

2018

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Knight, E.

Knight, E. (2018) 'Effectiveness of the Hospital Liaison Officer service on acquired brain injury patients, their families and healthcare professionals: A thematic analysis', *The Plymouth Student Scientist*, 11(1), p. 199-222.

<http://hdl.handle.net/10026.1/14178>

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The Plymouth Student Scientist  
University of Plymouth

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# **Effectiveness of the Hospital Liaison Officer service on acquired brain injury patients, their families and healthcare professionals: A thematic analysis**

Ellie Knight

*Project Advisor: [Dr Alyson Norman](#), School of Psychology (Faculty of Health & Human Sciences), Plymouth University, Drake Circus, Plymouth, PL4 8AA*

## **Abstract**

Whilst there has been an acknowledgement of service inconsistency during a patient's transition from hospital to home, very few attempts to 'bridge the gap' have been made. One of the ways to improve continuity of care and support for the acquired brain injury (ABI) population has involved the development of the Hospital Liaison Officer (HLO) role. Thus, the aim of this study was to explore the effectiveness of the HLO service on ABI patients, their families and healthcare professionals. Qualitative data was collected using questionnaire feedback forms and thematically analysed. Results revealed four main themes from the client dataset; Provision of support, Insight into brain injury awareness, Top-up support, and Negative aspects of the HLO service. Whilst three main themes emerged from the clinical dataset; Provision of support, Insight into brain injury awareness, and Smooth hospital to home transition. Overlapping themes from both datasets were merged together. All themes and sub-themes were discussed in relation to the current literature. Quantitative data of 161 ABI patients, referred to the HLO service over the course of a year, was also collated to be used as descriptive statistics. Whilst the consensus about the HLO roles was positive amongst both datasets, challenges faced by the clients were also explored to highlight areas of potential service improvement.

## **Introduction**

Acquired brain injury (ABI) is any sudden onset causing damage to the structure or function of the brain. This definition can be used as an umbrella term to characterise many different causes of brain injury (BI), including traumatic brain injury (TBI), stroke and haemorrhage. The most recent statistics by Headway (2014a) reported that a total of 348,934 people were admitted to hospital after suffering from an ABI. Further to this, Headway stated that men are 1.6 times more likely than women to be admitted with a BI, but female admission has risen 24% in the last 11 years. Unfortunately, this increasing number of ABI patients has been linked to a higher incidence of disability one-year post-injury. This in turn, goes far beyond the capacity that UK rehabilitation services can provide (Thornhill et al, 2000). This paper highlights some of the problems that ABI patients and their families experience post-injury. Many suffer from psychological difficulties and find it challenging to locate extra support due to a lack of services in the community.

## **Psychological difficulties**

Suffering from poor psychological wellbeing following on from an ABI is not uncommon. For example, researchers (Deb, Lyons, Koutzoukis, Ali & McCarthy, 1999) examined the psychological status of 164 patients one-year post-injury and found that rates of depression (13.9%) were significantly high. Akin to depression, anxiety after ABI was also reviewed (Osborn, Mathias & Fairweather-Schmidt, 2016) in 41 cases. Results found that the prevalence of Generalised Anxiety Disorder (GAD) (11%) and clinical levels of anxiety (37%) were high – peaking two to five years' post-injury; both studies suggest statistically significant levels of depression and anxiety compared to the general population. Researchers (Osborn, Mathias, Fairweather-Schmidt & Anstey, 2017) have observed a 10% comorbidity of anxiety and depression in TBI's, which suggests patients are at a higher risk of suffering from psychological difficulties. Therefore, screening and interventions for ongoing psychological support in the community could prove beneficial.

Current literature (Keenan & Joseph, 2010) has also revealed that family members and carers can suffer psychologically, in the aftermath of an ABI; thus, increasing their risk for mood and anxiety disorders. Researchers (Liu, Zhu, Liu & Guo, 2015) proposed that high psychological pressures on families, if not relieved, led to poorer interpersonal relationships between patients and healthcare professionals, resulting in conflicts over treatment. This could have a detrimental effect on the rehabilitation received by the patient long-term and becomes a bi-directional issue as it would inevitably impact the psychological wellbeing of the family. A combination of increased anxiety and depression levels, and an unhealthy family relationship was found to be a predictor for behavioural changes in ABI individuals, 2 to 5 years' post-injury (Ponsford & Schönberger, 2010). It is important to be mindful of the patient and family psychological states throughout recovery, so strategies to improve wellbeing may be implemented if required.

## **Support services**

The British Psychological Society (1989) proposed to improve service provision for ABI patients and their families across the UK; yet this domain is still sparse. They established that a lack of service support was due to (i) an absence of links within community services, (ii) patients falling through service gaps because they don't meet the admission criteria and (iii) a lack of specialist knowledge and skills amongst

professionals. Much of the literature has compared patient outcomes of those who have and have not received community-based support upon hospital discharge. Researchers (Hartman-Maeir et al, 2007) found that participating in community rehabilitation programmes significantly improved leisure activities and life satisfaction compared to controls however functional ability stayed constant in both groups. Controversial results (Huebner, Johnson, Bennett & Schneck, 2003) found significantly higher functional independence in rehabilitation patients which lowered levels of long-term disability and increased life satisfaction. However, 21 months later during the follow-up, patients rated the support they received for employment and opportunities to learn as 'dissatisfied'. This suggests that community rehabilitation programmes have mixed reviews on improving disability levels, yet consistent reports have demonstrated improvements in activity and overall satisfaction compared to those not receiving community support. In a review (Huebner et al, 2003) of ABI patients who had access to rehabilitation centres, only 24% received support services and this decreased as the number of years' post-discharge from hospital increased. A further report (McMillian, Teasdale & Stewart, 2012) found that only 3.2% of patients were still in contact with a specialist BI service, including counselling and support groups, 12-14 years later. This implies community services are beneficial to patient outcomes, but the prevalence of being admitted or receiving help from community services is low.

Qualitative analysis has enabled the ABI population to address problems they have had in current services to implement future developments. Researchers (Lefebvre, Pelchat, Swaine, Gelinat & Levert, 2005) investigated the experiences of ABI patients during the transition from hospital to home. They found that most participants were satisfied with the availability of services in hospital but this decreased when they returned home. This research highlighted several ongoing problems with support services post-discharge. Firstly, without family participation during the transition period, support provided to the patient is limited. Secondly, exhausted therapy teams provide patients with a reduced quality of care, inevitably decreasing the experience of rehabilitation received. Finally, not having structured services in place makes the transition from hospital to home, fragmented and inconsistent.

Case studies (for example, Norman, 2016) have emphasised the importance of having a support network to close the gap between hospital and home transition. Without services such as social workers supporting patients and their families in the community, adverse effects to their course of treatment may occur. Unfortunately, the idea of personalising the service to fit the needs of the patient and their family is currently limited (Holloway & Fyson, 2016). All ABI patients found they received limited input from social workers which hindered their (i) future involvement with support services, (ii) reception of a mental capacity assessment and (iii) accessibility to ABI information. This list of problems associated with poor care from adult social care is not exhaustive. It stresses that social workers need to be assigned to patients and their families as a support system early on and further training to improve awareness in these non-specialist ABI workers is vital.

### **Signposting**

With a lack of available support services also comes a lack of signposting for support following ABI. A survey (Brain Injury Group, 2012) examined the experiences BI

patients and their carers faced after hospital discharge, with 83% of respondents stating it 'very difficult' or 'quite difficult' to find specific BI information. However, 95% of people suggested that online signposting, as a resource for finding support services for those living with ABI would be a good idea. When family members were specifically asked about the quality of support service provided to them following on from a BI, they reported that healthcare professionals did not provide sufficient signposting information; so many were unsure about the future (Degeneffe & Bursnall, 2014). This type of research has implied that patients and their families have struggled to find information themselves and not all are being signposted by the hospital or other services they are in contact with. In turn this leads to a lack of understanding of ABI for both the patient and their family.

Signposting becomes particularly useful when an ABI survivor decides they are ready to return to work. Employment, following on from a BI, has been reported as a source for improving personal fulfilment, social recognition and life satisfaction (O'Neill et al, 1998). However, literature (Gilworth, Eyres, Carey, Bhakta & Tennant, 2008) found that when BI individuals returned to work, many felt their support systems were poorly coordinated and managed, such that they weren't provided with advice and guidance beforehand. This suggests that a large proportion of patients and their families are not receiving the signposting and information they need to increase their awareness about ABI where to search for top-up support services during big changes in their lives.

### **Early Supported Discharge (ESD) service**

Whilst limited support has been provided to the general ABI population, an intervention specifically for stroke patients has been implemented. The ESD service has been developed to speed up discharge times, providing specific rehabilitation at home by a co-ordinated team of multi-disciplinary therapists, similar to the intensity provided at an acute stroke or BI unit. Since the establishment of the ESD service at the turn of the century, research has been conducted into the effectiveness of the service for patients and their families. A meta-analysis (Langhorne et al, 2005) compared patient outcomes after receiving ESD services with standard stroke care and found a lower risk of death and dependency in the former. Many of the ESD service patients also reported being satisfied with support they received and scored significantly better on Activities of Daily Living (ADL) scales. ESD services have found to be more cost effective compared to the standard way of care (Teng et al, 2003), regardless of the patients' functional abilities.

Due to early discharge home, it is important to be aware of families and carers (Evans & Northwood, 1983) who are highly involved in the patient's rehabilitation compared to standard stroke care. Controversial evidence (Mayo et al, 2000) found that carers reported heightened stress and poorer mental health when in contact with the ESD service compared to acute care, even when patients scored significantly higher on physical health. Other researchers (Bautz-Holter, Sveen, Rygh, Rodgers & Wyller, 2002) found no difference in the psychological wellbeing of carers involved with the ESD or standard rehabilitation services. Further evidence has even suggested that ESD services reduce the prevalence of psychological problems such as depression (Berg, Palomäki, Lönngvist, Lehtihalmes & Kaste, 2005) and anxiety (Smith et al, 2004) during the transition from hospital to home. These studies suggest that further research is required into the effectiveness of such support

services and their impact on family and carer psychological wellbeing. As the impact is currently unknown, interventional support groups focusing on improving wellbeing should be implemented.

Qualitative research (Cobley, Fisher, Chouliara, Kerr & Walker, 2013) thematically analysing patient and carer experiences of the ESD service found an overall positive response. Whilst therapy received at home, support and response during the transitional period and intensity of rehabilitation were all satisfactory, participants felt support dealing with carer strain and a lack of education and training in carers were poor. This highlights the importance of supporting both the patient and carer using standardised outcome measures. Recent research (Fisher et al, 2016) found that ESD service users rated higher on ADL scales, significantly higher levels of satisfaction with the service, and carers scored significantly better on mental health scales compared to standard care. It seems that stroke patients clearly benefit from the continuity of support provided by the ESD service but support provided to their families is disputed, so strategies for future evaluation may need to be considered.

### **Rationale**

Headway (2014b) released a report stating that in the statutory care sector, provided by the National Health Service (NHS), there were extremely limited specialist services and information which provide support to the ABI population. Thus, patients and their families struggle to find the services they require. Much of the literature provides recommendations for programmes and strategies to overcome this, however there is limited evidence of this being implemented. Whilst there is an ESD service employed specifically for stroke patients, there is nothing concrete for the wider ABI community. Due to the lack of financial support available from the NHS, Headway Somerset funded two Hospital Liaison Officer (HLO) posts during a one-year pilot study. Their primary role was to “bridge the gap” between services offering support, information, advice and signposting to those transitioning from hospital to home. The following research explores the effectiveness the HLO service has had on ABI patients, their families and healthcare professionals with whom they are in contact.

### **Ethical clearance**

Full ethical clearance from Plymouth University Research Ethics Committee (UREC) was granted on 28<sup>th</sup> September 2016. Headway Somerset granted the researcher, Ellie Knight, authority to access the data collected from the Hospital Liaison Officer (HLO) service for research analysis purposes (see Appendix A).

### **Methodology**

#### **Participants**

One-hundred and sixty-one adult patients (91 males, 50 females, 20 unknown) were referred to the HLO service from various hospitals and community services in the South West between January and December 2016. All patients suffered from a range of ABI's. Of the thirty-five patients discharged from the HLO service and telephoned for a follow-up, eleven volunteered to participate in the study as part of a service evaluation. Participants were recruited via Headway Somerset; this included five patients and six family members. In this study no participants were excluded.

Six healthcare professionals also volunteered to participate as part of a service evaluation for the HLO team. Participants included three ward sisters, one neuropsychologist, one occupational assistant and one associate specialist. No further demographic information was collected.

### **Materials**

The 'Headway Somerset Hospital Liaison Feedback form' was designed and used by Headway Somerset to measure the impact of support provided by the HLO service for ABI patients, their families and healthcare professionals. This questionnaire was devised to collect qualitative data. The questionnaire took two forms and was adapted specifically for (i) ABI patients and their families and (ii) healthcare professionals. ABI patients and their families received the client evaluation form (see Appendix B) consisting of six open-ended questions plus a comments section. Healthcare professionals received the clinical evaluation form (see Appendix C) consisting of seven open-ended questions plus a comments section. Reliability and validity of these questionnaires has not yet been established but the ESD service created a similar questionnaire which acted as a pilot for this study.

### **Data collection**

The design of this study was mixed-methods, incorporating both a questionnaire and a numerical audit. Over the course of twelve months the HLO service collated data from all the referrals they had received; this has been displayed as descriptive statistics in the 'Analysis' section below.

The questionnaire was conducted by an independent from Headway Somerset who approached ABI patients (currently in hospital) and their families, and healthcare professionals, separately. All participants were asked for verbal consent before agreeing to complete the 'Headway Somerset Hospital Liaison Feedback form'. Participants were informed that all answers were confidential and reassurance was given to patients and their families stating that their interaction with the HLO service would not be affected. Families of ABI patients who were in contact with the HLO service were asked to complete an initial form in hospital giving consent for a follow-up telephone call. Once the patient was discharged from the HLO service an independent from Headway Somerset phoned patients and their families to interview them. In this interview participants were asked to complete the client evaluation form which the independent scribed. The telephone interviews lasted approximately fifteen minutes. If participants did not answer their telephone after three separate times of calling, they were excluded from the sample.

Healthcare professionals who had worked alongside the HLO service were given the clinical evaluation form to complete in a hospital setting. This took approximately five minutes. All participants were given a verbal debrief, asked if they had any questions and then thanked for their cooperation.

### **Analytic procedure**

Analysis was conducted once all of the data was collected from Headway Somerset. The client and clinical evaluation forms were analysed separately and in order of which they were conducted. The evaluation forms were read through thoroughly enabling familiarisation with the participants' experience. Potential items of interest were noted in the left-hand margin of the questionnaire. This was repeated several

times until a complex understanding of each participant's experience of the HLO service was established. The subsequent stage of analysis involved assigning complete codes to each answer segment which was marked in the right-hand margin of the questionnaire. Complete coding of this data involved the identification of anything relevant to the effectiveness of the HLO service. Great care was taken to ensure that codes and potential themes were in line with participants' use of language. An active process of identifying similar and overlapping codes and patterns within the dataset helped to develop candidate themes. Several candidate themes emerged with central organising concepts capturing the most salient patterns within and across the client and clinical datasets. Thematic maps were created to review the client (see Appendix D) and clinical (see Appendix E) data showing the link between provisional themes and sub-themes. In the final stage, themes and their coexisting sub-themes were clearly defined. Whilst analysis was time-consuming, it ensured all participant experiences of the HLO service were correctly represented within the themes; these themes are discussed in the 'Analysis' section below.

### **Justification of method**

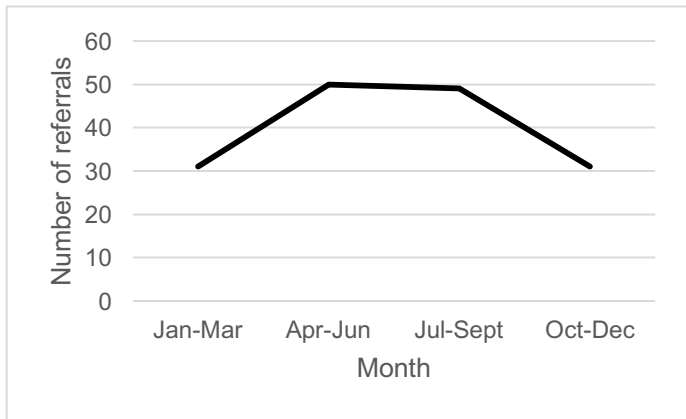
The aim of this study was to gain rich and detailed information from a range of individuals who experienced working with the HLO service. Thematic Analysis (TA), allows themes to be identified, analysed and reported from the data collected, which was accessible and theoretically flexible (Braun & Clark, 2006). This process involved more than counting the number of phrases and words which attributed to a theme; it identified implicit and explicit ideas that came from the datasets (Guest, MacQueen & Namey, 2012). By coding the data, it ensured that developing themes in the dataset were highlighted as important and encoded before interpretation occurred (Boyatzis, 1998).

A service evaluation questionnaire was used in this study because it obtained a large sample from the ABI population and those involved with their care. However, it should be recognised that the depth of detail is weaker compared to an interview. Yet, the time and effort of conducting such a method would be inefficient to gain a range of opinions from those working in conjunction with the service. Therefore, a TA of a service evaluation questionnaire was considered the most useful method capturing the intricate details and meanings (Guest et al, 2012) of experiences recorded by ABI patients, their families and healthcare professionals.

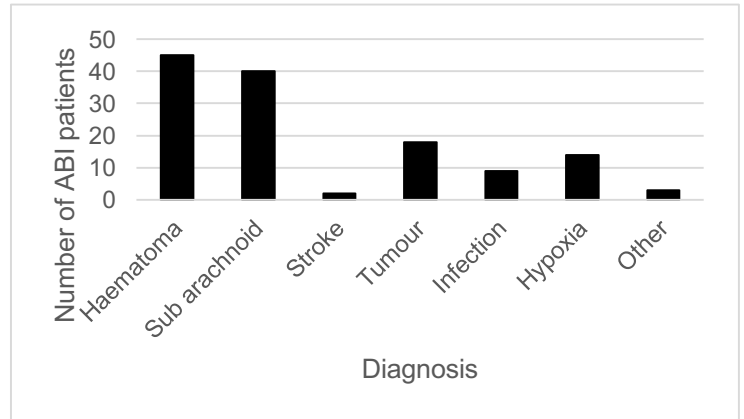
### **Analysis**

In the period between January and December 2016, one-hundred and sixty-one ABI patients were referred to the HLO service. Thirty-five patients and their families were telephoned to complete the interview and eleven (31.4%) responded. Descriptive statistics of the number, diagnosis and age/ gender of ABI patients referred to the HLO service are shown in Figure 1, Figure 2 and Table 1, respectively.





**Figure 1:** Line graph showing the quarterly number of ABI patients referred to the HLO service ( $n=161$ ).

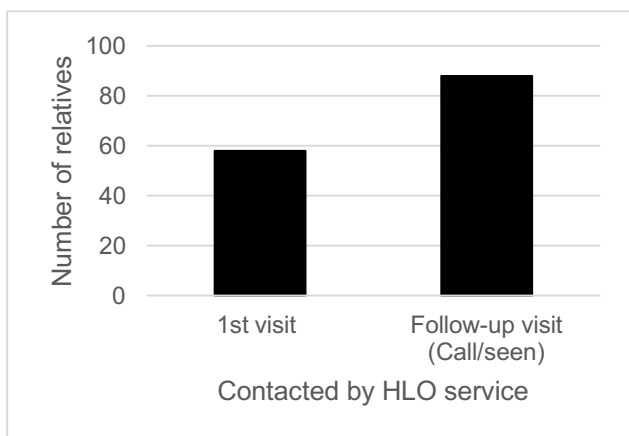


**Figure 2:** Bar graph showing the diagnosis of ABI patients referred to the HLO service ( $n=131$ , data unknown for 30 patients).

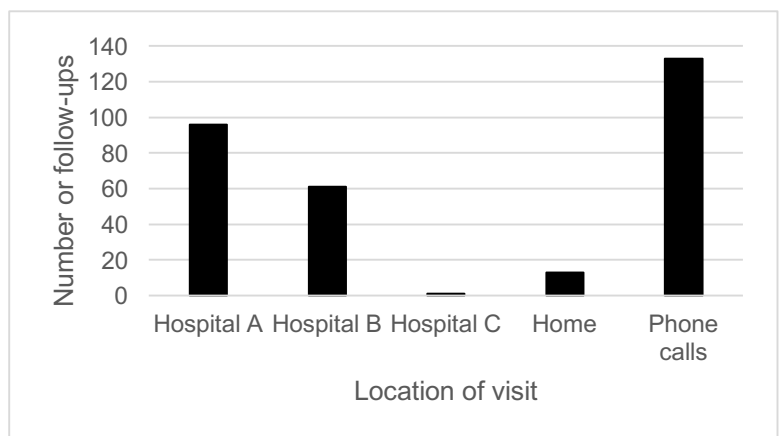
**Table 1:** Gender and age of ABI patients referred to the HLO service ( $n=141$ , data unknown for 20 patients).

Gender	Male	Female
<i>Age (years)</i>		
18-35	14	0
35-65	40	12
65+	37	38
<b>Total</b>	<b>91</b>	<b>50</b>

Descriptive statistics, presented via bar graphs, of the number of relatives contacted and the number of follow-up visits conducted, by the HLO service are shown in Figure 3 and Figure 4, respectively.

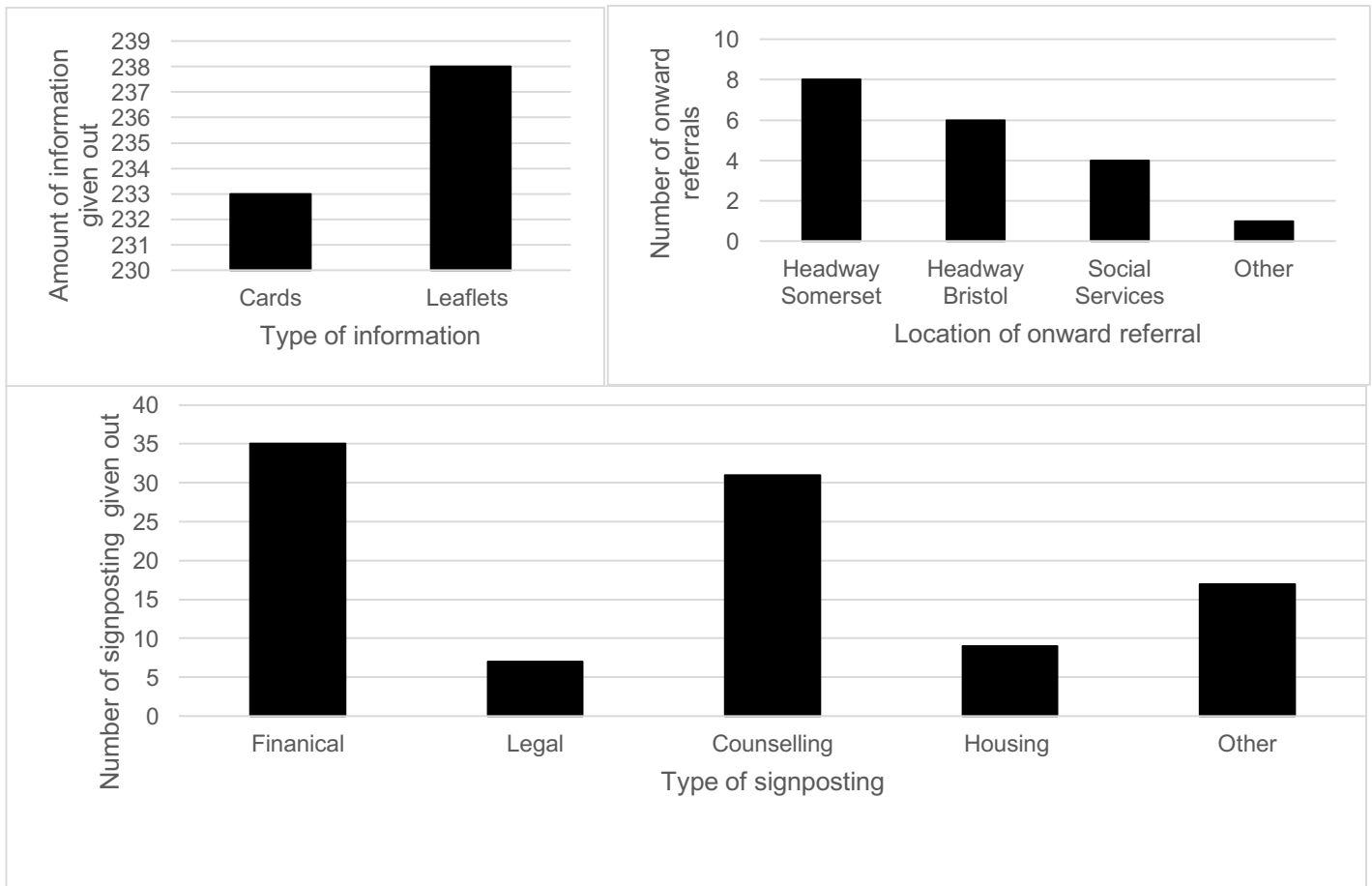


**Figure 3:** Bar graph showing the number of ABI relatives in contact with the HLO service.



**Figure 4:** Bar graph showing the number of follow-up visits conducted by the HLO service.

Descriptive statistics of the HLO service supporting ABI patients and their families with information, onward referrals and signposting, are shown in Figure 5.



**Figure 5:** Bar graph showing the different types of information, onward referrals and signposting conducted by the HLO service.

The purpose of this study was to explore the effectiveness of the HLO service on ABI patients, their families and healthcare professionals. It specifically focused on their involvement with the service in a hospital setting and upon discharge. Client questionnaire analysis revealed four main themes: Provision of support, Insight into BI awareness, Top-up support, and Negative aspects of the HLO service; across eleven transcripts (see Appendix D). Clinical questionnaire analysis identified three main themes over six transcripts; Provision of support, Insight into BI awareness and Smooth hospital to home transition (see Appendix E). Evidently there is overlap amongst themes and subthemes (see Appendix F), so for this reason some of the client and clinical analysis has been merged. Themes and subthemes have been discussed in relation to the current literature.

**Theme: Provision of support**

‘Provision of support’ was an overlapping theme (see Appendix F) identified by clients and clinicians, depicting the types of support the HLO service provide to ABI patients and their families. This was based upon the level of permanence and stability they received during their hospital stay and upon discharge home. Client 03 commented that ‘(HLO service) have been a continuous support for us’. This

extract exhibits that ABI patients require ongoing assistance throughout their recovery. Ensuring that support was provided to patients and their families upon discharge involves individualising the care and information they receive. Client 07 added '(HLO service) gave us all the guidance and support we needed', suggesting that the HLOs provide a specific support to accommodate a range of different patient/ family needs. Provision of support is concurrently low amongst community services, with only a handful of patients reportedly in contact with BI units 12-14 years' post-injury (McMillian et al, 2012). Yet, patients provided with service support score higher in life satisfaction and show less disability (Hueber et al, 2003). This reinforces the premise that receiving ongoing support during recovery can improve patient outcomes. Being in contact with the HLO service ensures that the long-term needs of ABI patients and their families are still being managed.

Clinicians suggested that patients considered the support they received from the HLO service as positive. One clinician highlighted the impact of the 'liaison' role as an alternative form of support, especially for communication purposes.

Clinician 02: 'the headway staff sometimes act as the 'go between' for the patients if they feel there is something they cannot talk to the unit staff about'

Whilst some patients found it difficult to converse with hospital staff on the ward, they used the HLO service as an alternative to find out information. Without clear and personal communication between the patient's surgical team and family, anxiety increases and satisfaction decreases. If family fears are not addressed by those who ultimately provide the correct information, the amount of support given to families becomes limited (Herd & Rieben, 2014). Therefore, providing 'liaison' enables support and communication improvements between hospital staff and families.

*Emotional/ psychological support* was a specific type of support, identified as an overlapping subtheme (see Appendix F), provided to patients and their families by the HLO service. A combination of 'emotional' and 'psychological' captures the varied vocabulary amongst patients/ families and healthcare professionals. It reflects the participant's medical background, whereby patients/ families without ABI knowledge tend to use the term 'emotional' and those with a mental health understanding tend to use 'psychological'. This subtheme uses these words interchangeably within the same context. Most of this emotional support was offered via hospital or home follow-up visits and calls. Client 09 stated 'we are still using Headway and will continue to [...] they check in with us especially if I have any worries'. This extract shows that continuity of emotional support is vital because new challenges emerge when the patient's environment changes. The hospital acts as a haven because care and support is provided continuously, therefore having someone to check in on them confronts and relieves worries. Receiving emotional support allows families to accept a change or loss in their loved one (Kirk, Fallon, Fraser, Robinson & Vassallo, 2015) and this reliance allows for a greater understanding into this 'new' person. Clinicians tended to focus on patient isolation and integrated psychological difficulties.

Clinician 06: 'this allayed the anxiety which they would inevitably have had if they had not had any contact with headway hospital liaison service'

This clinician suspected that without the emotional support provided by the HLO service, patient anxiety would have increased. Clinician 02 added, '(clients) have talked with the headway staff expressing anxieties which often relate to discharge'. The HLO service identified talking as a positive strategy (Amos, 2005) because it helped relieve anxieties related to change. This is something hospital staff found difficult to conduct due to time constraints. Allowing the HLO service to provide emotional support to patients and families can improve their psychological wellbeing.

*Support provided by others* was a conflicting client subtheme (see Appendix D) which captured both positive and negative views. Some patients were lucky enough to be in contact with other services, such as social workers and therapists, prior to hospital discharge. Rather than the HLOs, these other services would provide primary support to patients. Client 01 stated 'they listened to us and helped us make the decision but [...] I am in touch with social services mostly'. This extract suggests that even though the HLO service provides initial support to the patient, regardless of their interaction with other services, their support is usually displaced to make way for other services' support. This means the HLO service can focus on providing for those who are not currently in contact with anyone else. Social workers are finding it exceedingly difficult to assign ABI patients into their care because they are unlikely to fit into the social services provision in the UK (Higham, 2001). As ABI patients have a variety of needs, it becomes problematic because they do not often meet eligibility criteria. It is easy to understand why some patients and their families find a lack of other supporting services, therefore the HLO service is an important support network for those not detected by others.

Client 03: 'I went online and struggled to find the right information and the right people to contact [...] we were going through enough without having to research and find out who to contact for support'

Such comment provides an example of scarcity in community support because the client has not been acknowledged by other services. A lack of support has affected the clients' accessibility to ABI information and signposting towards other services. It implies that actively searching for BI support services is difficult and increases the amount of stress the client experiences. Most patients and their families are satisfied with the availability of services in hospital but this decreases when they return home (LeFebvre et al, 2005). Therefore, if patient resources are not available upon discharge, therapy teams work hard potentially exhausting themselves, to deliver it. This reduces the quality of care patients receive during rehabilitation and it can negatively affect their recovery outcomes if support is not offered by other services.

*Improvement in hospital provision*, a subtheme identified by clinicians (see Appendix E), as a beneficial result of working alongside the HLO service. Supporting hospital staff, by taking some of the weight off their workload, has relieved stress. Clinician 05 stated that 'having time to liaise with patients and families [...] gives therapy staff chance to improve the hospital stay and patients care'. This comment suggests that the HLO service supplied patients and their families with the time and knowledge hospital staff could not. By completing some of their supporting and caring duties, it freed up some time for hospital staff, improving the standard of medical practice and allowing them to concentrate on setting rehabilitation goals for patients. During a one-year review of patients' hospital experiences, only doctor

communication did not report significant improvements, yet nurse communication, responsiveness of hospital staff and discharge information all did (Elliott et al, 2010). As not all staff are able to provide effective communication with the patient, it is crucial to implement someone who can. Adding in a service, such as the HLO's, also allows an external view on the how the hospital staff treat patients and their families during acute care post-injury.

Clinician 02: 'having non-hospital staff involved with the patients helps us think outside the box when planning patients discharge [...] gives us feedback on patients that have been discharged from the unit'

This extract infers the importance of feedback in a clinical setting. Feedback is a process in which a desired standard of proficiency is compared with actual proficiency experienced by the individual. If given effectively, feedback is regarded as a vital component of improving training, knowledge and medical competence (Bagwandeem & Singaram, 2016). Therefore, the production of feedback from the HLO service is useful for hospital practitioner growth and support during patient recovery. It also relieves discharge planning because continuous check-ups are being provided to patients, whereas this would not usually occur.

### **Theme: Insight into brain injury awareness**

Another overlapping theme (see Appendix F) was the different levels of insight into BI awareness that patients/ families and healthcare professionals had. This relates to their BI knowledge over the course of their involvement with the HLO service.

Clinician 05 reported 'many people feel 'alone' with a lack of insight or understanding into what's wrong with them and why'. This extract highlights the absence of general ABI knowledge and the ongoing difficulties they experience in the wider community. This lack of awareness can lower mood because many feel a sense of isolation. Crucially up to 45% of ABI individuals demonstrate reduced awareness into their deficits caused by the injury, such as knowledge and emotional response (Flashman & McAllister, 2002). The aim of the HLO service is to provide BI knowledge to patients to improve general awareness. Families have also requested the need for more health information to help with their reaction to ABI's and the associated disabilities (Serio, Kreutzer & Witol, 1997).

Client 11: 'they gave a lot of information on brain injury and recovery and what my expectations should be about my wife's recovery and progress. They did an information presentation to our friends and family to help them understand so we could all help her recovery'

Client 11 was fortunate enough to be provided with information about BI's and their associated long-term implications. The HLO service also delivered more general information about BI's to the patient's closest family and friends to help improve post-discharge recovery outcomes. Whilst the ABI literature is sparse, other domains have shown benefits of training family and friends to improve patient outcomes. Diabetic (Rose & Harris, 2013) and eating disorder (Leichner, Hall & Calderon, 2005) populations have shown that educating family and friends about their condition supports the individual to make healthier, wiser choices about the future. This highlights the importance of training families to increase their ABI awareness because it allows them to understand and process recovery prospects. Healthcare

professionals have also benefited from the provision of the HLO knowledge. Clinician 05 stated that 'patients would be teaching me information from leaflets and print outs they had'. Even though hospital staff work with ABI's regularly it should not be assumed they have all the information and knowledge required (Oyesanya, Brown & Turkstra, 2016) or know about all the support services available in the community. Therefore, it is imperative that clinicians have primary knowledge about the care ABI patients should be receiving and this consequently should allow them to educate patients and families to improve insight.

*HLO service supplying signposting* was an overlapping subtheme (see Appendix F) encompassed within improving ABI awareness. Signposting examples include legal advice, financial support and welfare, support groups and helplines. In relation to the HLO service, clinician 03 stated they 'helped with signposting to other services'. Providing ABI patients with contact information for other services can help them obtain future support; those already in contact with other services received their primary source of signposting from them. For patients, not in contact with other services, the HLO's provided a signposting service. Client 10 stated 'they gave me as much information as I needed and leaflets to take away with me'. This client described receiving endlessly amounts of information from the HLO's. Finding a service which has all the information is difficult, but having such a support service in place causes less stress to patients and families. This has a beneficial effect, making them feel more relaxed and able to focus on their therapy.

Client 11 also described the HLO signposting service as positive, 'the fact sheets they gave us were really helpful [...] they also gave us good links to books'. Both clients were given information to take away with them. Being able to take hard copies of information home allows reference to the different types of signposting available. This makes it easier for patients to access because the information is directly provided and they do not need to actively search for it. Likewise, providing links to useful ABI books allows information to be studied at home. Repeated reference to these resources should help gain a greater understanding into ABI's and may open pathways to new support services. As a patients' needs change throughout recovery, the types of services they need signposting towards will also change (Khan, Baguley & Cameron, 2003). Thus, information will be easier to access if they already have signposting links available to them. Signposting for online information could be beneficial; families who reported using the internet several times a day had significantly better awareness about BI's (Bloodgood et al, 2013). However, with less than half of ABI patients using the internet, compared to 60% of the general population (Vaccaro, Hart, Whyte & Buchhofer, 2007), providing hardcopies of information may be more suitable.

*Low hospital satisfaction* was a negative, client-only subtheme (see Appendix D) associated with the hospital and its follow-up service. Regardless of the HLO's providing a relatively positive service, many seem disappointed by the hospitals' input. As the hospital and its staff provide little support post-discharge, some clients reported dissatisfaction. Client 08 stated 'I was very disappointed that they provide no follow up appointments'. This comment demonstrates that the client is not impressed by the absence of a required service. Unfortunately, a lack of hospital follow-up is not uncommon amongst ABI patients; with the most basic level of support and an insufficient follow-up provided. Literature (Tyson & Turner, 2000) has

shown that of the 51% of ABI patients referred for a follow-up, only 27% received an assessment and wellbeing support. Therefore, it is not uncommon for patients and their families to experience dissatisfaction with the lack of support they received from the hospital. Client 11 added 'they (HLO service) were very good in the main hospital especially when it was hard to find doctors and get information from them'. This extract shows that the patient values the HLO's because they provided a support service that the hospital cannot. It can be inferred that hospital staff have limited time to provide support and information to the patient. As hospital staff face strict time demands in the workplace, it was reported that the time spent with patients reduces by approximately 41% (Collins, Schoen & Sandman, 1997). Unfortunately, these time restrictions mean hospital staff cannot supply patients and their families with the standard of care they wish to receive; as a result of this they believe the hospital is providing a poor service. The HLO's have been implemented as a replacement to fill this follow-up gap.

### **Theme: Top-up support**

A client-specific theme (see Appendix D) described as 'top-up support' provided by the HLO service following on from a long-term community stay. It builds upon the support previously offered by the HLO service in hospital, especially when decisions or changes need to be made. An example of one of these changes is returning to work (RTW).

Client 10: 'I haven't had a need for them since leaving, but I am returning to work [...] I might call them if I have any problems [...] I've got all their details'

Although client 10 did not currently require HLO service support they may need them in the future when a change occurs. It can be inferred that the client has been given HLO contact information so they can use the service if or when they require support at home. Having a service on hand, becomes beneficial after discharge, because the stages of ABI recovery are variable (Novack & Bushnik, 2010). Integrating oneself back into the community can be difficult however with the right employment support more than half of ABI individuals retain their job after six months, compared to those not offered support (West, 1995). Essentially RTW after ABI requires prolonged support in the community to reach optimal functioning ability in the workplace (Rubenson, Svensson, Linddahl & Björklund, 2007). A client-centred service, over a long period, has been provided by the HLO's to help those RTW.

One of the biggest changes a patient will go through is returning home after a long stay in hospital or rehabilitation unit. Client 01 suggested the need for top-up support from the HLO service during the transition period, 'I am almost at the point of needing more guidance from them while I am trying to get (x) [patients name removed] back home again'. Such comment implies that the HLO service is a primary source of support for patients and their families when change occurs. Not only can it be inferred that patients and families believe the HLO service bridges the gap between hospital and home, but they also trust the service to guide their transition. The 'guidance' initially provided in hospital was enough to create an impact such that this family member actively sought it out again when support was needed. Supplying 'top-up' support to an ABI patient returning home, by a trained service, has shown significant improvements in cognition and daily functioning

(Pierini & Hoerold, 2014). This support service seems critical to enhance long-term patient outcomes in the working or health domain, post-discharge.

### **Theme: Negative aspects of the HLO service**

A main theme highlighted solely by clients (see Appendix D) addressed the negative implications patients and their families encountered with the HLO service. Although few problems have been associated with the service, some have suggested that support groups are inaccessible to them.

Client 01: 'the meeting was quite far away from me'

Client 06: 'carer groups were very good however it was too far away for us [...] they just aren't accessible to me.'

Such comments inform us that the support provided by the group is in fact positively viewed. Yet the accessibility of these groups is unsuitable because the travelling distance is too far from home; the problem of scarcity of support groups is ongoing. A Headway UK survey (2012) found that 60% of family members did not feel they receive adequate support in their caring duties, in the UK. ABI carers feel that despite the awareness that they need support, many still complain that services are not acting upon or understanding their need for support in the community (McPherson, McNaughton & Pentland, 2000). Unfortunately, scarcity in carer support services requires many to travel long distances to access them. Alternatively, patients and families have turned towards online support groups, which seemingly has shown a positive impact. Online social networking such as friending and sharing personal stories about health have been reported as helpful by patients and families as a way of providing emotional support (Chung, 2014).

Unsuitable time of intervention was highlighted by a client as another negative aspect of the HLO service. The aim of the service was to initially meet with the patient and their family in hospital and provide continuity throughout their recovery. However, client 01 stated 'it would have been more beneficial to have been in touch with them sooner, at the start of it all to get information'. This statement infers that the earlier the HLO intervention is, the more information patients and their families can extract and utilise in the future. Unfortunately, this client slipped through the service gaps and did not receive all the information they required. This emphasises the importance of hospital staff and the HLO service communicating and working closely together to prevent this from happening again. Information sharing can improve knowledge on the patient and about their needs across services (Cann, 2005; Pringle, Finucane & Oxenham, 2014). For the family, understanding changes in a BI individual can be important for long-term outcomes; when provided with an information booklet outlining symptoms and strategies one-week post-injury, patients and families reported lower anxiety levels and incidence of ongoing problems at three months' (Ponsford et al, 2001). Therefore, an earlier intervention of provision of BI information can relieve long-term physical and psychological effects. Critical feedback of the HLO service is important because it can be used to help make improvements for future service developments.

### **Theme: Smooth hospital to home transition**

A main clinical theme (see Appendix E) described as one of the positive outcomes of implementing the HLO service on ABI patients. It uses the idea of bridging the gap between hospital and home, to reduce the likelihood of patients falling between



services or feeling betrayed by the system. Frequent references have been made regarding the benefit continuity has on patients throughout the transition phase. Clinician 03 reported 'it helped prepare with coping and transition from hospital to home after spending a long time (in hospital)'. The clinician is referring to the usefulness of the service, especially as some patients spend a long time in hospital recovering before they are discharged. The average length of time following moderate TBI is, 15.8 days in hospital (Vitaz, Jenks, Raque & Shields, 2003) and 10 months in a rehabilitation programme (Ponsford, Olver & Curran, 1995). The presence of the HLO service allows for shorter discharge times, resulting in more beds becoming available on the wards and discharged patients carry on receiving support. Thus, it is not irrational to suggest that the transition home is unnerving.

Clinician 06: 'at the point of transitioning from hospital to discharge destination and then the community itself is not well structured and are quite fragmented [...] if the liaison service was to cease, this would have a negative impact as an important source of support and information would then not be available'

This clinician has commented on the poor structure of the discharge system in the absence of the HLO service and the harmful effects it could have on the patient and family. Without such a service, gaps form in the system and those transitioning from hospital to home are not provided with the support they require. Poor transitional care seems to reflect the general healthcare system being fragmented (Davis, Devoe, Kansagara, Nicolaidis & Englander, 2012) resulting in a limitation of clinician's ability to supply optimal care, support and information to the patient.

*Links to community services* provided by the HLO service, contributes to the patient's smooth transition home (see Appendix E). This structure was developed to connect hospital and community services together so that patients would not be lost in the system during transition. The HLO service delivers information about the community services they are in contact with to organise links before the patient is discharged from hospital.

Clinician 01: 'they are able to help us link into community based opportunities to enhance patient on-going rehab on discharge, they are always up to date with the latest projects'

This comment implies the HLO service were extremely informative about services in the community, that hospital staff were not aware of. Clinician 04 added 'it was great having on site people who can facilitate links to the community and time after discharge'. The HLO service working within the hospital seems to have an overall positive effect on clinicians; both describe the HLO service supporting hospital staff by supplying them with contacts for community services and someone to converse with when they are unsure. Similar studies (Jowett & Armitage, 1988) using liaison nurses have found that providing links to community services allows continuity of nursing care between hospital and home. Such links help build trust between liaison services and patients because it is another way of making the transition more manageable. In turn, these community links decrease patient stress levels during highly vulnerable situations (Wang, Zhao & Zang, 2014).

*Poor hospital follow-up service* was also encapsulated in this theme, justifying the need for a good transitioning service provided by the HLO's. It highlights the contemporary hospital failures in relation to the inadequate after-care provided to patients. Essentially patients and families find the HLO service useful to fill this void.

Clinician 02: 'when the patients leave us we provide no further support just an outpatients appointment, headway are still involved on discharge and this provides continuity and support'

The idea of the hospitals providing a poor follow-up service to its patients was also brought up by Client 08 and therefore overlaps with the sub-theme 'poor hospital satisfaction' (see Appendix F). Both consider that without the HLO service little follow-up support would be given and there is no guarantee the follow-up appointment would be with the clinician that primarily treated the patient. A combination of a change in clinician providing follow-up care, and a poor transfer of information between clinicians had resulted in significantly more negative patient outcomes such as readmission (van Walraven, Mamdani, Fang & Austin, 2004). It suggests that follow-up appointments with the clinician involved is critical for maintaining patient outcomes. Clinician 02 also suggested that the HLO support replaced hospital follow-up appointments because they provided 'continuity' that was not otherwise given. Neuro-services providing continuity has improved patient outcomes such as cognitive and emotional status over the course of the patient's recovery (Meyers & Pier, 2000). Clinician 03 reported 'patients would have very little or no follow up with experts that have time and knowledge to support these patients' if the HLO service was to discontinue in the future. This extract iterates Client 11's statement of clinicians having limited time to give to patients. It further suggests that even if the hospital does provide a follow-up service there is no promise of the appointment being with an ABI expert. An absence of foundational knowledge in long-term consequences and outcomes of BI hinders assessments and limits the effectiveness of this follow-up service (Holloway, 2014), once again emphasizing the positive impact of the HLO's follow-up service.

## **Conclusion**

The use of qualitative methodology permitted an in-depth exploration into ABI patients, their families' and healthcare professionals' experiences of the HLO service. The analytic comparison process identified similarities and differences between the client and clinical questionnaire datasets. Whilst benefits of the HLO service were highlighted by all participants, challenges experienced by clients were also identified. A comparison made by clinicians, towards the hypothetical ceasing of the service was constructed. Although, this did not provide information on the significance of observed differences, and hence any assumptions on whether the HLO's or current service provision was more effective.

Provision of support and signposting supplied by the HLO service was perceived positively amongst clients and clinicians, emphasizing the importance of providing service users with support and information upon their discharge. Whilst patients and families have reported using follow-up visits and calls to relieve anxiety, the need for current services to monitor their emotional and psychological wellbeing using standardised outcome measures should be implemented. This is because family

involvement during rehabilitation is crucial for patient recovery (Evans et al, 1983). Some patients and their families were grateful towards other services for offering support but it was not universally received and resulted in the HLO service becoming their primary source of support.

Clinicians perceived that the support and care contribution provided by the HLO service helped them to deliver a better quality of patient care and medical practice. Nevertheless, patients and their families reported their disappointment with the hospital. They focused on the low provision of support received from staff and little or no follow-up service after hospital discharge; the latter was also accentuated by clinicians. The idea of the HLO service 'bridging the gap' between services during the transitional phase was identified as efficient among clinicians. They found it imperative to implement continuity; achieving this by supplying hospital staff and patients/ families with links to community services. To ensure these links are developed in the community, GP's, social workers and nurses should be offered specific ABI training, by the HLO service to improve awareness. Different levels of insight into BI awareness was reported as a common theme amongst clients and clinicians. As many patients and family members had little ABI knowledge, the HLO service supplied them with information to acknowledge the effects and consequences of their injury. Therefore, future support and training for family members should be provided to increase understanding into daily functions and improve patient outcomes (Rose et al, 2013; Leichner et al, 2005). It was also established that some clinicians acquired new information from the HLO service about BI's and the availability of community support services.

Clients expressed satisfaction with the 'top-up' support they received within their home. It enabled them to cope with big changes in their lives, such as returning to work or moving home, in the community. In addition, patients and their families highlighted the challenges they faced when dealing with the HLO service. Further research should investigate how to make carer support groups more accessible to those who require them; this could involve setting-up an online support forum for those who cannot travel long distances (Chung, 2014). Another problem associated with the HLO service was the need for an earlier intervention of support. In the initial stages of the HLO service it was still possible for patients to slip through service gaps. Future provision, of an early and consistent interaction with the patient and their family should be considered after immediate referral.

An implication of this study was based upon participant reports and how they were open to biases related to self-evaluation. As with every voluntary study, the respondent's willingness to provide feedback tends to satisfy the HLO service; leading to exaggerated and inaccurate descriptions of their experiences. However, it can be seen in some responses that participants appeared appreciative of the HLO service but they also identified critical aspects which can be used to assist service improvements. All client interviews were conducted after the patient was discharged from the HLO service which could hinder accuracy of recall of their experiences. Yet, measures were taken to identify and deem those cognitively incapable of completing the client questionnaire. Two patients had such memory impairments and were not eligible to participate. Clinical questionnaires were conducted whilst the HLO service were still working alongside healthcare professionals; thus, timely and accurate recall of their experiences were noted.

Incorporating quantitative measures has been a useful way of summarizing information about the patients referred to the HLO service over the course of the year. This information can be used as feedback to understand the collective of ABI's referred to the service, to accommodate their needs. Knowing that the number of females being admitted into hospital with ABI's is increasing (Headway, 2014a) it allows the HLO service to plan their support around gender differences during recovery (Matud, Ibáñez, Bethencourt, Marrero & Carballera, 2003). It should also be noted that some of the ABI literature is sparse such as online support (Chung, 2014) and the effect of knowledge training in families (Rose et al, 2013; Leichner et al, 2005). For this reason, non-ABI patient research has been used as it does not affect the transferability of the research to the wider ABI population and should be considered important in future health psychology research.

Whilst this study is not cross-sectional, only the effectiveness of the HLO service on participants over a one-year period was captured. Member checking is a form of credibility check (Lincoln & Guba, 1985) referring to the practice of checking analysis with participants to avoid misrepresentation of their views of the service. As with all new stems of research, member checking and measuring the sustainability of the HLO service over a long-term intervention should ensure that quality research has been conducted.

This study involved a telephone survey to clients. This was the most efficient way of contacting those discharged from the HLO service but response rates were low (31.4%). This can be attributed to a nonresponse error because after three times of calling, clients were not contacted any further, making them unavailable to complete the questionnaire. A way to increase response rates would be to mail out an explanatory letter about the study describing its importance for future service users, prior to phone calls being conducted (Smith, Chewy, Jalaludin, Salkeld & Capon, 1995).

The idea of using multiple qualitative data sources from a range of viewpoints enhances the holistic understanding of experiences (Braun et al, 2006). This study has provided a unique insight into patient, family and healthcare professionals' experiences of the HLO service and highlighted areas for future developments. Without their support during (i) the transitional period, (ii) training to improve ABI awareness and (iii) the provision of tailored information, patients and their families may fall victim to the lack of continuity between hospital and community services.

### **Acknowledgments**

I would like to gratefully acknowledge my supervisor Dr Alyson Norman for her continuous support, devotion and wealth of knowledge into this vitally important topic. I would also like to express my sincere gratitude to Headway Somerset for allowing me access to their data and for taking the time to answer my questions. I would formally like to thank all of the participants for giving their time and effort responding to the Feedback forms - your answers are extremely valuable in helping to improve the HLO service. Finally, I would like to thank my family and friends for their unlimited support and encouragement throughout this academic year.

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