

2021-08-14

The inter-relationship between acquired brain injury, substance use and homelessness; the impact of adverse childhood experiences: an interpretative phenomenological analysis study

Adshead, CD

<http://hdl.handle.net/10026.1/15253>

10.1080/09638288.2019.1700565

Disability and Rehabilitation

Informa UK Limited

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.



**The inter-relationship between acquired brain injury,
substance use and homelessness; The impact of adverse
childhood experiences:
An Interpretative Phenomenological Analysis study**

Journal:	<i>Disability and Rehabilitation</i>
Manuscript ID	TIDS-07-2019-026.R2
Manuscript Type:	Research Paper
Keywords:	Brain Injury, Childhood, abuse, homelessness, substance, Adverse Childhood experiences

SCHOLARONE™
Manuscripts

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Implications for rehabilitation

- Need person-centred approaches to intervention for those with acquired brain injury who are homeless and have substance abuse issues
- Need to screen for the presence of acquired brain injury when engaging with individuals who are homeless or have substance abuse
- Need screening of acquired brain injury and adverse childhood experiences to improve access to services post-brain injury

For Peer Review

Running Head: Brain injury, substance use and homelessness

Abstract

Purpose: Acquired Brain Injuries, caused by a range of illnesses and injuries, can lead to long-term difficulties for individuals; mental health problems, cognitive and executive impairment and psychosocial problems including relationship breakdown, substance abuse and potentially homelessness. The study aimed to seek and gain a more definitive understanding of the inter-relationship of Acquired Brain Injury, substance abuse and homelessness by identifying key themes associated with the inter-relationship between these variables.

Materials and Methods: The study recruited eight participants through homeless organisations and treatment centres. Participants were screened for suitability (Brain Injury Screening Index; Drug Abuse Screening Tool; Alcohol Use Disorders Identification Test and then participated in recorded semi-structured interviews, transcribed and analysed using Interpretative Phenomenological Analysis.

Results: The study identified five master themes: Adverse Childhood Experiences and Trauma; Mental Health; Cognitive Decline and Executive Function; Services; Relationships.

Conclusion: Healthcare professionals need to engage with children, their families, and adults, who have been exposed to adverse childhood experiences and should employ routine screening tools for brain injury to ensure their presence is factored into developing appropriate models of intervention.

Key words: Brain injury, adverse childhood experiences, homelessness, mental health, rehabilitation

Introduction

In 2016-2017, approximately 350,000 people were admitted to hospital with an Acquired Brain Injury (ABI), which equates to approximately 530 people per 100,000 of the general population of the United Kingdom [1]. Specifically, ABIs are caused by, but not limited to; strokes, lack of oxygen to the brain, or blows to the head [2]. The latter is more commonly known as a traumatic brain injury (TBI). The most common causes of TBI are road traffic accidents, falls, sporting injuries, violence and violent physical child abuse [2]. Brain injuries, may have serious consequences in terms of impairments to physical, mental, cognitive, emotional and social functioning. While some or all of these impairments may be present in a survivor, and the symptoms may be readily observed, more often they are subtle and can go undetected [3]. Consequences of brain injury can include hemiplegia and epilepsy, anxiety and depression, executive dysfunction and cognitive difficulties, and personality change [2]. In addition to direct consequences, individuals may also experience psychosocial issues such as unemployment, social isolation, relationship breakdown, substance use and potentially homelessness, as individuals struggle to manage and come to terms with the functional impact of their injuries [4,5,6,7].

A review of eleven studies from the United States reported that one third of recorded hospitalisations regarding ABI show alcohol intoxication present and two thirds of individuals with brain injury in rehabilitation have had a history of substance abuse pre-injury [8,9]. Substance abuse alone is complex and, coupled with an ABI, presents a number of challenges to recovery and how an individual interacts socially.

Running Head: Brain injury, substance use and homelessness

Substances are often used as a coping mechanism to calm individuals and to enable avoidance of post-injury changes to functioning and emotional distress caused by the survivor's awareness of changes to their pre-injury self [10]. Substance abuse can lead to further cognitive impairments, as well as increasing the risk of future brain injury [11,12]. One area that substance abuse and ABI can affect in particular is executive function [13].

Mueller and Dollaghan [14] describe executive function as high level cognitive processes vital for maintaining relationships, managing finances and household responsibilities, and maintaining employment, and aids the ability to integrate within society [15]. Neuropsychological evidence has highlighted that the frontal cortex plays a vital role in the planning and execution of behaviour and that frontal lobe damage is associated with numerous cognitive difficulties [15]. These include initiation, planning, execution of activities, and self-regulation [15,16]. It is therefore the widespread understanding that the frontal lobe (although not the only structure) is the area that most likely supports executive function, which is considered to include self-regulation, inhibition, goal setting, initiation, working memory, planning and organisation among others. Initiation, planning and working memory are extremely important in integrating productively within society and any impairment to these functions can seriously impact a person's sense of self and ability to carry out simple everyday tasks [16].

Other research suggests that ABI, in particular frontal lobe damage, is associated not only with more obvious deficits in executive functioning, but also with impairment in pragmatic language use [17]. The inability to pitch conversations appropriately, to structure information or vary content, inevitably impairs social functioning for the affected individuals, increasing the likelihood of isolation, poor relationship outcomes,

Running Head: Brain injury, substance use and homelessness

and depression [17]. These difficulties faced by individuals can make it difficult to re-establish social networks and social activity [18,19]. Holloway [20] also reports that impaired executive function makes it extremely difficult to maintain post-injury social functioning and can lead to relationship breakdown and unemployment, which in turn further exacerbates social isolation and reduced social activity [21].

One potential consequence of poor social integration, alongside executive impairments, that can make maintaining rented or mortgaged accommodation difficult [22], is potential homelessness for those with ABI. Oddy et al, [7] investigated homelessness and identified that of a sample of 100 homeless individuals 58% had experienced a brain injury, of which 60% reported sustaining multiple injuries. Ninety percent of those with injuries reported sustaining their ABI prior to becoming homeless. This suggests that ABI is a predetermining factor for homelessness. This may be in part due to executive impairments, but is further complicated by the difficulties for individuals with ABI engaging with adult social care, mainly due to the cognitive and behavioural impairments associated with ABI [23]. This difficulty to engage increases the likelihood of homelessness through inability to receive appropriate packages of care and welfare support that enable individuals to remain in their homes and paying their bills [24,25]. ABI amongst the homeless population has also been associated with a sharp rise in mortality rates [24,25].

Substance abuse has been considered both a cause and effect of homelessness with many homeless people turning to substance abuse as a consequence of losing their homes [26]. According to Hwang [27], history of ABI is strongly associated with many adverse health conditions among the homeless population, including seizures, mental health and substance abuse problems. However, Hwang also states that the relationship

Running Head: Brain injury, substance use and homelessness

is bidirectional in that pre-existing mental health and substance use increase the risk of ABI and therefore homelessness could be both a cause and consequence of ABI. Those who drink alcohol are four times more likely to sustain an ABI and ABI can be a cause for substance abuse [28]. Some individuals only abuse substances once they are homeless and ABI is prevalent prior to homelessness [27]. Therefore, the inter-relationship between ABI, substance abuse and homelessness is incongruent with any one factor being a cause or consequence.

The research to date does not explore in any great depth how ABI, substance use and homelessness are linked in terms of directionality. Anyone of these populations consists of individuals who are often missing from research and healthcare services. Those with difficulties in all areas are a hard to reach population often overlooked by research and service provision. The current investigation aimed to seek and gain a more definitive understanding of the inter-relationship of ABI, substance abuse and homelessness by identifying key themes associated with the inter-relationship between these variables.

Materials and Methods

Participants

The study recruited eight participants consisting of four females and four males aged 25 to 59 from the South West of England (Table 1). This number is in keeping with appropriate numbers for studies using Interpretive Phenomenological Analysis (IPA) [29].

Running Head: Brain injury, substance use and homelessness

Given the nature of the present enquiry and the vulnerability of the participants, organising pre-arranged interviews proved difficult due to the participants lacking the stability, structure and routine to which most people in the general population are accustomed. This population is one that is hard to reach. As such most research misses this set of participant voices. The selection and recruitment process for participants was pro-active with the first author contacting local homeless organisations, addiction treatment centres and temporary housing organisations, and being given authority to approach and interview individuals on the organisation premises. In this way the recruitment process was opportunistic with the first eight participants to consent to the study being included.

There were no exclusion criteria once established that individuals had sustained an ABI and had at least one of the following factors: substance abuse problems (past or present) and/or homeless (homelessness included individuals in temporary accommodation). Participants did have to be able to speak and understand written and verbal English to be able to complete the written consent form and screening questionnaires. Participants were not excluded on the grounds of other diagnoses due to the complex nature of this participant group.

The interviewer met participants before the interviews and gained informed consent. They were then given a series of screening questionnaires to complete prior to interview to establish head injury, and drug and alcohol use. The summarised findings from these measures are reported in Table 1. There were no exclusion criteria concerning time since injury. The study received ethical approval from the relevant University faculty ethics committee (reference no. 9824).

Running Head: Brain injury, substance use and homelessness

Insert Table 1 here. Table 1. Participant Information Table

Screening Questionnaires

The participants were asked to complete the Brain Injury Screening Index (BISI) [30], Drug Abuse Screening Tool (DAST 20) [31], and the Alcohol Use Disorders Identification Test (AUDIT) [32]. Although the questionnaires were not intended to form an integral part of the analysis they formed a vital part of the interview process, as they set the tone and focus for the interview, allowing participants to take time to recall incidents that had taken place, in some cases up to fifty years previously. In some instances, the memory deficits associated with ABI [16] meant that participants required these prompts from the questionnaires to recall important experiences.

Interviews

The interviews were semi-structured, were conducted at the convenience of the participants in an environment that was comfortable, safe and private and were audio recorded with permission to provide a full verbatim transcription for each one (see supplementary material for interview schedule). One interview (Harriet) took place in the participant's home at her request with an advocate present throughout the interview. Each interview lasted approximately sixty to ninety minutes, with the exception of one interview (Gordon) which lasted approximately five hours. This interview deviated from the standard ones because the participant struggled to stay 'on topic' and was easily distracted, common side effects of brain injury [33].

Post interview participants were able to access support provided by the organisations where the interviews took place, with the exception of one participant

Running Head: Brain injury, substance use and homelessness

(Harriet) who had access to support from her advocate, a trained counsellor. The organisations were fully aware of the research aims and understood that support may be needed due to the nature of some of the experiences being discussed and the potential distress this may cause. Participants were fully debriefed and were able to contact the first and second author at any time post interview if they wished.

The first author was an active participant in the interview process and recognises that his ability to conduct the interviews may have affected the generation of rich data. The transcripts were analysed using IPA outlined below. The subjective experience of participants was actively interpreted by the interviewer, presenting a double hermeneutic. This involved the participant making sense of their world and the interviewer making sense of how participants made sense of their world [34]. Furthermore, semi-structured interviewing is a process whereby the interviewer must be aware of when to use the semi-structured interview schedule and when it is appropriate to deviate and ask appropriate questions relevant to the enquiry and the experiences being shared by the participant [34]. The initial interview schedule for this study was informed by research already conducted (as discussed in the introduction) concerning the experiences of homeless individuals who have sustained an ABI and/or are substance misusers [27,28].

Analysis

Methodological Overview

IPA was employed within this study. IPA aims to seek knowledge regarding how people view the world and it is assumed that accounts reveal something about an

Running Head: Brain injury, substance use and homelessness

individual's private thoughts and emotions [29]. IPA has an idiographic focus, seeking to represent in as rich depth as possible the participant's own view of their 'lived experience' in relation to the research area [29]. As this was the purpose of the current research, the use of IPA here was appropriate. This phenomenological approach takes the stance that people seek to explain their experiences in a form that is understandable to them [30] and an interview is a process that a person can use to describe their life world and in essence recreates this through the use of language. The researcher's role when conducting IPA must be one that acknowledges that insights discovered from the text will be a product of their interpretation and the depth of understanding and analysis is dependent on the researcher's level of engagement and interpretation of the text [35]. The process of analysis is outlined below.

Stage 1 – Transcription

During the transcription stage the first author began immersing himself in the life world of the participant, paying close attention to the words used to build a narrative of their lived experience [36].

Stage 2 - Transcript Analysis – Emergent Themes

Once full transcriptions were completed the first author subjected each transcript to IPA, based on the model proposed by Smith and Osborn [29]. This process involves coding sample text to form emergent themes within each transcript.

Stage 3 – Clustering of Emergent themes and Superordinate Themes

The emergent themes were then reorganised so that related ideas and interpretations

Running Head: Brain injury, substance use and homelessness

and ways that experiences were described were clustered together thematically according to conceptual similarities. Clustering themes together allowed for broader concepts to be identified which run through the account at a deeper level. The final list then comprised of superordinate themes and subthemes.

Stage 4 – Master Themes

Once all of the transcripts were analysed individually, recurring superordinate themes, broader concepts and higher-level concepts from each account were integrated into master themes and form the basis of the results and discussion sections in the following chapters. This approach allowed the first author to make comparisons with similarities and differences of emerging themes with the analysis culminating in the drawing together of shared lived experiences, identifying both commonalities and differences of shared phenomena and how the impact of these experiences shaped the life of each individual [29].

Stage 5 – Validity checking

The first author then discussed the analysis with the second author, a qualitative researcher with experience of working with individuals with ABI. The second author independently checked and verified the analysis. Smith [37] identifies two broad criteria for assessing reliability and validity in IPA research: internal coherence of the study; and appropriate presentation of evidence. Coherence means ensuring the research process reflects the research question and objective and is in keeping with the epistemological underpinnings of IPA. The methodological approach used here is consistent with the aims of the study: to explore the interrelationship between substance abuse,

Running Head: Brain injury, substance use and homelessness

homelessness and brain injury through the lived experiences of individuals. Equally, the data collection and analysis process outlined above are in keeping with IPA with each stage focusing on the task of shedding light on the participants' own 'lived experience', as made sense of through words. Appropriate presentation of the research process allows transparency of inquiry [37]. The research process is outlined above to ensure this process of transparency. Rigour is also important in qualitative research [37], and the authors have clearly outlined the involvement of the interviewer in the research process to ensure this element has been addressed.

Results

Overview

IPA of the eight interviews resulted in the emergence of five master themes. Data were supported through verbatim extracts from the participant's accounts represented here with pseudonyms to protect the identities of participants. Information about the substance use, homeless status and brain injury status of these individuals is displayed in Table 1. Although each of the emerging master themes were contributed to by all participants, not all participant accounts were used to describe each theme; 1) Adverse Childhood Experiences and Trauma, 2) Mental Health, 3) Cognitive Decline & Executive Function, 4) Services and 5) Relationships (see Figure 1 for a thematic map).

Insert Figure 1 here

Running Head: Brain injury, substance use and homelessness

Master Themes

(1) Adverse Childhood Experiences and Trauma – “...a lot of abuse, verbal, physical, financial, you name it...”

This master theme captures the considerable level of childhood abuse and trauma experienced by the participants ranging from, but not limited to: road traffic accidents, sexual abuse, neglect, violence and bullying. The theme captures the psychological effects of these experiences and how these ultimately impacted their adult lives. This master theme underpins the other themes as the abuse and trauma experienced happened to the participants prior to other factors and either directly led to an ABI as a result of physical injuries or led to other psychological and mental disturbances prior to the participants engaging in substance use and/or becoming homeless. In essence, this master theme lays the foundation for interpreting the data. The theme highlights the need to consider adverse childhood experiences when working with individuals with ABI.

Child Physical Abuse – “They put a cigarette out on me once...”

Four participants reported experiencing abuse inflicted by their parents. Participant accounts described volatile, often violent, environments they lived in and a lack of nurturing. The participants found it difficult to talk about these experiences initially but once acknowledged, they spoke freely and shared experiences that had often been left unaddressed for many years. The participants talked about experiencing various forms of abuse at the hands of their parents and feeling “unwanted” by them. One participant was fifty-nine when interviewed and his distress during the interview highlights that

Running Head: Brain injury, substance use and homelessness

regardless of age, childhood experiences can remain with us throughout adulthood. Further participant accounts described feeling 'worthless' and the impact such abuse had on their self-worth, often leading to further adverse situations such as becoming a sex worker or moving on to abusive adult relationships. In one instance the abuse experienced by the participant led to a head injury, identifying the direct link between adverse childhood experiences and ABI. These connections are of paramount importance in understanding the interconnectedness between ABI and adverse childhood experiences, with adverse childhood experiences either directly leading to injury or bringing about significant life events that make injury more likely.

"They put a cigarette out on me once, it was a lot of abuse verbal, physical, financial, you name it..." Arthur - 3:109:102

"...my Mother picked on me certainly and (...) he [referring to his Father] would always take her side and I would get a beating, which was strange as when we were at work together it was great." Arthur - 2:90-95

"I was always battered mentally and physically" 'he never used to bruise my face but I'd have lumps and bumps all over my head, scars and bruising all over me." Carol 1:20-26

"I fractured my skull once...I was thrown down the stairs and I fractured my head at the bottom..."Carol - 4:207-211

"I never had any self-worth about myself like I said it was drilled into me from the start really that I was not wanted and worthless and evil so I never had any self-worth or self-belief and like I said I was already damaged so I may as well earn from it mightn' I (...) I was broken from day dot." Carol - 25:1210-1219

Childhood Sexual Abuse – "...when I was thirteen I was raped..."

All four female participants shared experiences of sexual abuse, which they found extremely difficult to discuss. In her account Fran reveals that when she was seven years old she was abducted by a stranger and abused, although she does not expressly state it was sexual abuse. Fran goes from being confident and talkative to being extremely shy and her voice becoming quieter when she spoke. Harriet during her account (the only

Running Head: Brain injury, substance use and homelessness

participant to have an advocate present at her request) is not even able to talk about the incident and the interviewer reflects that if it was not for the presence of her advocate she would not have broached the subject at all. As with childhood physical abuse, some instances of sexual abuse led to direct brain injury, such as through hypoxia from being strangled. One participant described the experience of sexual abuse as stealing the rest of her childhood from her, or at least the *'bits that I did have of it'* implying that her childhood had already been snatched through previous adverse events such as parental suicide attempts and physical ill health, and parental separation. As with physical abuse it is clear that there are both direct and indirect connections here with ABI.

Fran: well abuse yeah it was a stranger I have only recently been talking about that so if that's ok I would rather not(...)

Int:Can I just ask how old you were?

Fran:7

Int:Was it shortly after that...

Fran:I started seeing things yeah

Int: That's when the psychosis happened?

Fran:Yeah. – Fran - 8:444-457

Adv: When Harriet was a young teenager she went to the house parties that she had mentioned previously and she was effectively groomed by an older male man.

Harriet: (crying, distressed, tears rolling)

Adv: It's ok we don't have to talk about that.

Harriet: (crying, distressed, tears rolling) Harriet - 11:502-513

"One of the Foster dads used to, used to abuse me, when he sexually abused me and that, he strangled me to the point I stopped breathing..." Carol - 8:357-366

Childhood Traumatic Experiences and Bullying – “...I said when is she coming back and he just told me she was dead...”

Seven participants shared accounts of bullying and/or trauma that fall outside of childhood physical or sexual abuse. Gordon, Arthur and Harriet all experienced high

Running Head: Brain injury, substance use and homelessness

degrees of bullying, Fran and Erian were both involved in serious car accidents, Betty experienced numerous maternal suicide attempts, and Dexter's Mother died when he was young. These experiences likely impacted their childhood and adult life.

The participants clearly describe the impact that these traumatic events had on their lives long-term. In his account, Gordon describes how his life was made "*a misery*" from bullying when he was at school and affected his ability to form relationships leaving him isolated. Dexter describes his mother distancing herself from him before her death to protect him. Yet this only served to deny Dexter a close attachment relationship. Dexter describes never knowing his Mother's love and '*you can't miss what you didn't have*' but his words suggest that it is something that he has desperately missed with the reflection "*a mother's love being unconditional, I'm sure that has had some sort of impact on me*".

Erian and Fran both describe being involved in road traffic accidents at the ages of 8 and 2 years old respectively. For Fran, this resulted in permanent brain damage that doctors later revealed was responsible, alongside her sexual abuse, for her mental health issues. Both participants reveal through their accounts how the traumatic experiences affected them. What is different about these participants, and Gordon's, in comparison to the other participants is that they come from stable families that have not abused them physically or psychologically, and external forces outside of the family home were responsible for impacting their childhood. Despite this, these childhood trauma had a profound impact on their development. The interconnectedness between ABI and adverse childhood experiences is present again with some directly causing injury (e.g. through road traffic accidents), whilst others lead to poor attachment relationships which left the participants vulnerable to situations where ABI may be more likely to

Running Head: Brain injury, substance use and homelessness

occur.

“...it was the ritual and it was done in front of other people and it was humiliating and I remember who they were ...” Gordon - 36:1984-1996.

“Four and a half just a month before my fifth birthday. The manner which I found out was I guess my first real exposure to alcohol, my Dad was off his tits... because they told me she had gone on holiday, and I said when is she coming back and he just told me she was dead and I didn't really register at the time(..)and that was my first exposure to abuse, my Dad was physically violent and abusive and chaotic in the house” Dexter - 7:368-399

“I don't think I lost consciousness but I was sat there thinking what has happened and I could see my shoe my trainers over there and looked at my feet and I could see bone”. Erian - 9:486-497

“...when I was 2 I got run over by a car it was pretty bad apparently they drained the blood from my nose because it was going into my eyes and into my brain....” Fran - 1:19:25

2. Mental Health – Causes and Consequences “...mental health was all over the place...”

The second master theme aims to capture the level of mental health issues that pertain to participants through their lived experiences and how they make sense of them. It captures the struggles faced each day because of mental health problems prevalent prior to, or following, an ABI, substance abuse and/or homelessness, including consequences and causes. All participants contributed to this theme describing the difficulty they faced concerning diagnosis, treatment and the impact their mental health has on their everyday lives. Some participants describe how substance abuse has exacerbated any pre-existing mental health issues, as well as using substances to relieve symptoms of mental illness.

Participants highlighted difficulties with getting a diagnosis of their mental health problems and receiving appropriate treatment. This was noted in the case of several different mental health difficulties and where both substance use and mental health problems were at play. In many cases the mental health difficulties experienced by participants were so severe they led to suicide attempts and overdoses, some of which led to ABIs. Harriet describes

Running Head: Brain injury, substance use and homelessness

the extent of her overdose, which consisted of “*prozac, quetiapine, amitriptyline, diazepam, lorazepam, coke, propranolol, gin... as well as tramadol and neurofen*”. Harriet required resuscitation after being found by her advocate. This led to her experiencing a lack of oxygen to the brain on top of a series of multiple head injuries throughout her childhood. In the case of Fran, her suicide attempt led to the diagnosis of a previously undetected brain injury suggesting that many injuries often go many years without recognition. In this way there is clear interconnectedness between mental health and ABI, with some mental health difficulties leading directly to ABIs. In other instances, ABIs existed alongside mental health conditions. The interplay between these factors demonstrates an important element to consider when providing suitable intervention.

“...I’d seen psychiatrists as I’d had breakdowns and things, er, but mental health was all over the place, I couldn’t get proper treatment or diagnosis or anything like that...” Arthur - 17:882-888).

“...once [community drug treatment centre] tried to get me referred to the complex needs team...when I was bad on cocaine really bad on cocaine(...)I was 24 but because [community drug treatment centre] said they couldn’t really help because it was my mental health not the drugs and [community mental health team] were like it’s the drugs not the mental health we can’t see you when you’re taking drugs, so then they decided to try and get me to this complex needs team and then they said no we can’t help you either, because they’re supposed to help you with both mental health and drug problems because they, they said no because I wasn’t bad enough...” Harriet - 27:1239-1272

“Int: So what diagnosis ...have the doctors given you? Part: They haven’t really and that’s why in a way and you know the diagnosis really is just suffering from [participant lists several mental health diagnoses] because that really covers quite a few things, nobody knows.” Gordon - 123:6669-6678

“...I had a head scan like, when I OD’d basically they said they’d done a head scan...they put it down to, my[mental health condition], to maybe the head injury and the trauma of the abuse and they said it definitely, I don’t know what they found.” Fran - 8:472-486

3. Cognitive Decline and Executive Function – “I feel that I am not myself anymore, I’m a shadow of my former self, I feel my cognitive ability is not what it used to be”

Running Head: Brain injury, substance use and homelessness

This master theme captures the hidden disabilities that are a direct result of ABIs. The master theme focuses on memory, planning and organisation. All participants contributed to this theme and revealed how the effects have impacted their everyday lives and sense of self, including self-worth, esteem and identity. These impairments were connected with both homelessness and substance use. In some cases poor executive functioning increased risk-taking behaviour among participants leading to greater substance misuse. In others substance use exacerbated impairments leading to further functional impairments. In both cases this increased the likelihood of homelessness occurring for these individuals.

Memory – “my memory is shot”

Several participants highlighted difficulties with their memory over and above that which you might expect from getting older. These memory deficits in some cases were directly attributable to the ABI and in others causality was unclear. These deficits were identified as having an impact on the participants’ ability to function day to day. These memory problems were implicated by participants in their homelessness, as sometimes they failed to attend relevant appointments to engage with services, or had forgotten to pay bills, which directly linked to their homelessness.

“Yeah it was the first stroke, yeah the first TIA that was....., no, no, it wasn’t, it was the blow to the head beforehand,, no I had the first stroke and then the blow to the head, but since the blow to the head, that’s when my memory, frontal lobe, you know, its crap, it’s awful, er er and I do feel disabled...” Arthur - 23:1249-1257

“...It’s hard financially because I lose things, I forget things, leave things on buses, leave shopping behind, lose money, erm ,ah, ah its disturbing it really is...” Arthur - 18:938-942.

Adv:... and certainly the September incident hasn't help improve things [suicide attempt which led Harriet to experience hypoxia]

Harriet: No, I just forget I've got like Post-it notes everywhere all around here I've got post-it notes everywhere and I just like always have to double check with my other half and my

Running Head: Brain injury, substance use and homelessness

other half looks at me like I'm a right idiot sometimes because she will say something and then ten minutes later I'll be like right what we doing tomorrow and she would be like I've just told you but I literally just can't remember.' Harriet - 17:767-785

Planning and Organisation – “...I used to find that shit easy...”

Participants also highlighted deficits in planning and organisation that have come about either through the ABI or substance misuse (or a combination of the two). These difficulties with planning and organisation made maintaining housing and engaging with services problematic.

*“I used to find that s*** easy, I would travel, book a plane, get a ticket pack my bag and get the f*** out of here but I would forget things I wouldn't pack properly, I'll be confused, I keep forgetting what time I was going but that was because of anxiety, I didn't like planning, I've never liked planning.”* Dexter - 23:1234 – 1255

Int: 'How about your ability to organise and plan things...?’

Harriet: I used to be alright at it but I'm not very good at it now. Harriet - 16:742-748

Self and Emotion Regulation – “I feel really bad when I have simmered down”

Arthur reveals that since the TBI and bleeds in his brain he can now lose his temper very easily and is something that he needs to be careful of, but often lacks the ability to take this into account in real time due to a lack of anticipatory awareness of his difficulties [38]. He has reflected on this and realises that he does get upset and it makes him feel bad. His account implies that he has not always been like this and that his sense of self has been affected. These moments of uncontrollable anger have led to Arthur being perceived as non-compliant with services that may support his conditions and made it difficult for him to maintain a stable home environment.

“...I can lose my temper and be very angry, no violence, never ever hurt anybody but you know I can and I have snapped, and it can go on you know, into a bit of a tirade and then I feel really bad when I have simmered down and I have thought about it, you know, ha ha... things do upset me quite badly, hmmm, you know...” Arthur - 28:1505-1514.

Running Head: Brain injury, substance use and homelessness

4. Services – “...you are just so stupid, just so stupid, just stupid people...”

This theme captures the participants’ experience of services they were involved with; mental health hospitals, psychiatrists, housing organisations, council departments, substance abuse treatment organisations. The majority of participants echoed feeling these services did not communicate with one another or listen to what the participants told them. It illustrates the frustration felt by the participants concerning diagnosis and consistency of treatment, and identifies safeguarding concerns. This theme highlights that protocols and procedures within organisations often work against this patient group, making it difficult for them to successfully engage and receive the support they need. A few of the participants accounts describe positive outcomes with services they have engaged with but these are the exception and not the rule and appear to be as a result of the individuals representing the service, not the service as a whole.

Communication – “...Just listen they don't listen, they just hear what they want to hear...”

A lack of communication was identified by several participants; organisations not communicating with one another or ineffective communication within organisations. This led to failure receiving the services required, thus maintaining their homelessness, mental health difficulties or substance abuse over a longer period of time. Harriet expressed her frustration and anger in how she has been treated. Fran’s experiences concerning psychiatry were also similar.

Int: Ok, so what do you think you needed or what do you think they could have done for you better?

Running Head: Brain injury, substance use and homelessness

Harriet: Just listen they don't listen, they just hear what they want to hear, and like...and realise that things are connected either...they just want to know how much you're drinking how much you're eating, how little you're eating, how often you're self-harming. It's not all about that, it's not as simple as that, and sometimes I will be like, I will self-harm like really bad every day and then I might not do it for a couple of weeks but I don't know.... Harriet - 32:1498 – 1524.

Int: When were you diagnosed with....

Harriet: [states mental health diagnosis]

Int: Yeah

Harriet: Erm bloody hell I think it was about sometime, it was before we spoke probably

Adv: You didn't have a formal diagnosis did you erm although technically speaking you did although nobody had bothered to tell you, she received the documentation of the diagnosis, it must have been that summer wasn't it?

Harriet: Yeah

Adv: that summer...but it would appear that it had been on record a few years previously

Harriet: a few years before that I think [states year] ish Harriet 19:890-912

"Rubbish, rubbish, really because they just didn't know what they were doing they were very textbook like you know and I would just think you just do not get it do you, because unless you're in my shoes I don't suppose you'll ever get it because one would say one thing, and another say another thing and I would just like you know, I used to think God. I would think 'you are just so stupid, just so stupid, just stupid people'...'You can't remember what I said to you yesterday' so therefore I was very ignorant like that with them because 'you just don't even attempt to' 'oh well, well we'll put you in this category' 'you don't even read up on the person that's coming to see you', it's just like, so I just thought 'you were ignorant', so I didn't bother so when I went down 'I'm not going to talk to you, just pointless'." Fran - 23:1313-1341).

Safeguarding – “I got hold of a razor, I snuck it out of one of the rooms, one of the secure rooms”

Harriet illustrates a series of safeguarding issues associated with a lack of effective service provision. Harriet's account refers to an incident when she was admitted to hospital for a psychiatric assessment and another that took place while she was in an acute mental health facility following her overdose. This incident suggests a lack of care by professionals to ensure the needs of individuals with complex needs are being met.

“...if they [community mental health team] suggested a hospital [inpatient psychiatric care] or anything like that I would do it and like he [psychiatrist] didn't, he was just like no you're fine basically...and then I got seen by a Psychiatrist 2 days before I took the overdose...because I was in hospital when I was brought in in handcuffs and they said

Running Head: Brain injury, substance use and homelessness

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

‘what are you going to do when we discharge you’ and I said ‘I’m going to drive somewhere, anywhere, and I’m going to take all the tablets that I’ve got in my bag’ and they went ok discharged and that is exactly what I did like...” Harriet - 23:1041-1069

Harriet:... the psychiatrist, he was just, just spoke to me like I was crap, a piece of crap basically and that I was inconveniencing them and then I can't remember what happened really but I got hold of a razor, I snuck it out of one of the rooms, one of the secure rooms where all the stuff is kept and yeah and did like whatever and then....

*Adv:it was a suicide attempt wasn't it, she tried to, well you did slit your wrists.’
Harriet - 25:1142-115.*

(5) Relationships “...it was always violent relationships and toxic relationships even friendships were toxic...”

This master theme illustrates the negative and positive relationships formed within participants’ lives and captures the gulf between these. The theme also captures how individuals may gravitate towards certain types of people. This theme links directly with the adverse childhood experiences theme and demonstrates how negative past experiences can shape later relationships in adulthood. The presence of ongoing negative relationships has been instrumental in progressing and maintaining some of the participant’s homelessness and substance use. Extracts from Carol’s account will be used to illustrate this theme as her experiences show how an individual can move from abusive relationships to relationships that are encouraging and life affirming

Relationship Role Models – “It was my cousin I first started having heroin with (...) he had a similar upbringing...”

Carol elicits through her account some of the early childhood relationships and role models that she had, all of which were detrimental to her wellbeing and self-worth.

Running Head: Brain injury, substance use and homelessness

Carol's father was physically abusive and her mother was implicit in the abuse, leaving her with very few loved ones she trusted except a cousin who "had a similar upbringing". These relationships that Carol describes are the foundation for future relationships that she forms based on violence, destruction and abuse. These left Carol feeling isolated and led to her involvement in substance abuse as well as directly causing her head injuries.

"...the only thing I can remember about my dad is that he just used to hit me, I never really spoke to him, I was never allowed to eat with them or anything he's hit me all my life."
Carol - 5:261-261

"I didn't have a relationship with my mum as I didn't trust her; she's never helped me she just sat back and watched. She never stepped in." Carol - 5:251-255

"... He [her cousin] is the only member of the family that I have gotten on with really do you know what I mean the others I don't have any sort of connection with whatsoever"
Carol - 9:447-454

Fear of Love & low self-worth– "...fear of being loved and being hurt..."

Carol describes how she never had any love which led to a "fear of love" caused by a protective mechanism against being hurt and a feeling that she was unlovable. These mechanisms made the involvement with substances more likely because she was able to escape from her feelings of isolation and hurt. Carol describes how heroin was the only relationship that gave her "peace", and allowed her to feel "at home". Her experience of using gave her a sense of protection from others.

"I never cared about anyone else, what I've always said like I've always had a fear of love I suppose, I never had it, fear of being loved and being hurt and fear of loving someone else and being rejected by it, it's all fear." Carol - 25:1182-1189

"I never felt that I mattered and I didn't allow anyone else to matter to me...total destruction... my whole life" Carol 2:90-96

"I never had any self-worth about myself like I said it was drilled into me from the start really that I was not wanted and worthless and evil so I never had any self-worth or self-belief and like I said I was already damaged so I may as well earn from it might'n I. I was broken from day dot." Carol - 25:1210-1219

Running Head: Brain injury, substance use and homelessness

“using drugs, they gave me more of an armour than I already had, literally everyone was at arms length, friends and things like that, even partners I would let them in so far and then they would hit a brick wall and they wouldn’t get any closer.” Carol - 20:931-939

Violence and Anger – “...it was was just straight away violence mode, anger mode...”

Carol’s describes her life as full of “always violent relationships and toxic relationships, even the friendships...” leading her to resort to violence and anger when people tried to get close to her. As a result of her low self-esteem Carol’s relationships took a similar trajectory to those of her early ones; punctuated by abuse and distrust. Carol only ever knew abuse so in the end it was what she indirectly felt comfortable with. These behaviours are likely to increase the risk of homelessness through antisocial behaviours and a lack of social support networks to fall back on in times of need.

“...violence was a big thing for me do you know what I mean, if you made eye contact half the time I’d hit ya, even if someone was just trying to get to know me it was was just straight away violence mode, anger mode, so they didn’t try in the end, I didn’t want them to, I just wasn’t interested, at all...” – Carol - 20:947-956

“it was like a trademark move of his every time we got into an argument he would bounce my head off a wall, it was just his thing, he only ever knocked me out once though – Carol - 15:703-709

‘I was staying at this heroin addict’s who was selling drugs, I wasn’t staying with him do you know what I mean, basically I was sleeping with him for drugs and I ran to get away from them and they chased after me and got me in the car and because we were arguing they started hitting me and they crashed and my head went through and I was in the passenger seat and my head went through the passenger window” Carol - 13:603-616

Positive Relationships – “...she has proper un-caged my heart...”

Carol describes how she eventually did put her trust in somebody whom she met in a café for the homeless. Carol describes how she was lucky to get the counsellor that she did describing her as the ‘first person I’ve trusted, I think’ and having ‘proper uncaged’

Running Head: Brain injury, substance use and homelessness

Carol's heart. This positive relationship was the turning point for Carol in terms of understanding the impact her brain injuries may have had on her life, becoming free of substance use and gaining stable housing.

"...a fund to help the homeless and to help recovering addicts anyone like that really, she does a lot of work around it so to help me rebuild my life really when I get back because everything was just a mess when I came here." Carol - 19:891-897

Carol describes how her recovery process using the 'Twelve Step Fellowship' ethos has enabled her to change her thoughts and attitudes in a fundamental way [39, 40]. Carol was able to identify and form positive relationships with other people at the meetings and may have started to form a positive relationship with herself.

"...changing my thought process that's what it's about it's about change isn't it, if you're willing and want to at the end of the day the amount of passion I put into 22 years of addiction, do you know what I mean, I can put into recovery can't I?" Carol - 4:192-198

"...it is true there is no better way to help an addict than another addict absolutely anything you say...I guarantee there is one other person that can relate at least one other person, you know what I mean, nobody outside an addiction can understand."
Carol - 28:1313-1321

Discussion

The study aimed to seek and gain a more definitive understanding of the inter-relationship between substance use, homelessness and ABI by identifying key themes associated with the inter-relationship between these variables. This understanding will help to better inform healthcare professionals when developing person-centred approaches to intervention. The study identified five key themes of 1) adverse childhood experiences and trauma, 2) mental health 3) cognitive decline and executive function, 4) services and 5) relationships.

The main overarching theme within the study was that of adverse childhood experiences and trauma. Felliti et al [35] defined adverse childhood experiences as any of the

Running Head: Brain injury, substance use and homelessness

following; domestic violence, parental abandonment (through separation or divorce), parents with mental health conditions, being the victim of abuse (physical, sexual and/or emotional) being the victim of neglect (physical and/or emotional), a member of the household being in prison, growing up in a household in which there are adults experiencing alcohol and/or drug use problems. The participant accounts covered many of these areas. This particular theme was important as adverse childhood experiences and trauma were implicated in the lives of the participants prior to them experiencing any other factors (e.g. poor mental health, cognitive impairment, or substance use). While participants in the study varied in terms of which factors occurred first between ABI, substance misuse and homelessness, all experienced adverse childhood experiences first (or at the same time as ABI), suggesting that these form the root or partial cause for many of the other factors. Adverse childhood experiences and trauma are fundamental to understanding the inter-relationships between ABI, substance use and homelessness, and understanding how the five themes relate to one another.

The presence of adverse childhood experiences and trauma was associated with participants experiencing negative relationships in early life, either within their family environment or with peers through bullying or sexual assault. Research suggests that children exposed to adverse childhood experiences face difficulties in later life building positive relationships and are more likely to form relationships that are detrimental [41]. Children who are maltreated can develop attachment difficulties, including poor emotional regulation, lack of trust and fear of getting close to other people [41]. This is important for considering intervention approaches for individuals in adulthood. Models need to be based on building strong positive and supportive relationships.

Running Head: Brain injury, substance use and homelessness

These negative relationships, along with the trauma from adverse childhood experiences led to the development of a wide-range of mental difficulties, including psychosis, anxiety and depression, and the misuse of substances, as indicated in previous literature [42,43,44]. Furthermore, some participants who had experienced adverse childhood experiences and trauma identified that their ABIs were often as a direct result of their experiences (e.g. through physical abuse), as supported by previous literature [42], highlighting the need for adverse childhood experiences screening and treatment. Furthermore, adverse childhood experiences can lead to structural changes in the developing brain of the child in areas associated with cognitive and emotional functioning [42]. Mental health problems were at points caused, and in others exacerbated, by the presence of an ABI and substance use, and substance use in turn led to greater cognitive impairment and decline. Furthermore, evidence suggests that adverse childhood experiences also lead to poorer health for physiological reasons, for instance, potentially due to allostasis and increased allostatic load [45]. These mental health difficulties may have also exacerbated the likelihood of homelessness and been associated with the increased use of substances in this population.

A recent review [43] concluded that there was a positive association between adverse childhood experiences and traumatic brain injury (TBI) and the review highlighted the need for adverse childhood experiences screening and treatment. The review also provided evidence that the effects of adverse childhood experiences impact the anatomical development of a child. The review discussed structural imaging studies that have shown that child maltreatment effects developmental changes in the brain

Running Head: Brain injury, substance use and homelessness

compared to controls. These structural alterations in particular effect areas of the brain associated with cognitive and emotional functioning such as the pre-frontal cortex and the limbic system, functional studies support the anatomical evidence and have indicated that maltreated children may experience impairment to executive function and display hypervigilance in response to emotional threats as shown through neural activation. The review also suggested that children exposed to adverse childhood experiences were more susceptible to mental health problems including psychosis, anxiety, depression as well as substance abuse and violence. Of the eight participants in the present study, six participants fell under the definition of adverse childhood experiences as defined above, five of which sustained an ABI in the form of a TBI. Another recent review [44] provides evidence that people who had experienced four or more categories of childhood exposure to adverse childhood experiences, had a four to twelve-fold increased health risk to alcoholism, drug use, and depression and suicide attempts compared to those who had experienced none. The review also suggests that a person with exposure to several adverse childhood experiences as a child is more likely to have children that also experience adverse childhood experiences.

Risk-taking behaviours were also implicated in the development of ABIs, where poor relationships within their homes and adverse childhood experiences, may have led them to engage in substance use and other risk-taking behaviours, leaving them more prone to situations that might cause head injury (e.g. assaults, bullying, domestic abuse). The relationship between adverse childhood experiences and other factors including poor educational achievement and engagement in risky behaviours increasing susceptibility to poor mental and physical health, substance abuse, low employment and social

Running Head: Brain injury, substance use and homelessness

deprivation has been previously identified [46]. ABIs themselves may also exacerbate risk-taking behaviours due to executive impairments such as disinhibition and impulsivity [28]. It is essential that those vulnerable to sustaining an ABI (including the homeless and individuals with substance abuse issues) are monitored and engaged with by healthcare professionals. This should take place in an environment that is suitable and safe, such as psychologically informed environments, within homeless shelters, drop in centres, or addiction treatment centres [47].

The inter-relationships between these variables were in part responsible for the poor interactions participants experienced with services. Their lack of trust in others made it difficult for them to engage due to previous adverse childhood experiences and poor relationships. In many cases, their ABI and cognitive impairments were not considered, and often went undiagnosed, as part of their package of care. In cases where services performed well for our participants, was in situations where individual members of staff took the time to build positive relationships with them and go beyond policies and procedures to offer personalised support. When considering intervention, it is important to note that interpersonal relationships are further hindered following an ABI and may cause social isolation, feelings of loneliness, increasing vulnerability [48,49]. This highlights the need for professionals to establish and build trusted, meaningful relationships with their clients.

Clinical Implications

Children exposed to a high number of adverse childhood experiences [41] need to be identified early and provided with support and education to aid positive mental, physical and emotional well-being. By providing training to healthcare professionals and other

Running Head: Brain injury, substance use and homelessness

institutions in order to spot the signs and then providing opportunities to young people outside of the family home to become socially connected.

The most vital clinical implication from this study is the need to routinely screen for the presence of ABI within client groups. Symptoms of ABI are often hidden particularly those associated with executive function (e.g. initiation, planning and organisation) [28]. Screening for brain injury is important for ensuring service provision is appropriate to the individual. If an individual has cognitive impairments, particularly executive impairment, they may be less able to engage with standard addiction support models or self-help strategies. For example, the presence of memory deficits may mean that individuals are more likely to miss appointments and are often misconstrued as “not engaging” with services. Executive impairments lead individuals to engage more willingly in risk-taking behaviours such as substance misuse without fully understanding the consequences of their behaviour [49, 50]. The combination of these factors and poor financial decision-making and planning difficulties leaves individuals with ABI at an increased vulnerability to homelessness [7]. This screening alongside screening for adverse childhood experiences would allow clinicians to gain a full clinical picture of individuals in order to tailor interventions more effectively. Understanding the presence of brain injury and adverse childhood experiences are important for overcoming the barriers associated with these factors in rehabilitation and to prevent further difficulties in the future. For a comprehensive and holistic approach to neurorehabilitation to be undertaken, a complete understanding of functioning pre-injury, experience of prior service use and the impact of adverse childhood experiences needs to be integrated to encompass the bio-psycho-social nature of the condition. Rehabilitation needs to be

Running Head: Brain injury, substance use and homelessness

tailored to each individual accordingly to humanise the process and support engagement and goal attainment [51,52,53]. Further research is needed into the effectiveness of screening tools in providing more detailed and nuanced assessments that help to structure and design rehabilitative responses.

It is also important for healthcare professionals to be aware that there may not be any obvious external clinical evidence that a person has a brain injury, and somebody may not even be aware they have an ABI and may be living with impairments without an understanding of their true cause (as in the case of Fran). Tools such as the brain injury screening index [30] are readily available and provide an excellent way of ascertaining if a person has had any significant traumas to the head or if they are experiencing any symptoms synonymous with ABI. Professionals also need to be aware that TBIs are just one way that an individual can injure their brain, whereas other causes may come from lack of oxygen to the brain, overdose, bleeds or infections such as meningitis or encephalitis [1], which requires detailed searching of medical records to pick up, particularly if they occurred in childhood.

A final recommendation from this study would be for improved access to neuro-specific rehabilitation services. While routine mental health, substance use and homelessness services may all be of use to these service users, the nuances of brain injury are often poorly understood by professionals [20, 54], and as such specialist service provision is required that can provide intervention in a holistic and integrated manner. To not do so unfairly places the blame for the failure of a brain injured person to engage and fully benefit from standard mental health, homelessness and

Running Head: Brain injury, substance use and homelessness

substance use services with the service user. If brain injury specific difficulties are overlooked or not understood by services, chances for positive changes are missed and “revolving door” service use can commence with the concomitant wasted costs and opportunities.

Limitations

Although eight participants in an IPA study is considered an adequate number, eight people’s experiences are not truly indicative of the general population. This is not the focus of IPA, which explores the meaningful experiences of a small number of individuals, but does make it difficult to draw conclusions about the wider group.

The research team encountered difficulties recruiting participants that fit all the criteria, leading to participants being included if they had an ABI and either substance abuse issues and/or homelessness. This limitation in some respects was also a strength, as areas of convergence occurred regardless of the participant differences. For example, Fran was not homeless but displayed serious self-neglect and her home was unsanitary in nature. In contrast Arthur who did not have substance abuse issues but was homeless was extremely well presented and took pride in his appearance. However, both had serious mental health issues, deficits in executive function, been exposed to adverse childhood experiences and had both sustained an ABI.

The population being investigated often showed signs of cognitive decline and memory impairment. Harriet was the only participant to have an advocate present. Throughout

Running Head: Brain injury, substance use and homelessness

the interview a number of events, times and areas pertinent to the study were prompted by the advocate to discuss. Therefore, this raises the issue of how many of the participants missed out key events or information that may have aided the study. Further research would benefit from having an advocate or trusted friend or family member present in order to assist during the interview process through prompting or triangulating evidence. Although a limitation, it does raise an important clinical implication; clients who are interviewed or assessed by healthcare professionals without an advocate, or without corroborating information from others close to the individual, are more likely to miss the subtle nuances of the impact of the ABI, or key information relevant to the individual [50, 55]. Further research is therefore needed into the routine use of advocacy within the clinical environment where an absence of expert knowledge may lead to important clinical information being missed [50].

Conclusion

This investigation has provided evidence highlighting the complex inter-relationship between ABI, substance abuse and homelessness. Although the investigation highlighted a number of areas of convergence including: Mental Health; Cognitive Decline and Executive Function; Services; and Relationships, the most striking discovery was that of adverse childhood experiences and the impact these have, increasing susceptibility to ABI and psychosocial consequences such as substance abuse and homelessness, impacting an individual's adult life, including the ability to form positive relationships. This research study has finally given a voice to those hidden from previous research and service provision. From a clinical perspective, healthcare professionals must ensure that intervention models are designed to build positive, strong and

Running Head: Brain injury, substance use and homelessness

supportive relationships. Furthermore, healthcare professionals should routinely screen for ABI and TBI when undertaking assessments with individuals to ensure they receive the right support and intervention. Until then, ABI will remain a hidden disability, impacting vulnerable individuals as they remain undiagnosed, untreated and ultimately alone.

Acknowledgements: Thank you to the homelessness organisations who helped with recruitment and to our participants for sharing their difficult stories.

Data availability statement: Data can be obtained through contacting the first or second author.

References

1. Headway UK. *Statistics* [online]. Nottingham; 2018. Available at://www.headway.org.uk/about-brain-injury/further-information/statistics/ [Accessed 5 Mar. 2018].
2. Maas AI, Menon DK, Adelson PD, et al. Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *Lancet Neurol.* (2017); 16(12):987-1048.
3. Silver J, McAllister T, Yudofsky S. *Textbook of Traumatic Brain Injury*. Washington: American Psychiatric Publishing; 2004.
4. Jumisko E, Lexell J, Soderberg S. The meaning of living with traumatic brain injury in people with moderate to severe traumatic brain injury. *J Neurosci Nurs.* 2005; 37(1): 42-50.
5. Velikonj, D, Warriner E, Brum C. Profiles of emotional and behavioral sequelae following acquired brain injury: Cluster analysis of the Personality Assessment Inventory. *J Clin Exp Neuropsych.* 2009; 32(6): 610-621.

Running Head: Brain injury, substance use and homelessness

6. Hesdorffer D, Rauch S, Tamminga C. Long-term psychiatric outcomes following traumatic brain injury: a review of the literature. *J Head Trauma Rehab.* 2009; 24(6): 452-459.
7. Oddy M, Moir J, Fortescue D, et al. The prevalence of traumatic brain injury in the homeless community in a UK city. *Brain Injury.* 2012; 26(9): 1058-1064.
8. Ponsford J, Whelan-Goodinson R, Bahar-Fuchs A. Alcohol and drug use following traumatic brain injury: A prospective study. *Brain Injury.* 2007; 21(13-14): 1385-1392.
9. Corrigan JD. Substance abuse as a mediating factor in outcome from traumatic brain injury. *Arch Phys Med Rehab.* 1995; 76(4): 302-309.
10. Hayes SC, Barnes-Holmes D, Roche B. *Relational frame theory: A post-Skinnerian account of human language and cognition.* New York: Kluwer Academic/Plenum; 2001.
11. Gould TJ. Addiction and cognition. *Addict Sci Clin Prac.* 2010; 5(2): 4-14.
12. Heirene R, John B, Roderique-Davies G. Identification and Evaluation of Neuropsychological Tools Used in the Assessment of Alcohol-Related Cognitive Impairment: A Systematic Review. *Front Psychol.* 2018; 9: 2618.
13. Gustavson DE, Stallings MC, Corley RP, et al. Executive functions and substance use: Relations in late adolescence and early adulthood. *J Abnorm Psychol.* 2017; 126(2): 257-270.
14. Mueller JA, Dollaghan C. A systematic review of assessments for identifying executive function impairment in adults with acquired brain injury. *J Speech Lang Hear R.* 2013; 56: 1051-1064
15. Anderson V, Jacobs R, Anderson PJ. Executive functions and the frontal lobes: a lifespan perspective. London: Taylor & Francis; 2008.
16. Gonzalez CL, Mills KJ, Genee I, et al. Getting the right grasp on executive function. *Front Psychol.* 2014; 5: 285.
17. Douglas J. The relationship of executive functioning and pragmatic outcome following severe Traumatic Brain Injury. *J Speech Lang Hear R.* 2010; 53: 365–382.

18. Hofgren C, Esbjornnson E, Sunnerhagen KS. Return to work after acquired brain injury: facilitators and hindrances observed in a sub-acute rehabilitation setting. *Work*. 2010; 36: 431-439.
19. Odumuyiwa M, Kennedy M, Norman A, et al. Improving access to social care services following acquired brain injury: A needs analysis. *Journal of Long Term Care*. 2019; in press.
20. Holloway M. How is ABI assessed and responded to in non-specialist settings? Is specialist Education required for all social care professionals? *Soc Care Neurodis*. 2014; 5(4): 201-213.
21. Wood RL, Liossi C, Wood L. The impact of head injury neurobehavioural sequelae on personal relationships: Preliminary findings. *Brain Injury*. 2005; 19: 845-851.
22. Norman A. A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury". *J Adult Protection*. 2016; 18(6): 341-352, doi: 10.1108/JAP-08-2016-0017.
23. O'Connor T, Panenka W, Livingston E, et al. Rates of incident traumatic brain injury in marginally housed persons. *Brain Injury*. 2019; 33(s1): 602.
24. Mason K, Cornes M, Dobson R, et al. Multiple Exclusion Homelessness and adult social care in England: Exploring the challenges through a researcher-practitioner partnership. *Res Policy Plan*. 2017; 33(1): 3-14.
25. McMillan TM, Laurie M, Oddy M, et al. Head injury and mortality in the homeless. *J Neurotrauma*. 2015; 32: 116-119.
26. National Coalition for the Homeless. *Substance abuse and homeless*. Washington, USA; 2017. Available at: [Http://nationalhomeless.org/wp-content/uploads/2017/06/Substance-Abuse-and-Homelessness.pdf](http://nationalhomeless.org/wp-content/uploads/2017/06/Substance-Abuse-and-Homelessness.pdf) [Accessed 5 Mar. 2018].
27. Hwang S, Chambers C, Chiu S, et al. A Comprehensive Assessment of Health Care Utilization Among Homeless Adults Under a System of Universal Health Insurance. *Am J Public Health*. 2013; 103(S2): pp.S294-S301.

28. Olson-Madden JH, Brenner LA, Corrigan JD, et al. Substance use and mild traumatic brain injury risk reduction and prevention: a novel model for treatment. *Rehabil Res Prac.* 2012; 174579: doi: 10.1155/2012/174579.
29. Smith JA, Osborn, M. Interpretative Phenomenological Analysis. In Smith, J. A. (ed) *Qualitative Psychology: A Practical Guide to Research Methods (2nd edition, pp. 53-80)*. London: SAGE Publications; 2008.
30. Disabilities Trust Foundation. Brain Injury Screening Index. Wakefield, UK: 2018. Available at: <https://www.thedtgroupp.org/foundation/brain-injury-screening-index> [Accessed 27 Aug. 2018].
31. European Monitoring Centre for Drugs and Drug Addiction. Drug Abuse Screening Test (DAST 20). Lisbon, Portugal; 1982. Available at: <http://www.emcdda.europa.eu/html.cfm/index3618EN.html>. [Accessed 27 Aug. 2018]
32. World Health Organisation. World Alcohol Use Disorders Identification Test (AUDIT). Geneva; 1989. Available at: <https://auditscreen.org/> [Accessed on 27 Aug. 2018]
33. Whyte J, Schuster K, Polansky M. et al. Frequency and duration of inattentive behavior after traumatic brain injury: Effects of distraction, task, and practice. *J Int Neuropsychol Soc.* 2000; 6(1): 1-11.
34. Smith JA, Flower P, Larkin M. *Interpretative phenomenological analysis: theory, method and research*. USA: Sage Publishing; 2009.
35. Brocki J, Wearden A. A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychol Heal.* 2006; 21(1): 87-108.
36. Dahlberg K. The essence of essences – the search for meaning structures in phenomenological analysis of lifeworld phenomena. *Int J Qual Stud Heal.* 2006; 1: 11-19.
37. Smith JA. Reflecting on the development of Interpretative Phenomenological Analysis and its contribution to qualitative research in psychology. *Qual Res Psychol.* 2004; 1: 39-54.

Running Head: Brain injury, substance use and homelessness

38. Crossen B, Barco P, Velozo C, et al. Awareness and compensation in post-acute head injury rehabilitation. *J Head Trauma Rehab.* 1989; 4(3): 46-54.
39. Smith B, Wilson, B. *The big book of alcoholics anonymous.* New York: Createspace; 2013.
40. Walters ST, Rotgers F. (Eds.). *Treating substance abuse: Theory and technique.* New York: Guilford Press; 2011.
41. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *Am J Prev Med.* 1998; 14(4): 245-258.
42. Hughes K, Lowey H, Quigg Z, et al. Relationships between adverse childhood experiences and adult mental well-being: results from an English national household survey. *BMC public heal.* 2016; 16(1): 222.
43. Ma Z, Bayley MT, Perrier L, et al. The association between adverse childhood experiences and adult traumatic brain injury/concussion: a scoping review. *Disabil Rehabil.* 2018; 41(11): 1360-1366.
44. Hughes K, Bellis MA, Hardcastle KA, et al. The effect of multiple adverse childhood experiences on health: a systematic review and meta-analysis. *Lancet Public Heal.* 2017; 2(8): e356-e366.
45. Danese A, McEwen BS. Adverse childhood experiences, allostasis, allostatic load and age-related disease. *Physiol Behav.* 2012; 106: 29-39.
46. Anda RF, Felitti VJ, Bremner JD, et al. The enduring effects of abuse and related adverse experiences in childhood. *Eur Arch Psy Clin N.* 2006; 256(3): 174-186.
47. Haigh R, Harrison T, Johnson R, et al. Psychologically informed environments and the "Enabling Environments" initiative. *Housing, Care Support.* 2012; 15(1): 34-42.
48. Salas CE, Casassus M, Rowlands L, et al. "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychol Rehabil.* 2018; 28(7): 1161-1178.
49. Hwang S, Colantonio A, Chiu S, et al. The effect of traumatic brain injury on the health of homeless people. *Can Med Assoc J.* 2008; 179(8): 779-784.

- 1
2
3 50. Moore S, Wotus R, Norman A, et al. Behind the cloak of competence: Brain
4 Injury and Mental Capacity Legislation. J Adult Protection. 2019; 21(4):
5 DOI:10.1108/JAP-02-2019-0007.
6
7
8
9 51. Todres L, Galvin KT, Holloway I. The humanization of healthcare: A value
10 framework for qualitative research. Int J Qual Studies Heal Well-being. 2009; 4:
11 68-77.
12
13
14 52. Yeates G. Avoiding the skull seduction in post-acute acquired brain injury
15 services: individualist invitations and systemic responses. Clinical psychol
16 forum- new series. 2007; British psychological Society: 33.
17
18
19 53. Gracey F, Malley D, Wagner AP. Et al. Characterising neuropsychological
20 rehabilitation service users for service design. Soc Care Neurodis. 2014; 5: 16-
21 28.
22
23
24 54. George MS, Gilbert S. Mental Capacity Act (2005) assessments: why everyone
25 needs to know about the frontal lobe paradox. The Neuropsychologist. 2018:
26 59 - 66.
27
28
29 55. Clark-Wilson J, Giles GM, Baxter DM. Revisiting the neurofunctional approach:
30 Conceptualizing the core components for the rehabilitation of everyday living
31 skills. Brain Injury. 2014; 28: 1646-1656.
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Running Head: Brain injury, substance use and homelessness

Participant	Age	Gender	Brain injury	Substance Abuse	Housing status	Cognitive: motor and mental health
Arthur	59	Male	TBI* aged 14 unconscious, 4 strokes; TBI aged 51 unconscious Small vessel brain disease	Recreational cannabis use every two weeks; occasional cider; experimented with hallucinogens	Street homeless; currently engaged with services for housing	insomnia; working memory deficits; speech impairment; emotional regulation Mental health problems
Betty	25	Female	TBI aged 14; slow growing tumour removed; residual remaining	Heroin, crack, cocaine abuse (smoked); ketamine, cannabis, heavy alcohol use	Street homeless	Poor memory; concentration; Mental health problems
Carol	37	Female	TBI – fractured skull aged 7 unconscious; TBI: car accidents (aged 14 & 20 years) unconscious; TBI aged 24 unconscious	Heroin (IV); crack cocaine (smoked); heavy alcohol use; currently clean for 6 weeks at time of interview	Recently permanently housed after 20 years street homelessness	self-regulation; seizures; blackouts; poor memory Mental health problems
Dexter	31	Male	TBI aged 19; numerous blows to the head fighting; possible alcohol-related	Alcoholic; heavy cocaine use; previous cannabis user	Never been homeless	Planning & organisation; memory; concentration; alcohol-related blackouts Mental health problems
Erian	39	Male	TBI aged 20 unconscious; alcohol-related brain injury	Heavy alcohol use last 12 months. Currently in treatment	Never been homeless	Working memory; concentration Mental health problems

Running Head: Brain injury, substance use and homelessness

Fran	51	Female	TBI aged 2 unconscious; TBI aged 47; possible alcohol-related brain injury	Amphetamine sulphate; heavy alcohol use	Never been homeless but serious self-neglect	Working memory Mental health problems
Gordon	58	Male	TBI aged 17 car accident; TBI aged 20 unconscious; TBI aged 38 unconscious; TBI aged 56 10 day coma; possible alcohol-related injury	Heavy synthetic hallucinogen use in twenties; cocaine use in 30s and 40s; heavy alcohol use	Homeless in temporary accommodation	Undergoing psychiatric assessment: possible high functioning autism; motor skills Mental health problems
Harriet	26	Female	TBI aged 12; TBI aged 16 unconscious; TBI aged 18 unconscious; TBI aged 22 unconscious; possible hypoxia due to overdose aged 23 unconscious	Ketamine; heavy alcohol use; crack cocaine and heroin (smoked); prescription medication	Recently permanently housed; Previously homeless living in tent then temporary accommodation	Gait and movement; Aphasia & apraxia; language production; self-harm; Multiple mental health problems

*TBI = traumatic brain injury

Table 1. Participant Information Table

Running Head: Brain injury, substance use and homelessness

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For Peer Review

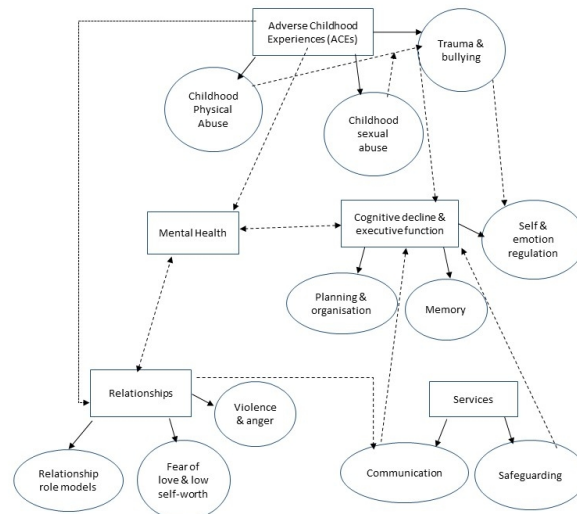


Figure 1: Thematic map showing relationship between themes

Figure 1: Thematic map showing relationship between themes

338x190mm (96 x 96 DPI)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Supplementary material: Interview Schedule

Part A – narrative

‘I am interested in learning about how you came to be homeless, your experience concerning brain injury and your experience using drugs and alcohol. Please begin where you would like to. I will listen first, I won’t interrupt you. I’ll take some notes in case I have any questions, so I can ask you when you’ve finished telling your story.’

Part B – specific

- What was your childhood like growing up?
- When did you first experience a head injury or can you recall when you first significantly hit your head? Can you please describe this?
- What was it that made you seek medical attention?
- Can you tell me how many head injuries you have received and the impact these have had on you? Please describe them and when they happened.
- What was your life like prior to your head injury?
- Can you describe any differences you noticed after your head injury?
- Did you notice any cognitive impairment? Eg memory loss, speech
- Did you notice anything different in the way you felt about your self?
- Can you describe your diagnosis/medical experience?
- Can you describe your experience of referral to other professionals and services?
- Can you describe your experience concerning drugs and alcohol and when you first started using?
- Why did you first start using drugs and why do you use them now?
- Can you describe your experience of the care you have received from the services you have been involved with? Concerning substances, homelessness, head injury.
- How do you feel about your role in making decisions about your health and situation?
- Do you feel well-informed and included in the decision-making process in terms of treatment and interventions you have received or currently receiving?

1
2
3 Do you feel that your emotional, psychological needs have been met?
4

5
6 Do you feel your physical needs have been met?
7

8 Do you think that there are any other services or interventions you would like to receive?
9
10

11
12
13 **Part C- generic**
14

15 What was important to you before becoming homeless and what is important to you now?
16

17
18 What was important to you before using drugs and alcohol? and now?
19

20 What was important to you before sustaining your head injury? and now?
21

22 What do you think the future holds for you?
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60