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Brachial plexus injury: living with uncertainty

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ABSTRACT

Purpose: A traumatic brachial plexus injury (BPI) has life-changing consequences for patients and their families. Despite advancements in treatments final outcome is unpredictable depending on factors including time to treatment, injury severity, neural regeneration, and available interventions. The final outcome may not be seen for up to four years. This study aimed to explore the impact of uncertainty on people with a traumatic BPI.

Methods: Secondary qualitative analysis was conducted on data from a study exploring outcomes important to patients with a traumatic BPI. Data from semi-structured interviews with adult traumatic BPI patients ($n = 13$) were analyzed using reflexive thematic analysis.

Results: Three major themes were identified in the qualitative data: (i) "I don't know what happened to me," focused on uncertainty in diagnosis. (ii) "I went to work one day... and then it all changed" centered around uncertainty in the future. (iii) Coping with uncertainty.

Conclusion: The results illustrate that people with a traumatic BPI face uncertainty regarding diagnosis, prognosis, and surrounding their roles in the future. Individuals respond to uncertainty in different ways and this needs to be understood by health care professionals.

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► IMPLICATIONS FOR REHABILITATION

- Health professionals should consider uncertainty in all their contacts with people who have experienced a traumatic brachial plexus injury.
- People with a traumatic brachial plexus injury experience uncertainty in different ways therefore education and information given may be optimized if tailored to the individual rather than generic.
- Increasing awareness of the injury and its presentation in non-specialist acute care clinicians may accelerate diagnosis and reduce initial uncertainty.
- Acknowledging the presence of uncertainty is important during the shared decision-making in brachial plexus injuries.



Introduction

A brachial plexus injury (BPI) is a devastating injury to the nerves that provide sensation and movement to the upper limb. BPI occurs most commonly in young adults following a road traffic collision [1] and, although rare [1,2], has life-changing consequences for individuals and their families. Despite new treatments, there is evidence that individuals with a BPI continue to suffer emotional and psychological distress [3]. People with BPIs report significant challenges with returning to work [4–6] body image [5,7] and social anxiety [5,7,8] and financial uncertainties exacerbate these concerns [6,8]. Qualitative studies highlight changes in role and identity [4,6], experiences with healthcare [4,6,8], and negative psychosocial impacts [6,7,9].

BPIs are diverse, depending on the level and severity of the injury, and are often associated with polytrauma [1,2,10]. Most injuries have a significant effect on physical functioning [11,12] including long-term paralysis [1] and neuropathic pain [5,9,13]. Advancements in microsurgery have made nerve repair and

reconstruction possible for some patients [14]. However, outcomes regardless of having surgery, remain unpredictable [15] and dependent on several factors including timely surgical intervention [16], extent and severity of the injury, capacity for neural regeneration and surgical reconstruction, and the capability of the surgical team [15]. Recovery takes many years and is often incomplete [17] with expectations frequently not met [7] which means professionals find discussing prognosis after a BPI with patients challenging [15]. Additionally, patients have expressed frustration at the lack of information both online and from non-specialist health professionals [18,19] which potentially adds to the uncertainty.

Patients living with uncertainty in illness and healthcare may experience heightened emotional and psychological distress [20–23] including reduced quality of life [22]. Unaddressed, this can result in poor adaptation to illness [23] and poor coping strategies, such as searching unrealistically for medical certainty potentially leading to conflict with health professionals [24]. There is a wealth of research exploring uncertainty in other traumatic

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and long-term conditions, such as spinal cord injury, Multiple Sclerosis [25,26], and cancer [27]. This has informed service development and interventions for some conditions [28], however, its impact on people with a BPI has not yet been explored. Since uncertainty cannot be eliminated, it is crucial to understand how patients with a BPI experience it. This will inform how best to support patients coping with uncertainty.

This paper presents interview data from people with BPI and explores the impact of uncertainty on the lives of those with a traumatic BPI to inform service design, pathway development, and future research.

Methodology and methods

This paper draws on data from a broader qualitative study, exploring outcomes important to patients with a BPI to develop a Core Outcome Set [29]. A recurring theme in participants' narratives was uncertainty. These data provide the empirical basis for the article. We followed the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines for reporting qualitative analysis as far as these apply to secondary analyses [30].

Patient recruitment and sampling

This study was conducted in a tertiary care peripheral nerve injury setting (Queen Elizabeth Hospital Birmingham) in the United Kingdom between February and November 2019. All participants received treatment including rehabilitation from the national health service free at the point of delivery. Participants were adults, aged 16 or over with a traumatic BPI who were sampled purposively [31] to represent a diverse range of traumatic BPIs and sociodemographic characteristics including age, sex, and occupational status. The sampling framework is available in [Supplementary Information A](#). Invitations and participant information sheets were mailed or handed to patients who met eligibility criteria. The sample size was deemed sufficient when data saturation was achieved with no new analytical concepts emerging.

Data collection and analysis

One-to-one in-depth, semi-structured interviews were conducted using a topic guide developed by the research team and a patient advisor who has a BPI ([Supplementary Information B](#)). It included feelings when first injured and diagnosed, coping and support received, and impact on life and relationships. Space and opportunity were created during the interview to allow participants to elaborate on other important topics which would not otherwise have been discussed [32].

All interviews were conducted face to face by the first author. She was open about being a physiotherapist who treats individuals with BPI but emphasized she was undertaking this as part of her doctoral research. Interviews were conducted in a location of the participant's choosing (e.g. consulting room at Queen Elizabeth Hospital Birmingham, UK or the participant's home), recorded using a digital audio recorder, and transcribed verbatim using a transcription service. Field notes were recorded immediately after each interview to document the interviewers' perceptions of the interviews and the dynamics of the interaction.

The first author conducted an initial reflexive thematic analysis [33], following the stages recommended by Braun and Clarke [34,35]. She familiarized herself with the data and provisionally coded by actively reading and re-reading the transcripts. Initial coding conveyed the participants' physical and emotional

responses to described situations, such as initial diagnosis, treatments, ongoing impact, and role within family and society. To ensure rigor the research team met regularly to discuss the analytical strategy, interpret the data and refine and confirm the themes. These discussions were recorded to provide an audit trail of decision-making and aid reflexivity.

A reflexive standpoint was maintained throughout the study to understand the interviewer's influence on the research process and co-construction of the data with the participants [36]. Some of the participants were known to the interviewer through her work as a physiotherapist in the peripheral nerve injury unit. A reflexive journal was used to record beliefs, actions, and observations that might have influenced the collection and analysis of the data [37]. The interviewer (CM) considered how her positionality (White, female, middle class, physiotherapist) may have shaped interactions with the participants [36]. During the interviews she became an active participant in the discussion and story being told, providing whatever extra information asked for. This included disability income, advice on driving, and orthotics, such as slings [38].

Ethical approval

Ethical approval was granted on 1 March 2019 by West Midlands Solihull Research Ethics Committee (Ref 18/WM/0297) for the primary study.

Results

Thirteen participants (nine men and four women) were interviewed for between 46 and 113 min. Participant demographics and injury information are in [Table 1](#).

Themes

In this analysis of the interviews, we focused on uncertainty, keeping an open mind and with no predefined definitions of uncertainty. Thus, we explored how participants experienced uncertainty to understand how this impacted their lives. All interviews opened with an invitation for participants to describe how their injury happened, followed by a discussion about their initial experience with health care. This frequently revealed a period time of uncertainty about the diagnosis. Similarly, discussions about expectations or goals of treatment showed recurring uncertainties as patients were unclear about outcomes. Participants' accounts highlighted a variety of sources of uncertainty, not limited to the diagnosis and treatment of a BPI but also interpersonal relationships, daily activities, and future roles.

Our findings are presented in the following themes supported by illustrative quotes from the interviews.

- **"I don't know what was happening to me"**: experience of diagnosis and treatment decisions—participants' initial experience of diagnosis and the reality of dealing with uncertainty regarding the outcome of a BPI and interventions for it.
- **"I went to work one day ...and then it all changed"**: uncertain identity now and in the future—a loss of identity, change in previous life roles, and uncertainty regarding the future.
- **Coping with uncertainty**—the role that health professionals, family, and hope play in how individuals learn to cope with uncertainty.

Table 1. Demographics of included patients.

Pseudonym	Sex	Age (years)	Years from injury	BPI (supraclavicular /infraclavicular)	Upper/lower/pan plexus injury	Surgeries	Mechanism of injury
Jake	M	21–30	3–5	Supraclavicular	C5, C6, C7, C8 avulsion T1 in continuity lesion	Nerve transfer ×2 FMT ×1 Wrist arthrodesis	Motorbike
Amy	F	21–30	3–5	Supraclavicular	Pan plexus	Nerve grafts ×2 Nerve transfer ×2 FMT ×1	Car accident
Alan	M	31–39	<1	Supraclavicular	C5,6,7 rupture C7, T1 avulsions	Neurolysis	Motorbike
Henry	M	71–80	<1	Infraclavicular	Medial and lateral cord	Neurolysis	Shoulder surgery
Maurice	M	51–60	1–3	Infraclavicular	Posterior cord	No operation at time of interview	Dislocation
James	M	31–40	1–3	Supraclavicular	C8, T1 avulsions	Nerve transfer ×1 Tendon transfer ×1 MCP capsulodesis	Motorbike
Colin	M	31–40	1–3	Supraclavicular	C5, C6, C7 avulsions		Motorbike
Peter	M	41–50	1–3	Supraclavicular	C5,6,7 (upper)	Nerve transfers ×5	Motorbike
Emma	F	21–30	1–3	Infraclavicular	Lateral and posterior cord	Neurolysis ×1 Nerve graft ×1 Nerve transfer ×1	Work accident
Valerie	F	51–60	3–5	Infraclavicular	Pan plexus	Tendon transfer ×1	Dislocation
Sue	F	21–30	1–3	Supraclavicular	C8, T1 (lower)	Nerve transfers ×3 Tendon transfer ×1	Car accident
George	M	21–30	3–5	Supraclavicular	Pan plexus	Nerve graft ×1	Motorbike
William	M	31–40	1–3	Supraclavicular	C5,6 (upper)	Nerve transfers ×4	Pedestrian hit by car

F: female; M: male; FMT: free muscle transfer.

Theme 1: “I didn’t know what was happening to me”

This explores participants’ uncertainty in relation to their “Experience of diagnosis” and “Uncertainty in prognosis and outcomes of treatment.”

Experience of diagnosis

Participants were involved in major accidents and sustained other life-threatening injuries which were often prioritized leaving some participants unable to explain why their arms were not moving or why they were experiencing severe pain. Some felt their concerns about pain and loss of movement in the arm were not listened to or acted upon while more urgent or obvious injuries were treated. Maurice and James discuss their experiences with health care staff immediately after the injury.

I tried to mention something to someone about it but they were more interested about getting my bone back in. (Maurice)

I think ... (Hospital) thought they knew best because they were the hospital and the only thing I was complaining about the whole time was my arm! That’s the only thing I had problems with and that’s the only thing they didn’t concentrate on until it was too late in my opinion. (James)

Many participants highlighted that their own lack of knowledge and understanding of nerve injuries contributed to their feelings of loss of control and uncertainty. Emma describes how she didn’t know it was possible to injure nerves.

All I thought was I had broke my arm... .. I never knew anything and I never even knew like that I would damage my nerves do you know what I mean and that never even came into my head and (hospital name) kept saying that they was going to repair the breaks I was in a bad, bad place then, I just didn’t understand what was going on, I didn’t know what was happening to me... (Emma)

Similarly, Peter found it difficult to understand the terminology used by health professionals when discussing his nerve injury.

It is just confusing, there is so much, you hear all these words bounced around... .. They are not the words I understand! (Peter)

I thought it would be better yeah and err when they told me they cancelled the operation again I actually cried to be honest because I thought they were going to bolt me up and that was it and send me

home. You know I didn’t understand it, the err the extent of the injury, I think that could have been explained a little bit better to me to be honest, but apart from that all the care I received there was top notch.” (Peter)

Participants described experiencing non-specialist health care professionals’ lack of knowledge about BPI.

Yeah I was taken to (Hospital) first umm but they wasn’t, they wasn’t very clued up and they thought that I had just got breaks. (Emma)

I don’t think my GP even knows what it is, they haven’t got a clue, I talk to them about it and you know I say about working and they are like ‘and you could answer phones, use a keyboard’ so, I’m in constant pain all the time you know, you are not getting up for work when you are lying in bed all night trying to sleep. (Peter)

Uncertainty in prognosis and outcomes of treatment

Whilst confirming a diagnosis of BPI provided something concrete to relate to and explain to others, other uncertainties became apparent, such as outcomes. Alan, who was newly diagnosed with a supraclavicular BPI, discusses how difficult it was to decide to opt for surgery or not when outcomes are uncertain.

because I am like I don’t want to, for them to go ‘yeah we will do this operation and it will be great, it will be doing everything’ and then two years down the line you go ‘well actually no it didn’t work as good as we thought it would’ and then I go ‘right then amputation’ and that is two years wasted of trying to do things, trying to build my arm up and then it has just wasted a patient’s, my time in there where someone else could have been better off having it and then it is kind, it is kind of all them things. (Alan)

Similarly, Maurice discusses his frustration with this uncertainty and his desire for concrete timelines for recovery.

I wanted someone to say it would be over in six weeks, don’t worry (Maurice) this will be over in six weeks, everything will be back to normal and it is not and it is frustrating because you have got it in your head that by a certain time it will be better... (Maurice)

Faced with such uncertain outcomes and the limitations of medical interventions, some participants actively sought health information relating to potential interventions and prognosis.

William sought more information from online sources and discharge letters.

do you know, I didn't umm, I didn't fully understand it, I had done a lot of research on Wikipedia and things and read up about umm about it and on the, on the umm what's it called? On the discharge letters there was a bit of information written on there so I was reading that. (William)

Other participants did not feel informed enough to engage with the decision-making process and placed their trust in health professionals' decisions. Jake illustrates this,

Umm I don't know without talking to the consultant because obviously they have got their own ideas but you know whatever they think is best. I mean I don't know they are the experts, if you are going to someone you have got to think you are going to them so saying 'what do you think is next?' and so 'what we can do is, we can do that and that' and you can chose or, I don't know. (Jake)

Theme 2: "I went to work one day ... and then it all changed"

This explores participants' uncertainty regarding "Future role and identity" and "Personal relationships."

Future role and identity

Uncertainty was linked to anxiety about the future. Many participants worked in manual jobs and were worried about their income to cover current and future costs. They voiced dismay at lost opportunities in respect of future work and employment, life plans, and aspirations. Maurice worked in a warehouse prior to his injury.

Yeah I was doing warehouse work so I am a fit person and to me it has just brought me right down because I can't do nothing. So, of course, I am going through the worry what am I going to lose? What is it that I am going to actually lose I don't know you know so that is a worry as well. (Maurice)

Similarly, Emma worked in a factory and was progressing in her career. She was distraught about the prospect of losing future opportunities.

(CRIES) I had a career and I haven't got one now. I have lost it all. I went to work that day thinking that and then it all changed, it's the hardest part. (Emma)

She goes on to describe how she struggled with her employer's unrealistic expectations about her ability to return to work, influenced by their lack of knowledge about nerve injuries and their recovery.

He (employer) is telling everybody that it's about time you just manned up and come back to work and stop playing on it and all this, that's the sort of stuff I had because, because I couldn't take a picture, like an x-ray or something like that to say 'yeah this is what my problem is, it's nerves' no one really realises so they just look at it and think 'well she's had her op now so why isn't she back to normal' do you know what I mean, they don't realise it's a long time, it's a really long time, such a long process of getting well. (Emma)

Similarly, Jake explains here how he was given an ultimatum in his manual role which left him with limited choice.

So I worked on a site, where you know, I couldn't maintain equipment, or big machinery, cranes and stuff like that, so obviously I couldn't go back and do that, so when I went back to work they had me on just ordering spare parts and doing all the paperwork side of things and then it was around this time last year they called me in and said 'well we have had Occupational Health out here, you are not going to get better any time soon, we have found you a new role to do for work, you either do this or you walk' (Jake)

Some participants described feeling powerless to find secure living arrangements and pay for their needs in the future as a

result of loss of financial income. One participant became homeless for a time because of this.

Yeah so I literally lost, I lost my job, I lost my ability to do stuff and I lost my house all in one go ... so it was like sofa surfing from place to place, so but originally when I first had my accident my boss at the time let me stay with her for a couple of weeks whilst I had to get back on my feet and then once I got back on my feet I had to move out because obviously she couldn't afford to keep me and everything so and of course I wasn't actually renting a room off her so I couldn't get Housing Benefit for her or anything like that so but I have just sofa surfed pretty much for two years (James)

Personal relationships

Other people's lack of knowledge about the condition generated misunderstandings and misconceptions. Some participants discussed the uncertainty about whether to reveal the diagnosis to others and the frustrations of having to explain it.

because I couldn't take a picture, like an x-ray or something like that to say 'yeah this is what my problem is, it's nerves' no one really realises so they just look at it and think 'well she's had her op now so why isn't she back to normal' do you know what I mean, they don't realise it's a long time, it's a really long time, such a long process of getting well. (Emma)

Some avoided going out fearing continuing questions on what the injury was and when the recovery would happen.

So, going out with friends I would avoid, I think, well like it was thinking going for an interview or worrying about having to explain. I think, or having people question it so you will just avoid doing most things being there at the beginning. (Amy)

Theme 3: coping with uncertainty

This illustrates the role that health professionals and hope play in how individuals learn to cope with uncertainty.

Health professionals

Health professionals were key to supporting participants, acting as advocates on their behalf. Maurice discusses the support he received from a physiotherapist to navigate the sometimes unwieldy healthcare system.

last week, I think it was because, to be honest with you, I actually went to her(physiotherapist) about psychological help and she said 'well I am going to phone the doctor' and she got on the phone in front of me and got it all, got me the appointment and everything straight away and got me to see the doctor straight away and she really did help. (Maurice)

Amy really appreciated the regular appointments offered by healthcare professionals and found these helpful as she could talk to someone who understands her injury.

I think if you don't have appointments for a long time with the surgeons it is nice to be able to still, if you are worried about things, or you need help with stuff to be able to talk to someone that knows what they are on about. (Amy)

Hope

Some participants remained hopeful of a medical breakthrough many years following their injury. In the following extract, Amy discusses how important it is that she is not forgotten, and how important the hope for new treatments is.

I saw Doctor X, who still checks on me, he said there were, he was looking at technology which looked at more of your brain and that he would if it ever come out he would definitely put me down for that because I think everyone knows how I say yes to everything. He is still looking, I was really, I was really chuffed about that. (Amy)

Other participants preferred to live day to day. This enabled them to live more in the present and adjust to the changes in

their life, helping to prevent concerns about the future from becoming too overwhelming. Alan explains how important it was for him not to get his “hopes up”.

don't get your hopes up because I think the main thing is getting your hopes up because that was one of my biggest problems, I have got my hopes up thinking 'oh yes this will be over in six weeks' when the six weeks come, when the six weeks come and it is not, you sort of like go down back on a low again and then you build your hopes up again and then thinking 'this will be over in' and it is not going to happen. (Alan)

Discussion

Participants with a traumatic BPI face uncertainty about early diagnosis, outcomes, and prognosis in addition to uncertainties regarding their future role within family and society. Health professionals and hope can play an important role in helping participants deal with the uncertainty.

A key theme in this study was uncertainty around initial diagnosis and outcome after a traumatic BPI. Mischel [39] defined uncertainty in illness as an illness that is ambiguous, complex, with deficient information, and an unpredictable outcome. Participants in our study were often frustrated about the delay in diagnosis, feeling confused by the ongoing loss of movement, persistent pain, and “words” they didn’t understand. Non-specialist healthcare professionals’ lack of awareness of this relatively rare injury, the closed nature of a nerve injury, or the presence of other major injuries masking the BPI, may all have contributed to a delay in diagnosis. This is consistent with previous research in Australia [6] the UK and the United States of America (USA) [16]. Delays and missed injuries in polytrauma are recognized as a challenge [40] but for patients with a BPI, delays in diagnosis and referral for treatment result in poorer functional outcomes [16,41]. Research in other rare diseases identifies that delays in diagnosis contribute to uncertainty for patients [42]. To lessen the uncertainty around traumatic BPI diagnosis, and improve outcomes, raising awareness among non-specialist health professionals about the possibility of a BPI in a polytrauma situation is essential. Induction for staff in emergency care and trauma settings should include BPI training including referral pathways. Further research on the effectiveness of this training, in reducing missed BPIs, is also recommended. This could potentially accelerate diagnosis and access to appropriate specialist treatment and thus lessen the uncertainty for the patient.

When the diagnosis is established, decisions still need to be made about treatments, where the outcomes are variable and uncertain. The unpredictability of outcome and difficulties communicating the injury and its consequences to others, shown in this study, exacerbates patients’ uncertainty and has been shown in other rare diseases, such as childhood multiple sclerosis [43,44]. Some participants in this study responded to uncertainty, by actively seeking medical information, completing “research on Wikipedia” and reviewing “discharge letters.” However, others did not, and left the decision-making to health professionals citing “whatever they (surgeons) think is best.” In line with this study’s findings, people with BPI in the USA also report using numerous sources of information about diagnosis and treatment including doctors, online research, and media [19]. Online forums are frequently used by people with BPI to seek information about treatment, rehabilitation and recovery, and the process of seeking care [18]. Gathering information broadly can help patients develop a framework to interpret the meaning of the illness and understand the consequences to lessen uncertainty [39].

Healthcare encounters were meaningful for participants but when they felt they were not heard, this compounded uncertainty. Surgeons find discussing potential outcomes with patients with BPI challenging [15] which reflects findings in other areas of healthcare [45]. However, discussing and reflecting on uncertainties is essential for true shared decision-making and patient-centered care [46]. As part of shared decision-making, patient decision aids are recommended [47] to increase patient participation in decision making and help people to think about, clarify and communicate the value of each option to them personally [47]. Patient decision aids can therefore reduce decisional conflict and uncertainty from poor information and/or a lack of clarity about personal values [48]. With the increasing evidence base for BPI interventions [49–51], there is an opportunity for the BPI community (professionals and patients) to develop high-quality accessible patient decision aids and information to inform shared decision making and reduce uncertainty in this population.

Some participants discussed how hope was important to their adaptation to a BPI and this is reflected more generally in the disability literature [52]. Amy was “really chuffed” that her surgeon was still “looking” for medical breakthroughs and she had not been forgotten. This illustrates “concrete hope” partly framed by the *restitution* narrative [53] relating to the possibility of a medical cure and the restorable body-self. However, the loss of hope was also discussed by participants. Emma discussed how she has “lost it all.” This *chaos* narrative imagines life never getting better [53] and results in expressed despair. These narratives have also been identified as shaping types of hope used by men following spinal cord injuries (SCI) [54]. The sudden loss of physical ability in a younger demographic may account for the similarities in their narratives.

Despite some participants using hope to cope with the uncertainty of a BPI, health professionals fear providing false hope [15,45] seeing hope as a double-edged sword as there may be a gap between patients’ hope for recovery and the realistic outcome expectations [45]. However, there are ways for health care professionals to support hope during uncertainty. Normalizing a patient’s feelings by active listening [55] and affirming the patient’s values [56] are important. The patient may be hoping for a cure that will never occur, but their valuing of a pain-free life or active arm movement can be affirmed. Giving time, through rehabilitation, for patients to adjust to their new reality and limitations [45] is a strategy used in other areas of rehabilitation to maintain hope. This could also be used in BPI care. Tailoring communication to patient “readiness” may foster hope and limit negative reactions (frustration and demotivation) [45]. However tailoring communication requires knowledge of the patient’s perspectives, what they understand from other consultations, their hopes, and expectations. In essence, different narratives of hope were told in our study and as such it emphasizes the need for a person-centered approach to discuss unfavorable prognoses and favor hope.

Strengths and limitations

The study has some limitations. The chief investigator (first author) is a physiotherapist with experience in treating patients with a traumatic BPI. Preconceived ideas and their potential impact on data collection and analysis were discussed openly within the team and documented in a reflective journal. Engaging in this reflexivity evidenced the transparency of the data presented. Similarly, participants’ knowledge that the interviewer was a physiotherapist may have influenced their responses when

discussing their experiences. Data in this study were generated from one interview during each participant's recovery after a traumatic BPI. This does not illuminate how uncertainty may change over time from injury. To improve understanding of uncertainty throughout a patient's recovery, longitudinal serial interviews could be undertaken in future research.

This study has produced rich data about the lived experiences of a purposive sample of individuals with a traumatic BPI. The main strengths of our study are the different steps taken to ensure trustworthiness [57]. We used an audit trail and a reflective journal to support the analysis and credibility of the findings. Development of a topic guide, systematic analysis, and interpretations grounded in patient data evidence confirmability of the study [57]. To enhance transferability, participants were purposively sampled ensuring maximum variation in injury and other demographic factors including age and sex. Many individuals were recently injured which is unusual in such studies and provides insight into the experience of initial injury and treatment in the acute setting. Secondary data analysis was used to advance our understanding of uncertainty whilst minimizing the burden of research on participants.

Conclusions

This study provides an in-depth understanding of the impact of uncertainty on the lives of people sustaining traumatic BPIs. Uncertainty was particularly focused on initial diagnosis, future outcomes from the injury, and role identity. Health professionals and hope were important in dealing with the uncertainty associated with a traumatic BPI. This knowledge should enable health professionals to better support patients following a traumatic BPI.

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Consent

All participants in this research provided written consent to the inclusion of material pertaining to themselves. Participants cannot be identified *via* the paper and are anonymized.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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References

- [1] Cho ÁB, Guerreiro AC, Ferreira CHV, et al. Epidemiological study of traumatic brachial plexus injuries. *Acta Ortop Bras.* 2020;28(1):16–18.
- [2] Kaiser R, Waldauf P, Ullas G, et al. Epidemiology, etiology, and types of severe adult brachial plexus injuries requiring surgical repair: systematic review and meta-analysis. *Neurosurg Rev.* 2020;43(2):443–452.
- [3] Hruby LA, Pittermann A, Sturma A, et al. The Vienna psychosocial assessment procedure for bionic reconstruction in patients with global brachial plexus injuries. *PLOS One.* 2018;13(1):e0189592.
- [4] McDonald J, Pettigrew J. Traumatic brachial plexus injury: the lived experience. *Br J Occup.* 2014;77(3):147–154.
- [5] Wellington B. Quality of life issues for patients following traumatic brachial plexus injury – part 2 research project. *Int J Orthop Trauma Nurs.* 2010;14(1):5–11.
- [6] Brito S, White J, Thomacos N, et al. The lived experience following free functioning muscle transfer for management of pan-brachial plexus injury: reflections from a long-term follow-up study. *Disabil Rehabil.* 2021;43(11):1517–1525.
- [7] Franzblau L, Shauver M, Chung K. Patient satisfaction and self-reported outcomes after complete brachial plexus avulsion injury. *J Hand Surg Am.* 2014;39(5):948–955.
- [8] Verma C, Vora T, Thatte M, et al. Patient perception after traumatic brachial plexus injury – a qualitative case report. *J Hand Ther.* 2020;33(4):593–597.
- [9] Mancuso C, Lee S, Dy C, et al. Expectations and limitations due to brachial plexus injury: a qualitative study. *Hand.* 2015;10(4):741–749.
- [10] Kaiser R, Mencl L, Haninec P. Injuries associated with serious brachial plexus involvement in polytrauma among patients requiring surgical repair. *Injury.* 2014;45(1):223–226.
- [11] Aras Y, Aydoseli A, Sabancı PA, et al. Functional outcomes after treatment of traumatic brachial plexus injuries: clinical study. *Ulus Travma Acil Cerrahi Derg.* 2013;19(6):521–528.
- [12] Li GY, Xue MQ, Wang JW, et al. Traumatic brachial plexus injury: a study of 510 surgical cases from multicenter services in Guangxi, China. *Acta Neurochir.* 2019;161(5):899–906.
- [13] Brown H, Johnson K, Gilbert A, et al. The lived experience of motor recovery of elbow flexion following Oberlin nerve transfer: a qualitative analysis. *Hand Ther.* 2018;23(4):130–138.
- [14] Bhandari PS, Maurya S. Recent advances in the management of brachial plexus injuries. *Indian J Plast Surg.* 2014;47(2):191–198.
- [15] Dy CJ, Brogan DM, Rolf L, et al. Variability in surgeon approaches to emotional recovery and expectation setting after adult traumatic brachial plexus injury. *J Hand Surg Glob Online.* 2021;3(1):30–35.
- [16] Martin E, Senders JT, DiRisio AC, et al. Timing of surgery in traumatic brachial plexus injury: a systematic review. *J Neurosurg.* 2018;1:1–13.
- [17] Choi PD, Novak CB, Mackinnon SE, et al. Quality of life and functional outcome following brachial plexus injury. *J Hand Surg Am.* 1997;22(4):605–612.

- [18] Morris M, Daluiski A, Dy C. A thematic analysis of online discussion boards for brachial plexus injury. *J Hand Surg Am.* 2016;41(8):813–818.
- [19] Franzblau L, Maynard M, Chung K, et al. Medical treatment decision making after total avulsion brachial plexus injury: a qualitative study. *J Neurosurg.* 2015;122(6):1413–1420.
- [20] Han PKJ, Moser RP, Klein WMP. Perceived ambiguity about cancer prevention recommendations: relationship to perceptions of cancer preventability, risk, and worry. *J Health Commun.* 2006;11(sup001):51–69.
- [21] Thorne SE, Bultz BD, Baile WF, et al. Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psychooncology.* 2005;14(10):875–884.
- [22] Wright LJ, Afari N, Zautra A. The illness uncertainty concept: a review. *Curr Pain Headache Rep.* 2009;13(2):133–138.
- [23] Lütze U, Archenholtz B. The impact of arthritis on daily life with the patient perspective in focus. *Scand J Caring Sci.* 2007;21(1):64–70.
- [24] Lillrank A. Back pain and the resolution of diagnostic uncertainty in illness narratives. *Soc Sci Med.* 2003;57(6):1045–1054.
- [25] Pearce AR, Meyer SB. Patient perspectives on managing uncertainty living with multiple sclerosis. *J Commun Healthc.* 2020;13(2):111–118.
- [26] Sullivan J. Surviving uncertainty and projecting recovery: a qualitative study of patients' and family members' experiences with acute spinal cord injury. *SCI Nurs.* 2001;18(2):78–86.
- [27] Shaha M, Cox CL, Talman K, et al. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *J Nurs Scholarsh.* 2008;40(1):60–67.
- [28] Germino BB, Mishel MH, Crandell J, et al. Outcomes of an uncertainty management intervention in younger African American and Caucasian breast cancer survivors. *Oncol Nurs Forum.* 2013;40(1):82–92.
- [29] Miller C, Cross J, Power DM, et al. Development of a core outcome set for traumatic brachial plexus injuries (COMBINE): study protocol. *BMJ Open.* 2019;9(6):e030146. 14
- [30] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349–357.
- [31] Patton MQ. *Qualitative research & evaluation methods: integrating theory and practice.* 4th ed. Thousand Oaks (CA): Sage; 2014.
- [32] Given L. *The sage encyclopedia of qualitative research methods (vols. 1-0).* Thousand Oaks (CA): Sage; 2008.
- [33] Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Heal.* 2019;11(4):589–597.
- [34] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77–101.
- [35] Green J, Willis K, Hughes E, et al. Generating best evidence from qualitative research: the role of data analysis. *Aust N Z J Public Health.* 2007;31(6):545–550.
- [36] Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qual Res.* 2015;15(2):219–234.
- [37] Murphy E, Dingwall R, Greatbatch D, et al. Qualitative research methods in health technology assessment: a review of the literature. *Health Technol Assess.* 1998;2(16):iii–iix, 1–274.
- [38] Oakley A. Interviewing women: a contradiction in terms? In: Roberts H, editor. *Doing FEM Research.* London: Routledge and Kegan Paul; 1981. p. 30–61.
- [39] Mishel MH. Uncertainty in illness. *Image J Nurs Sch.* 1988;20(4):225–232.
- [40] Pfeifer R, Pape HC. Missed injuries in trauma patients: a literature review. *Patient Saf Surg.* 2008;2(2):20.
- [41] Hems TEJ. Timing of surgical reconstruction for closed traumatic injury to the supraclavicular brachial plexus. *J Hand Surg Eur Vol.* 2015;40(6):568–572.
- [42] Nutt S, Limb L. Practice survey of patients' and families' experiences of rare diseases reinforces calls for a rare disease strategy. *Soc Care Neurodisabil.* 2011;2(4):195–199.
- [43] Kerr AM, Haas SM. Parental uncertainty in illness: managing uncertainty surrounding an "orphan" illness. *J Pediatr Nurs.* 2014;29(5):393–400.
- [44] Gómez-Zúñiga B, Pulido Moyano R, Pousada Fernández M, et al. The experience of parents of children with rare diseases when communicating with healthcare professionals: towards an integrative theory of trust. *Orphanet J Rare Dis.* 2019;14(1):159.
- [45] Amati M, Grignoli N, Rubinelli S, et al. The role of hope for health professionals in rehabilitation: a qualitative study on unfavorable prognosis communication. *PLOS One.* 2019;14(10):e0224394.
- [46] NICE. Overview | Shared decision making | Guidance | NICE [WWW Document]; 2021.
- [47] IPDAS Collaboration. International Patient Decision Aids Standards (IPDAS) Collaboration [WWW Document]; 2017.
- [48] Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2017;4(4):CD001431.
- [49] Donnelly MR, Rezzadeh KT, Vieira D, et al. Is one nerve transfer enough? A systematic review and pooled analysis comparing ulnar fascicular nerve transfer and double ulnar and median fascicular nerve transfer for restoration of elbow flexion after traumatic brachial plexus injury. *Microsurgery.* 2020;40(3):361–369.
- [50] Rezzadeh K, Rezzadeh K, Donnelly M, et al. The association between number of intercostal nerves transferred and elbow flexion: a systematic review and pooled analysis. *Br J Neurosurg.* 2021;18:1–6.
- [51] Sneider D, Bulstra LF, Hundepool CA, et al. Outcomes of single versus double fascicular nerve transfers for restoration of elbow flexion in patients with brachial plexus injuries: a systematic review and meta-analysis. *Plast Reconstr Surg.* 2019;144(1):155–166.
- [52] Lazarus R. Hope: an emotion and a vital coping resource against despair. *Soc Res.* 1999;66(2):653–678.
- [53] Frank A. *The wounded storyteller: body, illness, and ethics.* 2nd ed. Chicago (IL): University of Chicago Press; 1995.
- [54] Sparkes AC, Smith B. Men, sport, spinal cord injury and narrative time. *Qual Res.* 2003;3(3):295–320.
- [55] Reinke LF, Shannon SE, Engelberg RA, et al. Supporting hope and prognostic information: nurses' perspectives on their role when patients have life-limiting prognoses. *J Pain Symptom Manage.* 2010;39(6):982–992.
- [56] Elliott JA, Olver IN. Hope, life, and death: a qualitative analysis of dying cancer patients' talk about hope. *Death Stud.* 2009;33(7):609–638.
- [57] Lincoln Y, Guba E. *Naturalistic inquiry.* Beverley Hills (CA): SAGE; 1985.