difficulties. Indeed, role changes may be experienced differently by parents, as illustrated by this person:

As a parent my role in some ways had changed little, as I have always looked after and cared for my child, albeit she is an adult now, however now she will always need that care and support and will never be independent. (Mother T6)

Nineteen respondents directly reported clear changes in role, most usually from partner to carer, often with increased responsibility for decision-making and with an end or changes to intimate relationships. Other respondents also reported similar significant changes without directly using the same words, for example.

Our roles have changed. My role is that of a carer and feels like being a parent sometimes. My identity within our relationship has changed. (Partner T10)

The issue of the relative/friend being responsible for the person with ABI as a result of changes brought about by the brain injury was a further repeating theme, for example:

No longer feels equal partnership – is all one sided with me needing to give all the time financially, responsibilities, planning relations with the children, grandchildren and socially, communication difficulties as well as anger and tears. (Partner T2)

Those whose relatives had very profound injuries resulting in ongoing need for 24 hours a day nursing noted the profound, even terminal impact this had upon the relationship, as one person commented:

Our relationship ended after it was apparent that no recovery is expected but I still visit her in her care home. (Partner U2)

Many respondents noted a greater distance in their relationships, sometimes exacerbated by a lack of insight and/or of ability on the part of the relative with the brain injury to empathise or reciprocate, for example:

I am not his first source of support in times of trouble, so I don't get to help and sometimes I don't even know despite living in the same town. He is not able to initiate contact so if I am unwell, I have to keep updating him myself – he appears not to care though I know that is not the case. But out of sight out of mind. I have to work to maintain contact. (Mother A10)

Our relationship with our son has been greatly altered – also tested to the limit, and indeed beyond I think. We walk on eggshells now. He now has mental health difficulties, which we are told were brought on by the brain injury. He has tried to kill himself many

times and he has also believed at one point that he needed to kill us and then himself. He is not the same person any more, but he is still my son. (Mother A10)

Some respondents noted that amidst the profound changes, a process of adaptation to the impact of the ABI and some positives they could draw from this, for example:

We have had to make compromises. My partner needs a sleep every day. My partner used to book holidays and be in charge of our finances/bills etc. Our roles in our relationship have changed and shifted, it has strengthened our relationship even though at times it is difficult. (Partner T6)

Q2: How well did these services include you and your knowledge/experience of the brain-injured party in their work? Thinking about the services you have used, what is the one thing that could have been done differently that would have improved your experience?

Sixty-nine respondents provided a response to this question, answers varying from single word replies to lengthy ones. Only three of these replies would be considered to have been overwhelmingly positive, the vast majority were either mixed or wholly negative.

Positive comments related to the use of specialist ABI services, independent and highly specialised brain injury rehabilitation units, brain injury case managers and specialist litigation solicitors. Often this support is long-term. As this person commented:

Since 1998 we have been supported as a family, by the rehab unit. There is a highly professional yet friendly approach to support and understanding. (Mother U10)

Involving the family was commented upon by some as making rehabilitation more effective as family are the people likely to implement plans over the longer term; for example:

The one thing that should be different – is to recognise that family are the cornerstone of neuro-rehabilitation. If you lose them then you lose the best chance for the person with the brain injury! (Partner T2)

Some respondents noted that they had needed to 'fight' to navigate the system and to become involved in formal plans for supporting their relative/friend, such as in this case:

I was included once I had found the way through to the correct people. The problem was knowing where to start and then being told to contact somewhere else. (Mother A2)

Negative comments about services focussed on several repeating areas, including the impact of the brain injury being missed entirely and neither assessed for, nor any services provided; a lack of information given to relatives

(most especially at time of discharge); lack of access to specialist rehabilitation; delay (sometimes of many years) in accessing services; poorly planned discharge from inpatient settings; lack of involvement of family in processes; and no overall co-ordination or continuity of services, as this person commented:

Intermediate rehab unit was extremely poor. Not enough physios or OTs. Nursing and therapy staff did not work as a cohesive team so no continuity possible. (Partner U2)

The length of time family members were left to cope with no services or non-specialist services was noted by several respondents, for example:

We were referred to Headway after 10 years of me coping. Social services did not help up to this point. (Mother A10)

A lack of specialist knowledge or services was also commented upon by some, such as this family member:

Local social services were useless at best and got things wrong time and again, no matter what clinical information was given to them. (Uncle A2)

With regards to respondents' suggestions of what is required to better support them and their injured relative/friend, issues raised were the need for accurate information to be provided in a timely fashion; the need to listen to, involve and integrate family into the processes of rehabilitation and discharge; the provision of specialist not generalist services; and the benefit of having an overall knowledgeable single point of contact to co-ordinate services and provide relevant information. As this person commented:

What was needed was some humanity and sympathetic communication and support but above all accurate info. (Sister A10)

Overall the responses indicated far greater levels of dissatisfaction with services, in particular with an absence of specialism, lack of knowledge of ABI and/or an entire absence of services.

Q3: Were you given the information you needed to understand brain injury and services?

More than twice as many individuals (42) reported that they were not given information required to understand brain injury and relevant services as reported that they were (20). Fourteen people replied with a one-word answer 'No' and eight with 'Yes'.

Of those that did report that they were given relevant information, a number noted it came via specialist voluntary sector organisations such as Headway, Child Brain Injury Trust CBIT and the Stroke Association. Others satisfied with the information provided to them stated that it came via specialist services (independent brain injury case managers or neurorehabilitation services), or by their own research. It

was notable that a number of respondents reported that the information they needed was not easily acquired as it had to be searched for and that on occasion this took a number of years to acquire, as these carers responded:

No one sat us down and explained what the brain injury was or which part of the brain had been affected. No one discussed the long-term effects or what we might expect. (Child U10)

No. For social services available, I had none. Few I contacted myself, still was disappointing. I felt no one understood nor aware of 'category' Brain Injury. Where autistic, dyslexic and other similar disabilities are known/grouped, I soon became aware that Brain Injury was not known. (Mother T6)

A few noted that they had felt well supported by professionals and family. In these instances, the professionals concerned were identified as working with the whole family rather than simply the injured person, for example:

Brain injury support team has given me tools to deal with my husband's behaviour moments, and my husband has had support through his anger management sessions. (Partner T2)

Q4: What are the three most difficult things that you face now as a relative/friend of a brain-injured person, and how well have you been supported to face these?

Responses to this question were broad but repeating themes were identifiable in relation to the difficulties faced by the respondents. Some noted functional/behavioural difficulties for the person living with the ABI as a direct consequence of the injury as being the most difficult aspect, such as:

Anger, frustration and dis-inhibition (Partner U2)

1. Having to do most of his thinking for him. 2. His lack of initiative & motivation (Partner T10)

Superficial assessments by staff, sometimes including defining a good recovery from ABI based on a person's appearance rather than their functioning, was also commented upon and criticised by respondents as an added difficulty they faced. As one person responded, apparent good physical recovery could be misunderstood as a genuinely good overall recovery:

Him looking normal, however not being understood by people in authority and others, therefore I am unable to protect him from himself and others. (Mother A10)

The lack of support, even of understanding of the situation, was commented by some as one of their difficulties to deal with, as this person commented:

I do not feel that I have been supported at all. Having to fight for every piece of support or rehabilitation for my husband. No empathy towards us. (Partner T2)

Others noted the ongoing burden of coping with changes, particularly when the respondent had other responsibilities or was the only party taking responsibility, and the process of adapting to changed circumstances. One person commented on feelings of isolation that limited assessments did little to help:

Isolation: I don't mean because I am on my own... but unless you live it daily you don't understand how hard it is...and it is hard to articulate this to someone who thinks he is 'doing so well' after a 15 min meeting. (Partner T2)

A lack of understanding of the difficulties faced by the person with the ABI and the respondent by their wider family/friends, by health and social care services and by the wider community, in particular owing to the invisibility of the consequences of ABI, was added to by the same carer:

Managing people's expectations of him – they still think he is the same as he was before. (Partner T2)

Others noted an absence of adequate/specialist service provision in the statutory sector and/or delays in receiving services. Overall a picture developed of relatives who were left isolated and lacking in information needing to fight for support, as this mother expressed her biggest challenges:

First, second and third, the constant battle for care and support-services is exhausting. (Mother A6)

Privately purchased specialist services were rated more highly, noted to be supportive of the respondent, knowledgeable about the condition and flexible in response, for example:

By getting the professionals who know about brain injuries involved and having a very good legal team that was able to fight for him helped us to deal with this very upsetting and very emotional time. (Sister A6)

Some expressed concerns regarding the future, as this mother commented:

Knowing my daughter will be on her own when I die. (Mother A10)

The impact that the injury has had upon the respondent and wider family, including children, was reported. As one mother commented about experiences following a son's ABI:

His brother and sister are still struggling to come to terms with it, and my 31-year-old marriage has ended. (Mother A6)

Sometimes this was felt long-term, even compared to mourning, such as by this person:

Extreme grief at the loss of my funny, intelligent son (an ongoing never-ending bereavement). (Mother U10)

Whilst the nature of the difficulties faced by respondents was very varied, from those who require round-the-clock nursing or behavioural interventions to those who had far less obvious or even very subtle difficulties, the impact was felt across time and by more than the person living with the injury. The respondents identified more regularly than not that the response they received from the wider community and services was either inadequate or actively damaging. The invisibility of most post-ABI difficulties and the impact loss of insight plays in this, alongside lack of knowledge by services, exacerbates the negative aspects of the many respondents' experiences.

Q5: Knowing what you know now, what would you do differently if you could go back to the time when your relative/friend was first injured?

Seven people noted that they would change nothing, either as they were satisfied that they did all that they could or that they did all that was possible for them to do at the time.

The majority of the answers to this question related to respondents stating that they would have become more involved at the earlier stages, asking more questions, seeking to gain more information, advocating for the use of specialist (not generalist) services, and sooner, and to have been more assertive in pushing for services for themselves as well as the injured person. These responses related to the spectrum of services and care, including inpatient, discharge and community settings. Discharge to the community was specifically mentioned most frequently as a problem area.

This question, of all the open-ended questions, appears to have provided the greatest degree of uniformity of theme in the responses, namely that of the need to learn to be able to effectively advocate on behalf of the injured person through assertive and informed involvement and insisting on appropriate, timely specialist services. A mother, for example, found it best to:

Contact a brain injury case manager early on to ensure he received the correct treatment, and the family were supported. (Mother A6)

The need for family to involve themselves and advocate on behalf of the person with the brain injury and themselves was noted in relation to litigation as well as to clinical decision-making, for example:

I would insist – or at least try to insist – that no settlement for compensation took place until several years post accident, and I would also insist on being present at all meetings with solicitors. I would also insist that compensation was put into a Special Needs Trust – nobody told us that such a thing existed... (Mother A10)

Other respondents noted that the knowledge gained would have made them change their approach signifi-

cantly or that they could not have done anything differently, for example:

I think I'd have given all of his friends more info, many of them have drifted away. (Father A2)

Not to trust social services. (Uncle A2)

For one mother the sense of what to do differently was very dramatic:

Pray for him to die rather than pray for him to live and possibly to die myself too. (Mother U10)

The responses to this question were amongst the first to highlight that the lack of respondent knowledge of the condition affected their decision making and actions at a point in time closer to injury. At this juncture respondents were unaware of the paucity of provision of services and, perhaps more importantly, the lack of knowledge of the condition by services and professionals. It is at this stage that the unavailability of the relative's future involvement commences.

Q6: Please use the space below to provide more information regarding the changes and difficulties that you and your relative/friend face. What would you suggest professionals need to do to improve the services provided?

A number of respondents reflected further on the difficulties that they and person they provided care for faced, on the often poor experience of services (if any were provided), their ongoing and complex grief and their fears for the future. A further theme was involving family more in planning care and as equals, particularly in terms of providing accurate information, working together, with a positive attitude to both family and family involvement. Other themes relating services were having a single point of co-ordination, having specialist knowledgeable services that were 'joined up', and provision of continuity of care in to the community and with long-term follow-up as necessary. The benefits of specialist ABI workers were noted, as by this mother:

It took some 6 years for us to get a brain injury case manager. We went through various people being case manager including a district nurse, community matron, mental health case manager, domiciliary agency manager. None could fulfil the role. Only when brain injury case manager became involved did my son start to get a proper multi-disciplinary team approach. (Mother A6)

The need for generalist social and health care services to be better informed about ABI was also a very regularly repeating theme. Sometimes social care was seen as particularly failing, as in this example:

The professionals still need educating in the needs of brain injury, especially Social Services; they seem to have no understanding. (Mother A10)

Respondents described how far from their prior existence the injury caused them to travel and how unprepared and unsupported they were with this. The injury had a clear impact upon them and the services/information that they are offered (if any) were regularly experienced as wholly inadequate. Service failings were reported as causing people extensive difficulties and need for input whilst in the midst of grief and endeavouring to develop an understanding of their losses. Such experiences give the respondents a position of great knowledge upon which to base their views of suggestions for changes to service provision, a genuine insider account of unwelcome and hard learnt wisdom.

Discussion

The participants in the survey provide a rich and critical review of the services they have encountered as a consequence of the ABI. This is contextualised by their descriptions of how life has changed for them and their relative since the ABI occurred. A lack of knowledge of ABI, especially that of the invisible impact of the condition, was noted to be a significant issue, as found in previous research (George and Gilbert, 2018). Social work practice in particular is criticised by the survey respondents, and ABI is not noted to feature highly in research by the academic branch of the profession (Mantell et al., 2017). Criticisms of practice and the harm caused by a lack of knowledge of the impact of ABI upon functioning are longstanding and would seem to remain unaddressed (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014; Flynn, 2016; House of Lords, 2014; Morgan, 2017; Norman, 2016; Summerfield, 2011).

The quantitative data presents a picture in which the invisible nature of some of the impairments arising from an ABI result in significant difficulties in interactions with others, including with services and those providing them. In terms of services, social care associated ones of home care and social work were rated more poorly than other services, and were used by at least half of the respondents. Beyond emergency care services, dedicated ABI ones were rated highly. The data paint a picture of specialist services with detailed knowledge of ABI and all its possible implications being more rated than generalist ones with less thorough knowledge of the topic.

The main and regularly repeating themes in the open-ended questions were:

1. Relationships between the injured and non-injured parties change and although some aspects of this are experienced positively, alterations to roles and responsibilities are difficult and are often mediated via unending and complex grief.
2. Relatives reported poor levels of involvement in decisions regarding the provision of social and health care services, a failure to be given good, accurate information in a timely fashion and the need to 'fight' for services.
3. Service provision, particularly post hospital discharge, was regularly criticized for being either entirely absent, unaware of the impact of brain injury, failing to take account of actual functioning and/or structured in ways not concomitant with the needs

of the injured party nor the relative. Lack of knowledge of the impact of ABI by non-specialist staff and services was highlighted as a barrier to progress and an added burden for relatives to contend with. Social work was commented upon most negatively most often for a failure to understand ABI.

4. Valued services and professionals are noted to be humane, knowledgeable about ABI, aware of the impact ABI has on the non-injured relative and be able to act as a single 'one-stop' focal point for service provision.

A number of key implications for practice suggest themselves from the results of the survey. First, that the impact of non-visible impairments is most keenly felt by respondents and yet this is less likely to be understood and responded to by non-specialist services. Respondents reported encountering services that lack basic knowledge or fail to take account of the long-term and multifarious nature of brain injury leading to fragmentation of response and increased burden and pressure felt. As social care services seem to be organised more on a generalist basis in this area, they do not seem to be as highly rated by the respondents. Professional knowledge and work practices which recognise the impact of the injury on the family member and the injured party are valued but are regularly absent.

Family members also report isolation. A failure to understand the actual nature of the impact of ABI leads, inevitably, to a failure to adequately conceptualise the role of the family member and, therefore, how they may also be best supported. Family members are often left with little (timely) information and no clear point of single contact to support them. Specialist ABI services, such as brain injury case management and neuropsychology, have been found to be rated considerably more highly than non-specialist ones and are noted to work across the lifespan (Clark-Wilson and Holloway, 2015), suggesting that all services and staff working in ABI could better serve clients and their carers if they had specialist knowledge of the topic (Holloway et al., 2019).

Commissioners and providers of long-term care services need to be fully aware of the knowledge and practices required to work effectively with families affected by brain injury. To do so it is necessary to recognise how the nature of the 'caring' role for family members is complex, generally requires adjusting to changes to roles, is long-term, may involve the management of complex issues such as behaviour changes, and multifaceted issues, such as loss of executive functioning skills in the context of reduced insight. Developing better working relationships with carers/families would seem to be required.

As the nature of ABI crosses many domains, affects successful functioning and community integration and may be amenable to rehabilitative approaches, providers and commissioners of long-term care services require an increasingly integrated, interdisciplinary and pan-sector approach. Individuals affected by brain injury form large parts of the present recipients of social care services but frequently without the ABI being acknowledged as the potential driver behind the need for service use. People with an ABI are significantly over-represented in homeless and prison populations and are identified within

substance use and mental health services (Bombardier et al., 2010; Corrigan et al., 2012; Oddy et al., 2012; Williams et al., 2010). A failure to recognise the full impact of a brain injury may lead to inappropriate referrals or even a lack of referral to potentially beneficial support, such as structured rehabilitative approaches. This may limit future development of skills required for a more independent life. Similarly, a failure to recognise the benefit of neurorehabilitation, a failure to 'invest' in people with the condition condemns funders and service providers to continue to support individuals who may well cost less to provide services for in the future if they had been properly served earlier. There are economic arguments for the better design and provision of services for people living with brain injuries. Current cost estimates may be significantly under-reported, but cost-benefits to specialist provision have been identified (Beecham et al., 2009; Turner-Stokes, 2008; Worthington et al., 2006). The structure of health and social care services is, presently, reported by family members to fail to take account of the reality of brain injury, a reality which may necessitate greater use of a broad range of care services, some over the very long term.

Conclusion

Acquired brain injury is a significant factor for those affected directly and their families and carers. Often it results in long-term use of a range of social and health care services. Relatives of individuals affected by an ABI are well placed to describe not only the impact of the condition on them and the injured party but also to report upon service provision. Individuals with an ABI intersect and interact with many aspects of social and health care service provision but not always in a manner which is found useful or promotes rehabilitation and increasing autonomy.

From this survey of family members of people with ABI across the UK it is clear that invisible aspects of the condition are reported as having more significance than physical impairment, and yet are more likely to not be recognised or acknowledged by service providers that do not understand the issues. Lack of knowledge of ABI by non-specialist social and health care services is reported as considerable. Better overall service co-ordination is desired by family members. The results of the survey place a question mark over whether generalist services can provide support rated by family members. This question seems particularly pertinent to be asked of social care services which seem to have not developed knowledgeable support for people with ABI. Social work in the UK in particular is criticised as lacking knowledge of ABI and how it impacts upon functioning, an issue which may require addressing in pre- and post-qualifying education and ongoing professional development.

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Competing Interests

The authors have no competing interests to declare.

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