2017-07-15

A qualitative assessment of the effectiveness of the Hospital Liaison Officer Service: Final Report to Headway Somerset

Knight, E

A qualitative assessment of the effectiveness of the Hospital Liaison Officer Service: Final Report to Headway Somerset

Authors: Ellie Knight[1], Wendy Copeman[2], Alison Parrott[2], Freya Suffield[1], Hilary Dicks[2] & Alyson Norman[1]

1: University of Plymouth, School of Psychology
2: Headway Somerset

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 is 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 were 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, not merely the cause of genetics or disorders associated with birth trauma (Headway, 2014a). Suffering from poor psychological wellbeing following on from an ABI is not uncommon. For example, researchers (Deb et al, 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 et al, 2016) in 41 cases. 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 et al, 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.

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. A further report (McMillian et al, 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 et al, 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.

Evidence (Norman, 2016) has 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 personalizing 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 a lack of social worker 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 on from an 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 BI's would be a good idea.

Early Supported Discharge (ESD) service

The ESD service has been developed to speed up discharge times for stroke patients, 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, an increase in literature has been conducted into the effectiveness of the service on patients and their families. A meta-analysis (Langhorne et al, 2005) compared patient outcomes after receiving ESD services with standard stoke 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.

Qualitative research (Cobley et al, 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 highlighted 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. The following research explores the effectiveness on a

Hospital Liaison Officer (HLO) post piloted by Headway Somerset to provide wider support for patients with ABI and their families during inpatient rehabilitation and signposting to service post-discharge.

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.

Methods

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 A) consisting of six open-ended questions plus a comments section. Healthcare professionals received the clinical evaluation form (see Appendix B) 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 qualitative questionnaire and a numerical audit. Over the course of twelve months the HLO service collated data from all the referrals received. Patients and families were given questionnaires during their hospital stay and were then contacted following discharge to go through the questionnaire with an independent scribe. The telephone interviews lasted approximately fifteen minutes. 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.

Analytic procedure

The client and clinical evaluation forms were analysed separately. 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 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 et al, 2012). By coding the data, it ensured that developing themes in the dataset were highlighted as important and encoded before interpretation occurred (Boyatzis, 1998).

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.
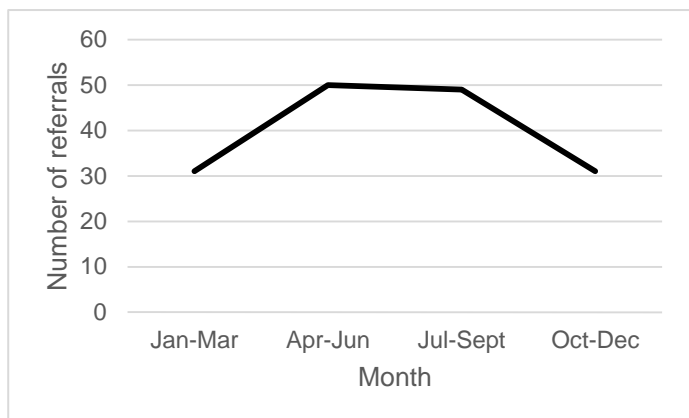
Figure 1: Line graph showing the quarterly number of ABI patients referred to the HLO service (n=161).
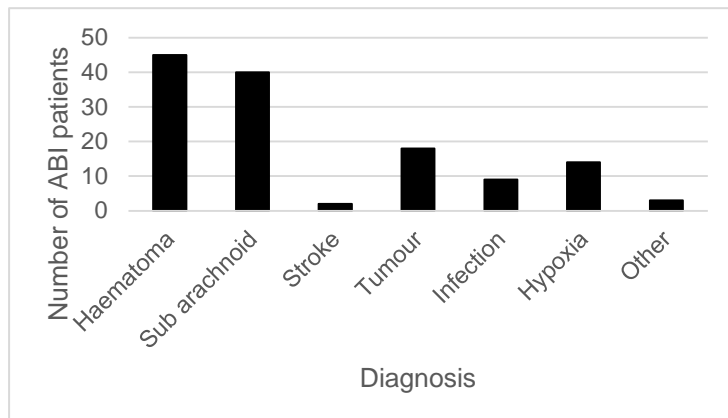
Figure 2: Bar graph showing the diagnosis of ABI patients referred to the HLO service (n=131, data unknown for 30 patients).

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

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

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.
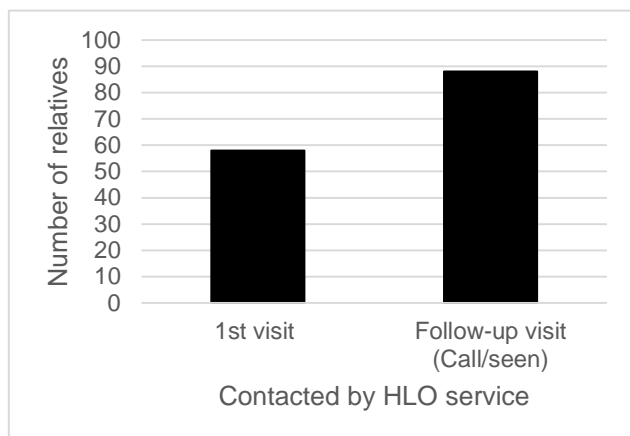
Figure 3: Bar graph showing the number of ABI relatives in contact with the HLO service.
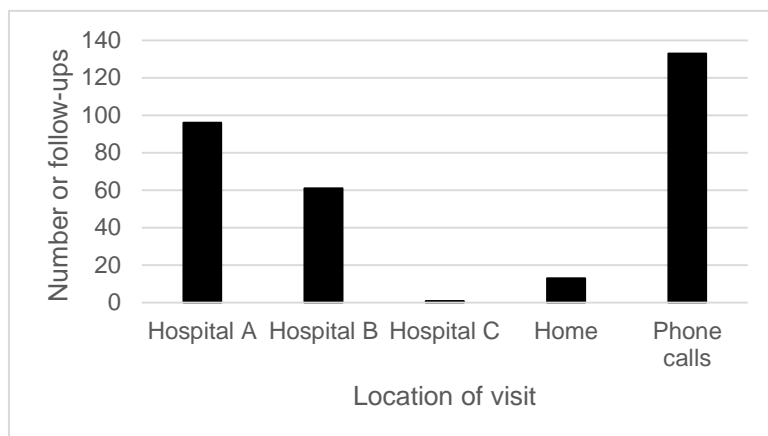
Figure 4: Bar graph showing the number of follow-up visits conducted by the HLO service.

Descriptive statistics of the HLO service supporting ABI patients and their families with information, onward referrals and signposting, are shown in Figure 5.
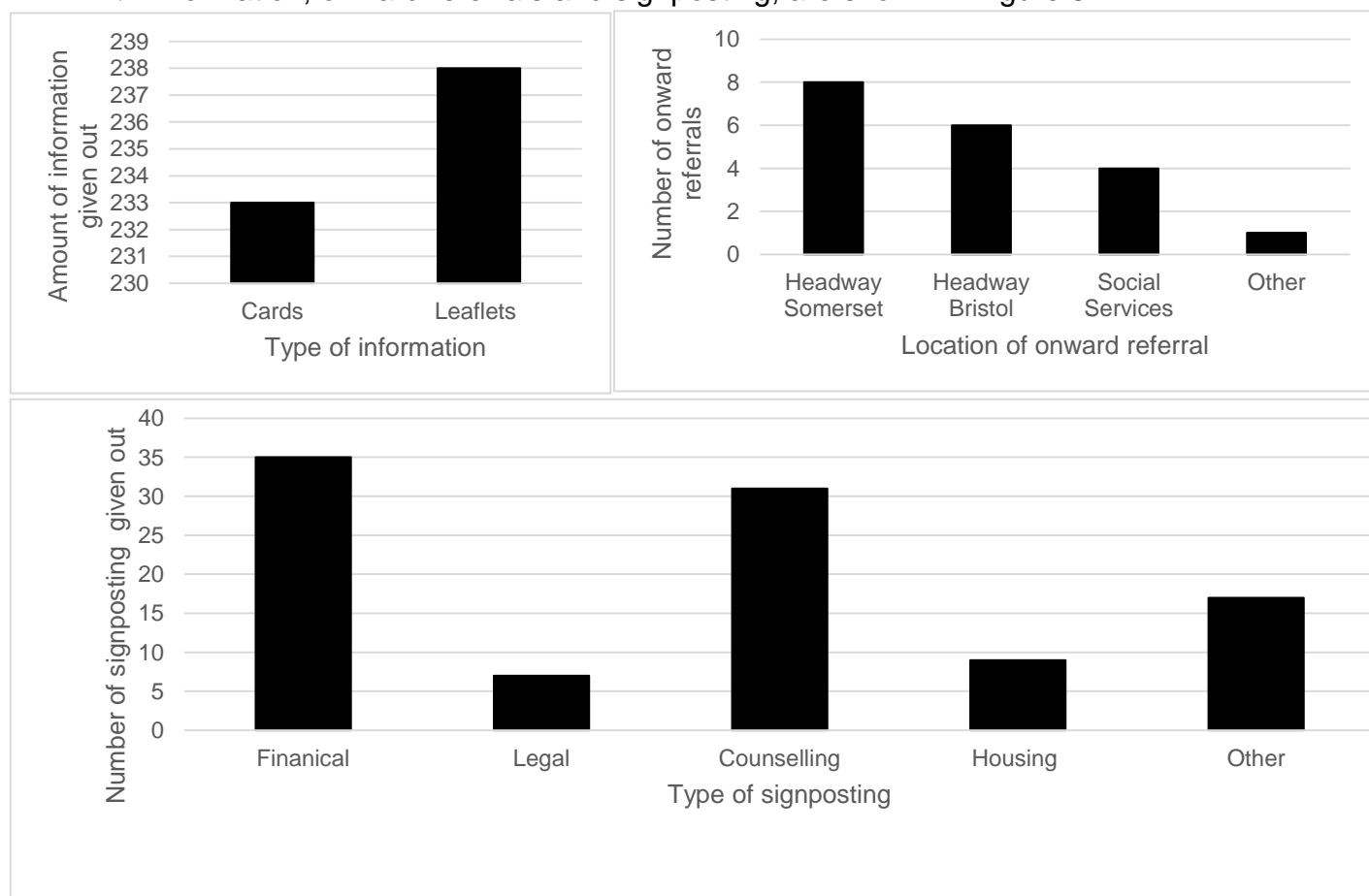
Figure 5: Bar graph showing the different types of information, onward referrals and signposting conducted by the HLO service.

The purpose of this study was to explore the effectiveness of the HLO service on ABI patients, their families and healthcare professionals. It specifically focuses 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 C). 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 D). Evidently there was overlap amongst themes and subthemes (see Appendix E), so for this reason some of the client and clinical analysis have been merged. Themes and subthemes have been discussed in relation to the current literature.

Provision of support

'Provision of support' was an overlapping theme identified by clients and clinicians, depicting the types of support the HLO service provided 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 is 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 HLO's 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 (Huebner 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, 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 participants' 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 et al, 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 find 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 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 may be displaced to make way for other support services. This means the HLO service can focus on providing for those whose needs are not currently being met by others services. 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 there is a decrease 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), was 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 frees 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 were able to provide effective communication with the patient, it is crucial to ensure someone is available who can. Adding in a service, such as the HLO's, also allows an external view on 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 (Bagwandeen & 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.

Insight into brain injury awareness

Another overlapping theme 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 et al, 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 et al, 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 et al, 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 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 describes receiving endless 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 et al, 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 et al, 2007), providing hardcopies of information may be more suitable.

Low hospital satisfaction was a negative, client-only subtheme associated with the hospitals and their follow-up service. Regardless of the HLOs providing a relatively positive service, many seem disappointed by the hospitals' input. As the hospitals 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 provide 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 stricter time demands in the workplace, inevitably will reduce (Collins et al, 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 hospitals are providing a poor service.

Top-up support

A client-specific theme provided by the HLO service building upon the support previously offered 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 does 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 et al, 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.

Negative aspects of the HLO service

A main theme highlighted solely by clients addressed the negative aspects 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 do 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 needs in the community (McPherson et al, 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 have 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 is 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 et al, 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.

Smooth hospital to home transition

A main clinical theme 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. 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 et al, 2003) and 10 months in a rehabilitation programme (Ponsford et al, 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.

> 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 et al, 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. 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 was 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 et al, 2014).

Poor hospital follow-up service is 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 hospital 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'. 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 has resulted in significantly more negative patient outcomes such as readmission (van Walraven et al, 2004). It suggested that follow-up appointments with the clinician involved were 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.

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. 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 to improve awareness. It was also established that some clinicians acquired new information from the HLO service about BI 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.

References

Amos, R. (2005). Finding time to talk to a patient can help reduce their anxiety. *Nursing Standard*, *20*(6), 29.

Bagwandeen, C. I., & Singaram, V. S. (2016). Feedback as a means to improve clinical competencies: Registrars' perceptions of the quality of feedback provided by consultants in an academic hospital setting. *African Journal of Health Professions Education*, *8*(1), 117-120.

Bloodgood, B., Inokuchi, D., Shawver, W., Olson, K., Hoffman, R., Cohen, E., Sarmiento, K., & Muthuswamy, K. (2013). Exploration of awareness, knowledge, and perceptions of traumatic brain injury among American youth athletes and their parents. *Journal of Adolescent Health*, *53*(1), 34-39.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.

Brain Injury Group. (2012, December 7). *Brain injured community calls for clearer signposting to support*. Retrieved from http://www.braininjurygroup.co.uk/brain-injury-group-news/brain-injured-community-calls-clearer-signposting-support/.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

British Psychological Society (1989). *Services for adults with acquired brain injury.* Leicester: BPS.

Cann, D. (2005). Sharing information about a patient's past can be useful. *Nursing Standard*, *20*(1), 29.

Chung, J. E. (2014). Social networking in online support groups for health: How online social networking benefits patients. *Journal of Health Communication*, *19*(6), 639-659.

Cobley, C. S., Fisher, R. J., Chouliara, N., Kerr, M., & Walker, M. F. (2013). A qualitative study exploring patients' and carers' experiences of Early Supported Discharge services after stroke. *Clinical Rehabilitation*, *27*(8), 750-757.

Collins, K. S., Schoen, C., & Sandman, D. R. (1997, March 1). *The commonwealth fund survey of physician experiences with managed care*. Retrieved from http://www.commonwealthfund.org/publications/fund-reports/1997/mar/the-commonwealth-fund-survey-of-physician-experiences-with-managed-care.

Davis, M. M., Devoe, M., Kansagara, D., Nicolaidis, C., & Englander, H. (2012). "Did I do as best as the system would let me?" Healthcare professional views on hospital to home care transition. *Journal of General Internal Medicine*, *27*(12), 1649-1656.

Deb, S., Lyons, I., Koutzoukis, C., Ali, I., & McCarthy, G. (1999). Rate of psychiatric illness one year after traumatic brain injury. *The American Journal of Psychiatry*, *156*(3), 374-378.

Elliott, M. N., Lehrman, W. G., Goldstein, E. H., Giordano, L. A., Beckett, M. K., Cohea, C. W., & Clearly, P. D. (2010). Hospital survey shows improvements in patient experience. *Health Affairs*, *29*(11), 2061-2067.

Fisher, R. J., Cobley, C. S., Potgieter, I., Moody, A., Nouri, F., Gaynor, C., Byrne, A., & Walker, M. F. (2016). Is Stroke Early Supported Discharge still effective in

practice? A prospective comparative study. *Clinical Rehabilitation*, *30*(3), 268-276.

Flashman, L. A., & McAllister, T. W. (2002). Lack of awareness and its impact in traumatic brain injury. *NeuroRehabilitation*, *17*(4), 285-296.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. Thousand Oaks, CA: Sage.

Hartman-Maeir, A., Eliad, Y., Kizoni, R., Nahaloni, I., Kelberman, H., & Katz, N. (2007). Evaluation of a long-term community based rehabilitation program for adult stroke survivors. *NeuroRehabilitation*, *22*(4), 295-301.

Headway. (2012). *Supporting carers*. Retrieved from https://www.headway.org.uk/about-brain-injury/professionals/gps/supporting-carers/.

Headway. (2014a). *Brain injury statistics 2015 infographic*, available online at https://www.headway.org.uk/media/2882/brain-injury-statistics-2015-infographic.pdf.

Headway. (2014b). *A ticking time bomb: The false economy of cuts to brain injury support services*, available online at https://www.headway.org.uk/media/3244/a-ticking-time-bomb-the-false-economy-of-cuts-to-neurological-services.pdf.

Herd, H. A., & Rieben, M. A. (2014). Establishing the surgical nurse liaison role to improve patient and family member communication. *Association of perioperative Registered Nurses Journal*, *99*(5), 594-599.

Higham, P. (2001). Developing an interactive approach in social work research: The example of a research study on head injury. *British Journal of Social Work*, *31*(2), 197-212.

Holloway, M. (2014). How is ABI assessed and responded to in non-specialist settings? Is specialist education required for all social care professionals? *Social Care and Neurodisability*, *5*(4), 201-213.

Holloway, M., & Fyson, R. (2016). Acquired brain injury, social work and the challenges of personalisation, *British Journal of Social Work*, *46*(5), 1301-1317.

Huebner, R. A., Johnson, K., Bennett, C. M., & Schneck, C. (2003). Community participation and quality of life outcomes after adult traumatic brain injury. *The American Journal of Occupational Therapy, 57*(2), 177-185.

Jowett, S., & Armitage, S. (1988). Hospital and community liaison links in nursing: The role of the liaison nurse. *Journal of Advanced Nursing*, *13*(5), 579-587.

Keenan, A., & Joseph, L. (2010). The needs of family members of severe traumatic brain injured patients during critical and acute care: a qualitative study. *Canadian Journal of Neuroscience Nursing, 32*(3), 25-35.

Khan, F., Baguley, I. J., & Cameron, I. D. (2003). Rehabilitation after traumatic brain injury. *The Medical Journal of Australia*, *178*(6), 290-295.

Kirk, S., Fallon, D., Fraser, C., Robinson, G., & Vassallo, G. (2015). Supporting parents following childhood traumatic brain injury: A qualitative study to examine information and emotional support needs across key care transitions. *Child: Care, Health and Development*, *41*(2), 303-313.

Langhorne, P., Taylor, G., Murray, G., Dennis, M., Anderson, C., Bautz-Holter, E., Dey, P., Indredavik, B., Mayo, N., Power, M., Rodgers, H., Ronning, O. M., Rudd, A., Suwanwela, N., Widen-Holmqvist, L., & Wolfe, C. (2005). Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. *Lancet*, *365*(9458), 501-506.

Lefebvre, H., Pelchat, D., Swaine, B., Gelinas, I., & Levert, M. J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, *19*(8), 585-597.

Leichner, P., Hall, D., & Calderon, R. (2005). Meal support training for friends and families of patients with eating disorders. *Eating Disorders*, *13*(4), 407-411.

Lui, W., Zhu, J., Liu, J., & Guo, Q. (2015). Psychological state and needs of family member caregivers for victims of traumatic brain injury: A cross-sectional descriptive study. *International Journal of Nursing Science*, *2*(3), 231-236.

McMillan, T. M., Teasdale, G. M., & Stewart, E. (2012). Disability in young people and adults after head injury: 12-14 year follow up of a prospective cohort. *Journal of Neurology, Neurosurgery and Psychiatry*, *83*(11), 1086-1091.

McPherson, K. M., McNaughton, H., & Pentland, B. (2000). Information needs of families when one member has a severe brain injury. *International Journal of Rehabilitation Research*, *23*(4), 295-301.

Meyers, S. T., & Pier, J. W. (2000). Continuity of care for brain injury patients: A model of neuropsychologists. *Archives of Clinical Neuropsychology*, *15*(8), 662-663.

Norman, A. (2016). A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury. *The Journal of Adult Protection*, *18*(6), 341-352.

Novack, T., & Bushnik, T. (2010). *Understanding TBI part 3: The recovery process*. Retrieved from http://www.msktc.org/lib/docs/Factsheets/TBI_Understanding_TBI_part_3.pdf.

Osborn, A. J., Mathias, J. L., & Fairweather-Schmidt, A. K. (2016). Prevalence of anxiety following adult traumatic brain injury: A meta-analysis comparing measures, samples and postinjury intervals. *Neuropsychology*, *30*(2), 247-261.

Oyesanya, T. O., Brown, R. L., & Turkstra, L. S. (2016). Caring for patients with traumatic brain injury: A survey of nurses' perceptions. *Journal of Clinical Nursing*, *6*(1), 1-13.

Pierini, D., & Hoerold, D. (2014). Back home after an acquired brain injury: Building a "low-cost" team to provide theory-driven cognitive rehabilitation after routine interventions. *NeuroRehabilitation*, *34*(1), 65-80.

Ponsford, J., Olver, J. H., & Curran, C. (1995). A profile of outcome: 2 years after traumatic brain injury. *Brain Injury*, *9*(1), 1-10.

Ponsford, J., Willmott, C., Rothwell, A., Cameron, P., Ayton, G., Nelms, R., Curran, C., & Ng, K. (2001). Impact of early intervention on outcome after mild traumatic brain injury in children. *Pediatrics*, *108*(6), 1297-1303.

Pringle, A., Finucane, A., & Oxenham, D. (2014). Improving electronic information sharing for palliative care patients. *BMJ Quality Improvement Reports*, *3*(1), 1-4.

Rose, V. K., & Harris, M. F. (2013). 'Training' friends and family to provide positive social support in diabetes self-management: Experience of ethnically diverse patients. *Diabetic Medicine*, *30*(3), 372-373.

Rubenson, C., Svensson, E., Linddahl, I., & Björklund, A. (2007). Experiences of returning to work after acquired brain injury. *Scandinavian Journal of Occupational Therapy*, *14*(4), 205-214.

Serio, C. D., Kreutzer, J. S., & Witol, A. D. (1997). Family needs after traumatic brain injury: A factor analytic study of the Family Needs Questionnaire. *Brain Injury*, *11*(1), 1-9.

Tyson, S., & Turner, G. (2000). Discharge and follow-up for people with stroke: What happens and why. *Clinical Rehabilitation*, *14*(4), 381-392.

Vaccaro, M., Hart, T., Whyte, J., & Buchhofer, R. (2007). Internet use and interest among individuals with traumatic brain injury: A consumer survey. *Disability and Rehabilitation: Assistive Technology*, *2*(2), 85-95.

Van Walraven, C., Mamdani, M., Fang, J., & Austin, P. C. (2004). Continuity of care and patient outcomes after hospital discharge. *Journal of General Internal Medicine*, *19*(6), 624-631.

Vitaz, T. W., Jenks, J., Raque, G. H., & Shields, C. B. (2003). Outcome following moderate traumatic brain injury. *Surgical Neurology*, *60*(4), 285-291.

Wang, S., Zhao, Y., & Zang, X. (2014). Continuing care for older patients during the transitional period. *Chinese Nursing Research*, *1*, 5-13.

West, M. D. (1995). Aspects of the workplace and return to work for persons with brain injury in supported employment. *Brain Injury*, *9*(3), 301-313.

Appendices

Appendix A: Client Headway Somerset Hospital Liaison Feedback form given to ABI patients and their families to complete.

Headway Somerset

Headway Somerset Hospital Liaison

Feedback Form

Your views are very important to us and will enable us to continually improve the service and support we offer. We would be really grateful if you could spare a moment to tell us what you thought about your experience of the Hospital Liaison Service provided by Headway Somerset.

Date: ....

Name: ....

E-mail/contact number ....

1: What did you feel you needed most from the Hospital Liaison Service?

2: What was actually provided to you by the Hospital Liaison Service?

3: How well has the Hospital Service met your needs in hospital, and is this need on-going?

4: Which other services/ bodies would you have turned to if you had not dealt with the Hospital Liaison Service?

5. Have you been supplied with signposting and support information by other organisations?

6: How do you feel the Hospital Liaison Service could be improved?

Comments - We would very much like to know if you have any further comments, experiences or recommendations:

Thank you for taking the time to complete this form – it is very much appreciated.

Appendix B: Clinical Headway Somerset Hospital Liaison Feedback form given to healthcare professionals to complete.

Headway Somerset Hospital Liaison

Feedback Form

Your views are very important to us and will enable us to continually improve the service and support we offer. We would be really grateful if you could spare a moment to tell us what you thought about your experience of the Hospital Liaison Service provided by Headway Somerset.

Date: ....

Name: ....

Position/Job title ....

E-mail/contact number ....

1: Did you find the support and advice of our Hospital Liaison Service helpful for your patients?

2: How do you feel the service helped your patients'?

3: Did the service help with the patients' transition between hospital and home, and if so how?

4: Did the information and support given by the Headway Somerset Hospital Liaison Service help improve patients' wellbeing?

5. In your opinion what are the benefits to you and other clinical staff members of having Headway Hospital Liaisons' involved in the support of patients with acquired brain injuries?

6: Would you recommend Headway Somerset services to other patients, families and clinical staff?

7: If the Hospital Liaison service ceased at the end of 2016 due to lack of funding, what impact do you feel this would have on your patients and their families?

Comments - We would very much like to know if you have any further comments, experiences or recommendations:
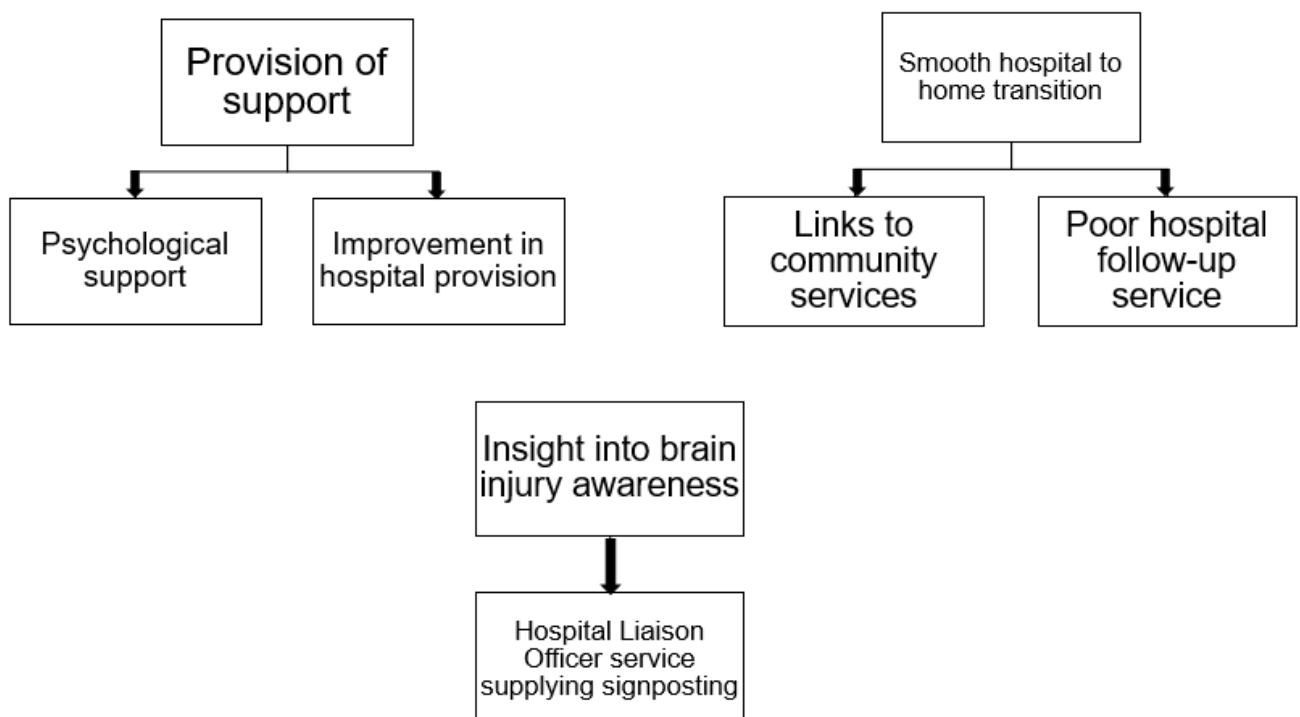
Thank you for taking the time to complete this form – it is very much appreciated.

**Appendix C: Thematic map of the client themes and subthemes.**
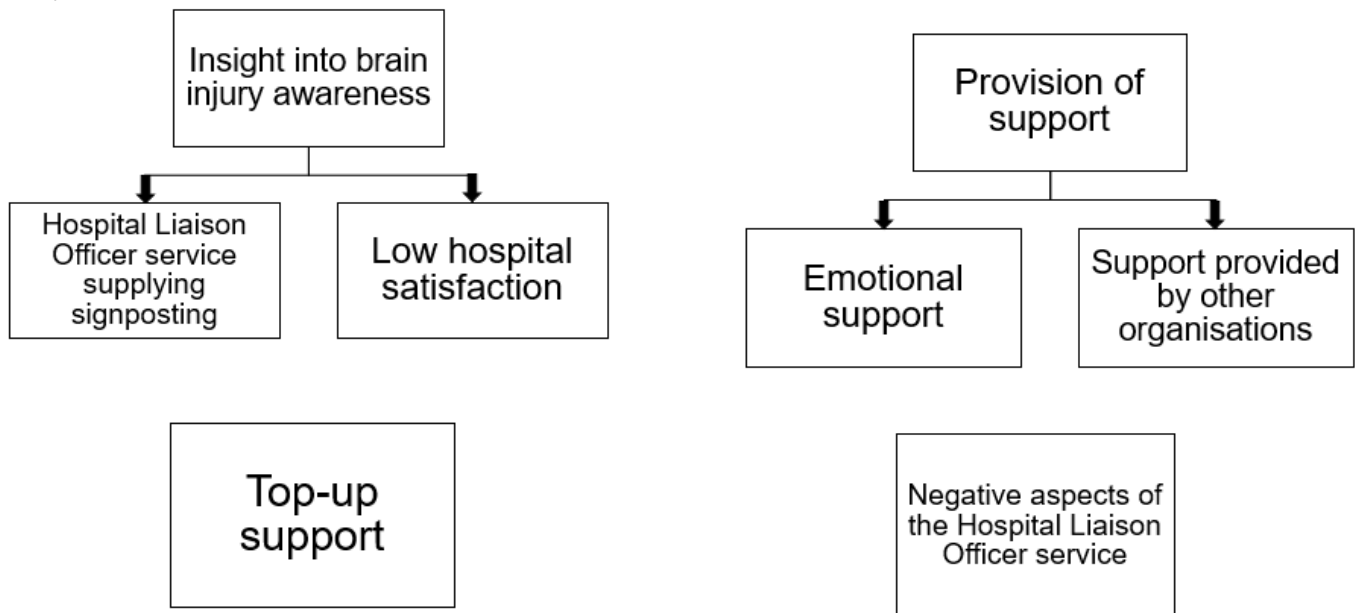
```
┌─────────────────┐                    ┌─────────────────┐
│ Insight into brain│                  │  Provision of   │
│ injury awareness │                   │    support      │
└─────────────────┘                    └─────────────────┘
     │        │                            │        │
     ▼        ▼                            ▼        ▼
┌──────────┐ ┌──────────┐         ┌──────────┐ ┌──────────────┐
│ Hospital │ │          │         │          │ │Support provided│
│ Liaison  │ │Low hospital│       │Emotional │ │  by other    │
│ Officer  │ │satisfaction│       │ support  │ │ organisations│
│ service  │ │          │         │          │ │              │
│supplying │ └──────────┘         └──────────┘ └──────────────┘
│signposting│
└──────────┘
```

┌──────────────┐   ┌────────────────────┐
│   Top-up   │   │ Negative aspects of│
│   support   │   │ the Hospital Liaison│
│   │   │ Officer service   │
└──────────────┘   └────────────────────┘

Key: Single directional solid arrows demonstrate hierarchical relationships between themes and subthemes.

Appendix D: Thematic map of the clinical themes and subthemes.

```
┌─────────────────┐                    ┌─────────────────┐
│  Provision of   │                    │Smooth hospital to│
│    support      │                    │ home transition │
└─────────────────┘                    └─────────────────┘
     │        │                            │        │
     ▼        ▼                            ▼        ▼
┌──────────┐ ┌──────────────┐     ┌──────────┐ ┌──────────────┐
│Psychological│ │Improvement in│   │ Links to │ │Poor hospital │
│ support  │ │hospital provision│ │community │ │  follow-up   │
│          │ │              │     │ services │ │   service    │
└──────────┘ └──────────────┘     └──────────┘ └──────────────┘
```

┌─────────────────┐
│ Insight into brain│
│ injury awareness │
└─────────────────┘
         │
         ▼
┌─────────────────┐
│ Hospital Liaison│
│ Officer service │
│supplying signposting│
└─────────────────┘

Key: Single directional solid arrows demonstrate hierarchical relationships between themes and subthemes

Appendix E: Thematic map of the client and clinical, themes and subthemes.
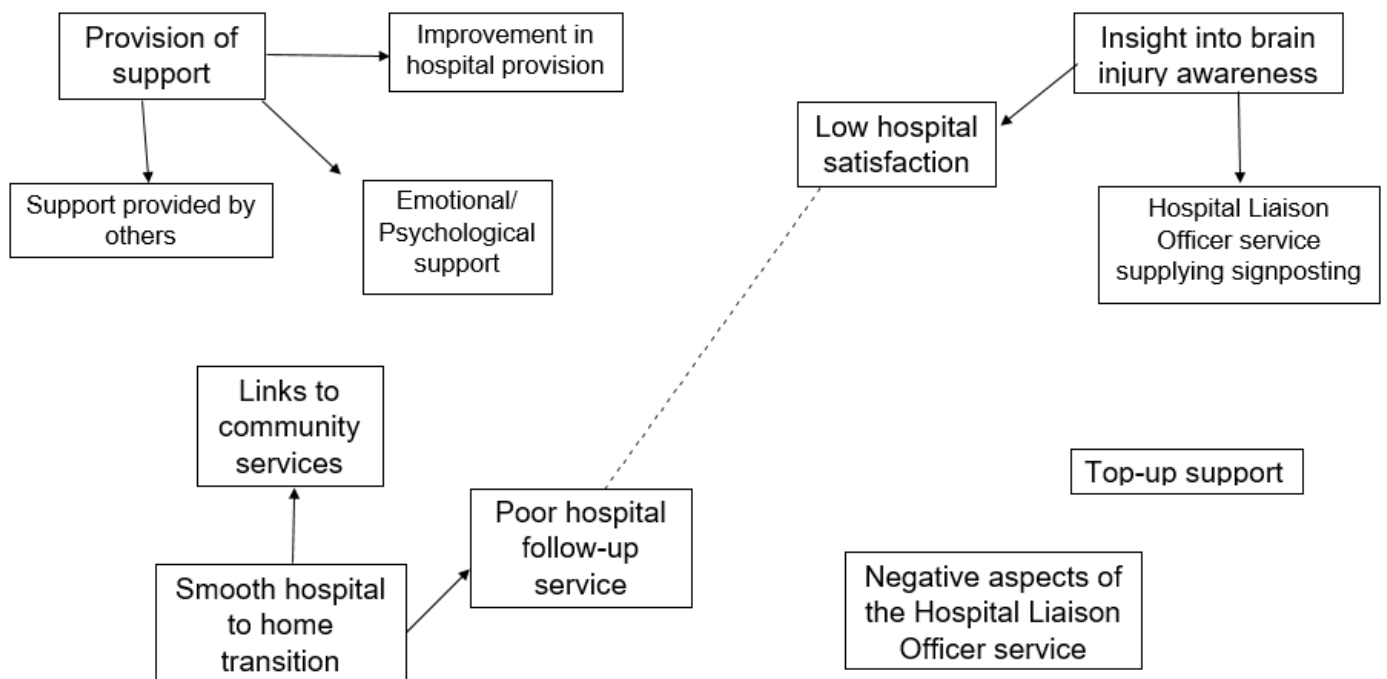
Key: Single directional solid arrows demonstrates hierarchical relationships between themes and subthemes; a dotted line indicates a corresponding relationship between two subthemes of different themes.