Patients' And Surgeons' Perceptions and Experiences of Brachial Plexus Injury Surgery in Cambodia: A Qualitative Study

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Abstract

Background: Brachial plexus injury (BPI) is a devastating injury, commonly caused by motor-vehicle accidents, especially those involving motorcycles. BPI causes physical limitations and psychosocial problems, which should be considered when assessing success of BPI surgery, not just by the degree of motor and sensory recovery.

Aims: The aims of this study were to explore the patients' and surgeons' perceptions and experiences of BPI surgery in Cambodia.

Methods: A qualitative study was used based on thematic analysis of the transcribed video -recorded interviews with two patients and two hand surgeons from the Children's Surgical Centre, Phnom Penh.

Results: The themes showed the importance of preoperative counselling to inform patients of the slow recovery and to encourage realistic expectations of the surgery. The patients' evaluation of surgical success may be different from the surgeon's assessment and goes beyond the physiologic measures in determining clinical improvement. The capacity to return to normalcy and to participate in life cannot be overemphasised. It is, therefore, important for the surgeons doing BPI surgery to understand and address the patients' needs.

It took the surgeons over five years to set up a robust training programme in Cambodia to train local surgeons to be able to perform BPI reconstruction to a level of satisfaction among the patients.

sue I, Key Words

Brachial Plexus Injury; BPI; Qualitative Study; Thematic Analysis; Patients' Perceptions and Surgeons' Perceptions; Volunteerism; Cambodia

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Introduction

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Brachial plexus injury (BPI) is a relatively uncommon but devastating injury which can cause paralysis, intractable pain, loss of sensation and function in the affected limb¹. Typically, it affects young men between 15 years to 30 years². 70% of these individuals present with multiple injuries, 70% are supraclavicular lesions and 70% of them have at least one of the roots avulsed. Of these, 70% involve C7, C8 and T1 and 70% suffer chronic pain. The 'rule of 7 seventies' also states that motorvehicle accidents, especially those involving motorcycles, account for over 70% of all traumatic BPIs³.

With growing urbanisation and motorisation in countries like Cambodia, where motorcycles are the main mode of transport, BPI is a significant cause of morbidity. Cambodia has the highest motorcycle death rate in South-East Asia at 79.3 deaths per 100,000 motorcycles in 2011^2 . The

prevalence of BPI in this country remains unknown. BPI has a profound impact on the daily lives of affected patients, with many having to endure the high levels of physical limitations, psychological stress, and discrimination of living with a flail limb. Regaining some form of ability to work and independence remain absolutely essential for their recovery and integration back into society⁴⁻⁷.

The medical treatment decision-making process in BPI is complex because of the limited recovery potential of the upper extremity in nerve injuries, and thus patient education with adequate information for an informed decision is crucial^{8,9}. The surgeons' priorities are treatment options and outcomes for BPI^{10,11}. A quantitative study by Choi et al¹² provided some insight into the perceived quality of life of participants with BPI. However, the study was researcher-led and therefore lacked the flexibility for participants to elaborate on what was relevant to them¹².

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Adults with BPI report a range of activities that are limited following injury and are under-represented in currently used patient-reported outcome measures¹³. There remains a paucity of qualitative research done on BPI to study patients' perceptions, experiences and emotions, but it is imperative that surgeons understand the lived experience of these patients to provide the help and support they need⁸. The use of qualitative research in total avulsion BPIs fills a void not addressed by its quantitative counterpart, as the former can provide an experiential perspective to help improve the quality of care of patients⁸.

As most qualitative studies have only looked at the patients' perspectives^{4–7}, we designed a study to explore both patients' and surgeons' perceptions and experiences of BPI surgery.

Materials and Methods

Study Design

The study was located at the <u>Children's Surgical</u> <u>Centre (CSC), Phnom Penh</u>, with the two surgeon participants being part of a team of visiting accredited hand surgeons from the United Kingdom and Singapore. The centre is a non-profit, nongovernmental and non-religious surgical hospital in Cambodia, founded in 1998. Approximately 5000 surgical procedures are performed there every year free of charge¹⁴.

This qualitative study is based on a thematic analysis of interviews with two patients and two surgeons from the centre, who were selected using nonprobability purposive sampling. The patients' information was obtained from their clinical records and an educational video-recording of their experiences post-surgery for pan-plexus BPI. The surgeons were interviewed remotely and in-depth using a semi structured interview guide via digital video-recordings of the interviews. Ethics approval was obtained from the local board of the Children's Surgical Centre (CSC), Phnom Penh. Informed verbal consent was obtained from all the participants.

The inclusion criteria were patients above 18 years of age with BPI, diagnosed clinically by accredited hand surgeons +/- electromyography (EMG), no confounding residual neurological problems or congenital anomalies affecting brachial plexus region or upper extremities; with normal function of the upper limbs prior to the injury and at least 1-year post surgery to allow the participants to have some experience of partial reanimation of the limb and a short period of adaptation of upper limb function.

The two patients were interviewed in Khmer, the official language of Cambodia, by a single investigator and were asked open-ended questions about their perceptions and experiences after BPI surgery. They were allowed time to express their concerns and feelings and elaborate on what was relevant to them. The interview was translated into English.

The two surgeons were requested to watch the video-interview of the two patients with English subtitles, following which they were interviewed, using a semi-structured interview guide consisting of non-directive, open-ended questions as follows: -

- I. What is your impression and impact of the patient reported outcome measure in the video?
- 2. What is your experience of developing the BPI service in Cambodia?
- 3. How has your experience in Cambodia affected your BPI practice?

Results

Table I Patients' demographics and clinical case summary of their injuries and reconstructive surgery

	Patient I	Patient 2
Age	28 years	28 years
Gender	Male	Male
Previous occupation	Motorcycle taxi driver	Construction worker
Referral	Self-referral – Seen at CSC on 28 th Feb 2013	Referred from an NGO medical clinic in Phnom Penh (PP)
History	Road Traffic Accident (RTA) on 1 st Feb 2013. No head trauma, no fractures, and no hospitalization.	RTA in Dec 2012 (motorcycle vs car). Had loss of consciousness x 2 days, taken to a government hospital in PP. Had craniotomy for evacuation of hae- matoma. Presented with complete pa- ralysis of left upper limb. Had gone to see traditional healers only prior to CSC.
Clinical findings	Presented with loss of function and sen- sation of left upper limb. Clinically, he had trapezius motor power of MRC grade 5 with grade 0 for shoulder ab- duction, elbow flexion & extension, wrist flexion & extension and hand movement. There was loss of sensation below the shoulder, except inner arm (T2 and T3 dermatome). There was no Horner's syndrome.	Presented with complete paralysis of left upper limb. Clinically, he had trape- zius motor power of MRC grade 5 with grade 0 for shoulder abduction, elbow flexion & extension, wrist flexion & extension and hand movement. There was loss of sensation below the shoul- der, except inner arm (T2 and T3 der- matome). There was no Horner's syn- drome.
Investigation	EMG showed latency of motor nerves: axillary, median, radial, and ulnar nerves.	No EMG was done.
Diagnosis	Pan plexus BPI left upper limb	Pan plexus BPI left upper limb
Surgery	On the 23 rd May 2013, with no further improvement, he underwent recon- structive surgery in the form of nerve transfers as follows: spinal accessory nerve to suprascapular nerve for shoul- der abduction, phrenic nerve to muscu- locutaneous nerve with sural nerve graft for elbow flexion.	On the 24 th May 2013 with no further improvement, reconstructive surgery in the form of nerve transfers were per- formed as follows: phrenic nerve to musculocutaneous nerve with sural nerve graft for elbow flexion. Spinal accessory nerve to suprascapular nerve for shoulder abduction was not possi- ble due to suprascapular nerve avulsion.
Follow-up	Progress was satisfactory with a three year follow up outcomes as follows: Shoulder abduction M4, elbow flexion M4	Progress was satisfactory with a one year biceps recovery of M3 and 2 years post-reconstruction a shoulder ar- throdesis was performed to improve upper limb function through scapulothoracic movement as he had functional scapulothoracic motion, peri- scapular musculature (trapezius,) and 6 months later a wrist arthrodesis for stable hand placement
Current employment	Security guard	Looks after other people's farms
Patient reported experience	Satisfied with outcome of his surgery	Reported satisfaction with the results despite some residual pain in the left forearm.

Table 1: Patients' demographics and clinical case summary of their injuries and reconstructive surgery

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Analysis

The video-interview of the two patients was transcribed verbatim by the first author, who watched the video repeatedly, paying attention to their speech, arm movements, facial expressions, and body language until saturation was reached. The analysis was done following the principles of thematic analysis. During the initial open coding phase, all verbatim responses were analysed line by line, by the first and last authors. The codes were discussed, following which they were then assigned to categories. The process was repeated to determine there was consensus following which the categories were grouped into themes through an iterative process. The qualitative analysis was corroborated by two investigators, the first author has previously done qualitative research and the last author is a consultant hand surgeon. Each investigator conducted the qualitative analysis independently and then through consensus, arrived at the final set of themes.

The video-interviews of the two surgeons were similarly transcribed verbatim and analysed based on thematic analysis. The videos were analysed, paying attention to the surgeon's language, tone, and facial expressions. Preliminary codes were assigned to the data, following which they were categorised and then placed into a coherent set of themes. The process was repeated several times until all relevant data have been coded and saturation achieved.

Trustworthiness and credibility of this study were ensured by having two researchers review the transcripts independently to ensure consistency of the interpretation of data. The first author repeatedly double-checked the transcriptions against the video-interviews to make certain they were true to the data. There were consistencies in the data from the patients while there were also consistencies in the data from the surgeons. Due to circumstances, only the surgeons were able to verify the accuracy of their transcripts.

Thematic analysis of patients' video-interview The analysis of the patients' video-interview identified eight categories, which were subsequently organised into five emergent themes. These themes were identified from the statements they made during the interview, which were entirely driven by their perspectives.

Categories	Themes	Description
Uncertainties of recovery time		
Not knowing what to expect	Desire to restore functions	Patients tried to make sense of the slow recovery post- surgery
Emotional "ups and downs"		
Commitment to rehabilitation	Experience of the health services	Patient I invested his time to help his recovery
To get life back on track	Employability	Being employed is part of their recovery
Return of some functions	Achieving goals and return to some normalcy	Described patients' satisfaction at return of some functions of the paralysed limbs
Participating in life		
Satisfaction of surgical outcomes	Perceived value of emotional and functional gains	Described the overall picture captured by the video during the interview

Table 2: Data analysis - Categories and themes of the interview with patients

Theme I: Desire to restore some functions

Both men reflected on what the doctors had told them before and after their surgery. They were unsure about what to expect and tried to make sense of the slow recovery. They were counselled by the surgeons about the slow recuperation.

Patient I: "I wasn't sure about what to think because before I had surgery, the doctor told me that it would take a long time!"

Patient 2: "After I had surgery, I was told to wait 2 years for the results."

The two men also had to deal with the 'ups and downs' of their emotions post-operatively during the recuperation, referring to feeling despondent at the slow recovery, frustration and pain and the happiness at small changes that occurred.

Patient I: With despondency, he repeated "I didn't know what to think!" (video showed him looking glum)

Patient 2: With frown lines on his face and looking serious, he said, "My arm would move when I took a deep breath, but I still had pain in my arm like before the operation."

Patient I: "When I saw results in the beginning, they were small. At first, I was able to make little movements and I felt very happy!" (video showed him grinning)

When asked to confirm by the interviewer, he replied laughing – "Yes, I felt maybe there can be results. Just like the doctor had told me before the surgery."

In the video, both men appeared happy and smiling whilst demonstrating their arm movements.

Patient 1: "I improved bit by bit for a year. By one year it got stronger and stronger."

Patient 2: "If I take a deep breath, I can lift my arm, but not all the way. I can only lift it up to here (video showed himself lifting his left arm to his chest), but only if I take a deep breath!"

Patient I: "Then my muscles grew bigger right here". (showing the interviewer his muscle bulk in the left upper arm)

When asked to confirm by the interviewer, he replied "Yes, once I built my muscles, I was able to lift my arm." (video showed him smiling)

Theme 2: Experience of the health services

As part of the post-operative care, patients at the hospital have access to a team of local Khmer physiotherapists who help them with early mobilisation, passive and active movements, and functional exercises. However, not all patients are aware of this service and some may not be able to attend the sessions because of financial constraints, they live too far away, or they have no transport or the means to get to the hospital.

During the interview it was apparent that Patient I was committed to his rehabilitation, investing his time to attend the physiotherapy sessions in the hope of restoring function of his paralysed limb.

Patient 1: "I thought I would try my best to follow the advice of the physical therapist."

While demonstrating his arm movements, he said "It took a long time to see results".

" I did three weeks of exercises after surgery at the hospital, then the doctor let me go home but I came frequently for appointments."

"I came back at 2 weeks, a month, three months, six months...".

"Then by six months, I started seeing results!"

Patient I was obviously pleased that he noticed some progress at six months and although initially they were small, he felt that he was getting results, just as the doctor had told him before his surgery. He continued to make slow progress over a year, and he got stronger and once his muscle bulk improved, he was able to lift his left arm.

Theme 3: Employment

Employability is a part of their recovery, to get their life back on track.

Patient 2: "Now I watch over other people's farms". (video showed him with a wide grin on his face)

Patient I did not report if he was employed in the video but from his clinical records he apparently went back to work as a security guard.

Theme 4: Achieving goals and return to some normalcy

Both men reported that they had some return of function in their paralysed limbs at 6 months (Patient I) and a year (Patient 2) post-surgery, which allowed them to participate in life.

Patient 2 still reported some pain when he regained

movement of his left arm, but it did not seem to affect him much when he was demonstrating his arm movements in the video.

Interviewer: "About a year after the operation, he could drive his motorbike, nearly the same as before the injury." (referring to Patient I who was showing off riding his motorcycle)

Theme 5: Perceived value of emotional and functional gains

Overall, this video has established and captured a significant link between the perceptions of

emotional and functional value and patient satisfaction with the outcomes of their surgery for BPI.

Thematic analysis of surgeons' videointerviews

The two surgeons were interviewed separately, and the videos have been analysed according to the questions posed to them. There were thirteen categories identified from the analysis of the surgeons' video-interviews and they were subsequently organised into six emergent themes. They were based on the statements made during the interviews by the two surgeons.

Table 3: Data analysis - Categories and themes of the surgeons' interviews

Categories	Themes	Description
Patient satisfaction	Capturing patients' perception of the BPI surgery Surgeons' perspectives of carrying out the BPI surgery	Video described the patients' overall satisfaction with their functional recovery
Managing patients' expectations		
Surgical interventions		Described the potential of nerve surgery, how surgeons assess the success of the BPI surgery
Functional outcomes		
Surgeons' outlook/resigned acceptance		
Needs analysis of the community	Developing the BPI service in Cambodia	Described how the environment dictates the services needed
Transfer of skills		
Identify interested surgeons	BPI training programme	Described a robust training programme to train local surgeons to perform the BPI reconstructive surgery
Workshops and hands-on training		
Overall impact of the project		
The value of doing BPI surgery	Meaningfulness of work	Described the impact of the experience in Cambodia on their own practice
Other lessons learnt from the BPI experience in Cambodia		
Qualitative study for measuring outcomes in healthcare	A change is needed for the future	Described subjective evaluation of participants' reported outcomes

Theme 1: Capturing patients' perceptions of the BPI surgery

Both the surgeons managed to capture the patients' positive perceptions of their BPI surgery when they watched the video.

Surgeon I: "The first impression ... was the satisfaction, that there was a sense of satisfaction in both the patients with the outcomes."

"Their expectations were generally managed quite well by the preoperative counselling."

Surgeon 2: "This was a very powerful video!"

He was extremely encouraged by the results achieved by the two patients despite one patient initially being lost to follow-up.

Theme 2: Surgeons' perspective of carrying out the BPI reconstructive surgery

Surgeon I: From his experience (spanning 3 decades) performing brachial plexus reconstruction – nerve transfer has been a significant shift in the management of BPI but "the outcomes from nerve transfer ... where we are bringing live nerves to damaged nerves to reanimate the upper limb has been rather poor from the surgeon's perspective, in the sense that the recovery that we get is not that satisfying!"

"The functional outcomes were just good for show, during presentations, where they have M3/M4 in the biceps, some shoulder function.... So, the objective assessment is not spectacular, but the video showed the patients found them useful subjectively."

"We resigned ourselves to the fact that this was all that we could achieve, especially, in pan plexus injuries ... we helped the limb to become an assisted living apparatus for the patient following the reconstruction."

"I can see that the patients' expectations have been managed and that they have a satisfactory outcome from their perception of the results from the brachial plexus reconstruction."

Surgeon 2: He was pleased with their decision to carry out the surgery – "..... Just the amazing potential of a nerve transfer surgery ... you need to have a little bit of faith because you are actually stitching two very small nerves together in the hope that something will happen."

"It was extremely encouraging to see the results of these two patients. So, you do something very small, but then, the impact is so profound as you can see in the video". "I think brachial plexus surgery can make such a big difference!" Furthermore, he felt that having the right skills were important in carrying out reconstructive surgery of this level of complexity -"To do something small, simple but really relying on my training ... "

"And just having the knowledge that nothing will happen for a year or so because that's the nature of nerve surgery, and then seeing the results, so that it requires a certain kind of perseverance ..."

Theme 3: Developing the BPI service in Cambodia

Surgeon I expressed that to develop the BPI service, they needed to understand the needs of the community - "...once you identify a need which we did in Cambodia that there was a high incidence of brachial plexus injury and they were only offered an amputation as a surgical intervention."

"One of the positive things that we have learned is that it is possible to bring the surgical skills and transfer these surgical skills over to the local surgeons to provide a sustainable form of surgical training that would continue."

Surgeon 2: "we realized that, shocking truth - that is, there are so many of these cases in Cambodia, and that nobody is doing it in the entire country, and that their standard treatment is amputation of the limb and shoulder fusion."

"..... we are constantly aware that whatever we do, we need to be able to pass on the skills and so we were not sure whether we can pass on these skills."

Theme 4: BPI training programme

Surgeon 1: "We found a core group of surgeons who were committed and dedicated to learn the skills. And this is crucial, and we therefore conducted a series of workshops to train them in basic microsurgery and did hands-on training in the operating theatre to help them gain these skills."

"We devised the training program, both in terms of cognitive elements and skill elements with the running of workshops, we were able to therefore produce a very robust system of training, which we then took time over a period of five years to train the local surgeons to be able to do this."

Surgeon 2 said they had started off with the two patients and the numbers increased subsequently. ".... the joy of teaching has been a very big part of our journey - in identifying interested surgeons, in training them exclusively for this and seeing them pick up the skills."

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"I think it brings a lot of hope, and so I think that really has been the sort of theme of this whole BPI service development. It brings hope to a hopeless situation!"

Theme 5: Meaningfulness of work

Surgeon I: "I was wondering whether it was worth the effort - the amount of time and resources that are being committed to brachial plexus reconstruction and the results that we obtained in terms of our perception of the outcomes weren't really very satisfactory but having seen the outcomes and the patients' perceptions, I realised that even though it is little from the patients' perspective, it is significant!"

".... this video and the outcomes I have seen in Cambodia, and the expectations, have spurred me on to continue to work on brachial plexus reconstruction, even when we perceive that the outcomes aren't as satisfactory, as it is, but from the patient's perspective, it is fantastic!"

Surgeon I believes that a qualitative approach should be undertaken to understand the patients' expectations and concerns following a major injury or disease.

"So the patient reported experience measures must go beyond the mere experience of how they were seen in the clinic or how they were consulted but through the disease itself, the impact of the disease, both in terms of biophysical and the psychosocial impact of the disease and its management."

"And I think this is how we need to measure the quality of outcomes rather than just using instruments and scores that don't mean much, though, it looks good, and statistical analysis and quantitative studies"

Surgeon 2: "I think it comes back to this theme of hope, the joy of teaching and learning, and I've certainly been able to apply that."

Surgeon 2 stressed "the importance of clinical skills - to go back to the basics of clinical skills because in Cambodia, difficult to get an MRI scan or nerve conduction studies. So, it's taught me the importance of examining the patient, getting a diagnosis. And all the other things are supplemental to that."

"I have picked up certain tips and tricks while doing this high-volume surgery in Cambodia. ... ways of innovating, thinking deeply about certain problems, why things work and why they don't work."

Theme 6: Change is needed for the future

Surgeon 1: "the impact of the disease or its treatment on the patient's life - qualitative patient reported outcome measures is what is needed for the future of measuring outcomes in healthcare."

Discussion

The aim of BPI surgery is to try and restore some functions of the paralysed limb and improve the patient's quality of life¹⁵. Patients with BPI have suffered greatly; for the treating surgeon, success must be measured not just by the degree of motor and sensory recovery, but also in its long term psychosocial and economic impact⁶.

This study is the first qualitative study to investigate, describe, and analyse the experiences and perceptions of patients and surgeons treating total brachial plexus injury in Cambodia. It has shown the importance of providing adequate preoperative education and counselling to patients with BPI to advise them of the slow recuperation, and to encourage realistic expectations of the surgery. In this video, both patients reflected on what their surgeons said to them beforehand, and only understood what was truly said, when they experienced the delay in their recovery. This realisation was important to overcome their initial frustration at the delay in their functional recovery. This has previously been shown to be true; patient satisfaction with surgical outcomes after complete avulsion BPI depends on whether their preoperative expectations are met¹⁶.

The patients' evaluation of success may differ from the surgeon's assessment. Both patients reported improvement in the movements of their paralysed limbs within six months to a year. Surgeon I questioned if BPI surgery was worth the effort as the results that they obtained in terms of their perception of the outcomes were not satisfactory. Levine et al.¹⁷ reported that patient reported outcomes were more accurate than physiologic measures in determining clinical improvement in carpal tunnel surgery. Liang et al.¹⁸ advised against an emphasis on surgeons' measures of technical success rather than on the satisfaction of the patient or the quality of life. The video-interview of the two patients was conceived in part to determine the long-term patient reported outcomes following surgical treatment for BPI. Despite the devastating nature of their injuries, both reported that they were satisfied with their overall functional recovery.

As BPI tends to occur in young men who are in the employable age, the issue of employment is an important one and may affect the type of work they do (4). Patient 2 in the video was pleased to be

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employed to watch over other people's farms and Patient I (from his records) gave up being a motorcycle taxi-driver to become a security guard. It is apparent from the video as in Patient 2 that returning to work was a positive step. Despite their severe nerve injuries, both patients are employed. <u>The capacity to return to normalcy, and what it</u> <u>does to a person's self-esteem, cannot be</u> <u>overemphasised</u>, as was evident in Patient I, which showed him riding his motorcycle in the video and participating in life.

Quantitative methods allow the researcher to test a hypothesis by systematically collecting and analysing data but tends to miss out on the experiences of the participants in-depth. Even if validated tools are used to study patient-reported outcomes they tend to be too restrictive and lack the flexibility for the participants to elaborate on matters that are important to them. The experience of health, illness and medical intervention cannot always be measured; researchers need to understand what they mean to the individuals. Qualitative studies allow for subjective evaluation of the patients' perceptions, experiences and emotions and can be incorporated into management strategies to inform clinical practice and improve patient experience. They allow surgeons to understand their own experiences and reinforce the impact of intervention beyond the quantitative outcomes¹⁸. The assessment of outcomes in terms of patients' subjective reports provides a deeper understanding of the effects of treatment^{17,19}. The results of the brachial plexus surgery are far from normal and despite that, the two patients reported their satisfaction with their functional recovery.

The expectations of the two surgeons on the development of the BPI service in Cambodia must also be appropriate and it took them over five years to set up a robust training programme, both in terms of cognitive and skill elements with the running of workshops, and hands-on training in the operating theatres to train local surgeons to be able to perform BPI reconstruction to a level of satisfaction among the patients.

Both surgeons have learnt from their experiences doing BPI reconstructive surgery in Cambodia, despite their initial scepticisms. The video-interview of the two patients has established and captured a significant link between the perceptions of emotional and functional value and patient satisfaction with the outcomes of their surgery for BPI.

Limitations

Potential limitations of this study include the recollection of data pre and post BPI surgery as the

patients' interview took place 4 years post-surgery. The sample for both patients and surgeons were small but data saturation was achieved. Since this study attempted to measure perceptions, there is a possibility of introducing a social desirability bias²⁰ but the videos have captured the voice, facial expressions and body language well to support patient satisfaction with the outcomes of their surgeries and surgeons' perceptions of their work on BPI surgery in Cambodia.

Further research using qualitative methods should be conducted to ensure comprehensive and authentic capture of patients' experiences following severe traumatic injuries to incorporate both the biophysical and psychosocial impact of the injuries on their lives. It is also important to include surgeons' or healthcare professionals' experiences in the care of these devastating injuries, as they are bound to be affected by the challenging encounters. This will allow the surgeons to understand the dynamics of the interactions between patients and surgeons.

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