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A qualitative study of patient experience of an open fracture of the lower limb in acute care

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Abstract

Aim

To explore patient experience of recovery from open fracture of the lower limb in acute care.

Patients and Methods

A purposeful sample of 20 participants interviewed on average 12 days after their first surgical intervention took place from July 2012 to July 2013 in two NHS trusts in England. The qualitative interviews drew on Phenomenology and analysis identified codes, which were drawn together into categories and themes.

Results and Conclusion

The findings identify the vulnerability of the patients expressed through three themes; being emotionally fragile, being injured and living with injury. The participants felt a closeness to death and continued uncertainty regarding loss of their limb. They experienced strong emotions whilst also trying to contain their emotions for the benefit of others. Their sense of self changed as they became a person with visible wounds, needing intimate help and endured pain. When ready, they imagined what it would be like to live with injury. Recovery activities require an increased focus on emotional wellbeing. Surgeons are aware of the need for adequate pain relief but may not be as aware that their patients require support regarding their body image and help to reimagine their future.

Take home message

- Patient experience of recovery after serious injury highlights the need for a heightened level of support for emotional wellbeing and body image
- In working towards discharge, patients need help to deal with feelings of uncertainty, hope, loss and support for being able to imagine the future

Introduction

This study explores the experiences of patients in acute care who had a severe open fracture of the lower limb [1, 2]. Quality standards for open fractures of the lower limb identify optimal pathways for surgical intervention and peri-operative care [3]. There is a gap in the literature regarding patients' experience of this injury during hospitalization. Qualitative evidence suggests later on in their rehabilitation they struggle to recover. Tricket, Mudge [4] followed patients up to 2.8 years post injury. The participants identified: a range of different types of pain including stiffness and discomfort; reduced mobility and flexibility; the impact of temperature on their body; frustration and fear; anxiety around their appearance; concerns about getting back to work; a fear of falling; reduced finances and the impact of injury on family and friends. Up to 12 years post injury participants managed their injury by using approaches to coping, problem solving practical difficulties and cognitive restructuring to identify positive aspects of experience [5]. Studies of a broader variety of traumatic injury also identify experiences of pain, difficulties with mobility, psychological issues, and social and financial concerns [6-8].

The aim of this study was to explore the early experience of patients who have major trauma. Surgeons looking after patients with severe open fractures of the lower limb are aware of the need for prompt and expert surgical intervention and peri-operative pain relief. This study highlights patients' vulnerability and the emotional impact of major trauma which also may have an important effect upon their patients' recovery.

Patients and Methods

A purposive sample of 20 patients were recruited from July 2012 - July 2013 from two major trauma centers (Oxford and Coventry) to include a range of ages, gender and breadth of experience. Participants had been hospitalized for treatment of open fracture of the lower limb and had consented to be part of the WOLLF Wound management of open fracture of the lower limb study [1, 2]. All patients had fractures, Gustilo and Anderson grade 2 (n=4) or 3 (n=16), often alongside other injuries; 2 participants had an extended period in critical care. Injuries had been sustained through motor bike/car collisions and activities at work or in the home. They were aged 20-82 years of age (mean=40 years). Time since first surgical intervention ranged from 5-35 days (mean=12 days). Interview length ranged from 25-86 minutes (mean= 54 minutes).

The method draws on Phenomenology and the work of Heidegger as outlined in other studies of injury [6] and the NIHR Monograph associated with this study [2]. This approach aims to enable participants to describe from their perspective what it is like for them to be injured. This is different from formalized assessments such as outcome tools that require a response to items, often generated from professional perspectives. The approach was lightly scripted and allowed participants to say what was important to them at that time. In this study interviews were undertaken in the ward environment, by an experienced qualitative researcher. There were two key questions focusing on what it was like for them to be injured and what is was like to take part in the main study; the latter is reported in the NIHR Monograph [2]. Prompts were used as required such as: tell me more about that, how did you feel, what did you think at that time, how did that differ from? The intent of the researcher was to enable the participant to provide their perspective and limit intervening with her own views gained from being a clinician/researcher. However interviewing and analysis is an interactive and interpretive process; to ensure rigour identifying decisions and peer review made the analytic processes explicit and open to challenge.

Ethical approval was granted by the Local Research Ethics Committee (reference 10/57/20, 6th February 2012). Participants received an information sheet and had at least 24 hours to consider participation before signing a consent form. Interviews were digital – audio recorded and transcribed verbatim. To analyse the data, the researcher read all the transcripts and worked through each one coding a group of sentences or paragraph based on the content within the text. For example text about the injury event and those that helped them was labelled 'being saved' as several of the participants used this phrase. Similar codes were gathered together within the category 'being alive'. All categories which reflected the emotional impact of injury were then placed together under the theme 'being emotionally fragile' [2]. NVIVO 10 (QRS International, Warrington, UK) is a software package that was used to help organise the data but did not perform the analysis. The results are presented as a condensed narrative of each theme using one patient quote as an illustration of the interview data.

Results

The results of this study identify the overall theme of vulnerability in which the impact of injury goes beyond the physical body to impact on all aspects of the individual's self and their life. The experience was extremely challenging, required dependency on others and a high degree of personal resilience. Vulnerability was expressed through three themes drawn from the data in this study: i) being emotionally fragile with categories of being alive, being close to losing a leg, being a person with strong emotions and being aware of others; ii) being injured with categories of being a person with wounds, being constrained and being in pain and; iii) living with injury with categories of being at home and being at work.

Theme 1: Being emotionally fragile

Being emotionally fragile reflected the emotional work the patients undertook to make sense of the event. They were pleased to be alive but worried about losing their leg. Whilst being aware of the impact of their injury on others they were unsettled by the strength of their emotions.

Being alive conveyed the dramatic life threatening nature of this injury mainly caused by high impact road traffic events often involving motorbikes or industrial incidents. There was a sense of being saved, being grateful that they had received such good care and being lucky as the event could have been so much worse. These notions were repeated throughout their interviews.

> I've just got to go with what happens really but at the same time I've still got to harp back to the fact that in the first place I was lucky. I could easily have died in that incident so you've got to think about relative situations really haven't you and the injury that I eventually sustained… *Participant 5*

Participants' were also horrified and shocked, when at some point in their recovery they felt or were told that losing their leg had been or remained a possibility. The resulting anxiety could lead to feelings of detachment from their body. Relief that they had kept their leg so far was mixed with apprehension regarding the uncertain progression of their recovery and the potential threat of its loss in the future.

> The only time I actually felt detachment was when Jim first mentioned the possibility, the extreme possibility of amputation. When another surgeon came in and mentioned it again I almost felt like I was in heaven and just detached slightly. I was listening to him and thought blimey I've completely disconnected from this, that's when I feel detachment when that gets raised, I'm not consciously, it's not a decision to detach but it just seems to happen because it's something that even though I'm aware of it I don't really want to have to consider it right now. *Participant 15*

The participants expressed an emotional fragility that purveyed every aspect of their life. Some had only felt similar feelings before when a family member had died. Strong emotions were experienced sometimes spilling out, described as 'meltdowns', when they cried and felt they were unable to cope.

> …it wasn't until I got right down to the anaesthetics room that the penny dropped and then I was like a big girl's blouse because I didn't have the wife there or anybody there just two strangers and I felt lonely and vulnerable and basically my life is in their hands. *Participant 3*

It felt like a rollercoaster as the slow realisation of the seriousness of the impact of injury on themselves, their family and their life unfolded. Some processed the fear and anxiety through regular dreams and nightmares. Where possible they contained their emotions for the sake of family and friends with the intention of maintaining normality and instilling a sense of hope that recovery was progressing. However the energy required to sustain this was often lacking suggesting their emotional resilience was compromised.

Theme 2: Being injured

Being injured was a shock for all participants. They were concerned about their wounds, could not move about as normal and were often in pain.

The wound itself and the state of the injured leg created a real sense of panic; participants were reluctant to see the actual wound and had to be ready to do so. The visual look of the wounds often left participants feeling shocked and sick. Participants were concerned about their body image and were surprised by staff who described their wound as brilliant, beautiful or healing well. They felt damaged and worried about what others would think.

> Oh God, I never saw anything as foul looking in all my life. The only way I could describe it was somebody had got a fillet steak, a nice thick fillet steak and slapped it on the side of my ankle, that's just what it looked like. I said to them how can you say that looks good when it's not good? *Participant 17*

Preparation of participants for seeing their wound was varied but good visual preparation for patients and their family was beneficial. The participants felt they were constrained by not being able to move, bored, and frustrated. Instead of being taken for granted their body now required surveillance, they noting the swelling, bruising and watched for signs of healing. Participants had to learn how to: cope with prolonged periods of bed rest and immobility, deal with the frustrations of limited mobility; accept the pace of recovery was dictated by healing and; move their bodies within the limits of their injuries.

> Yes, the strength in my legs is so reduced it's quite incredible and so you can imagine a few more weeks like this and it's going to take a while to get my strength back, it's your core strength. If I transfer from this to a wheelchair I'm absolutely exhausted and you've just got no trunk strength or virtually none. *Participant 2*

Participants at some point experienced extreme pain that they found difficult to control. Many had support from the pain relief team with some success. Others struggled to: find pain relief that suited them; get timely access to pain relief; balance activities around pain relief; control their emotions as a result of pain. Participants who had patient controlled analgesia were fairly happy with their pain control but timely access to oral medication was difficult. For some the pain varied in nature but was persistent, wearing down their ability to cope.

> Yes there are days that the pain is bad and there have been days where I can't bear the pain. I've been asking for pain killers and I've curled up...to try and deal with the pain. It does have its days of coming and going, the pain....It's not always just pain, it's like itching where it's healing and I can't itch it which is annoying. There's aching, itching, pain, throbbing, there's a burning pain like when you've got sunburn, it feels like that on my legs where they took the skin grafts from. *Participant 19*

Overall pain was a source of concern to all participants at some point in their recovery. This was complicated by the variety of sources of pain, access to medication, and a reluctance by patients to take medication. The group appeared to suffer considerably which reduced their energy to cope and impacted on their ability to actively manage their recovery.

Theme 3: Living with injury

Living with injury evolved as the patients found mental space to work out how they might live their life at home and at work in the future and was conveyed through the categories being at home and being at work. This thinking was done within the context of a high level of uncertainty. The participants felt that the future was unknown but they were lucky to have a future. The need to get home was overwhelming but as they progressed it was something they felt was more tangible and they could imagine what it would be like to go home. Participants were anxious, sometimes expressed in nightmares, but were still keen to go home. They were concerned about their physical abilities, how their family would cope, their dependency on others and managing false hope. Returning to or not being able to return to their hobbies was also a preoccupation. There was sadness at the loss of the life they had before and a degree of uncertainty about what would happen.

> It's really hard and it sickens me the thought of losing my bikes but it's a small sacrifice. If I want to live another thirty years on this planet and I want to walk these beautiful girls down the aisle, then it's a small price to pay. *Participant 3*

Going back to work was difficult to visualise due to the uncertainty regarding the degree of functional recovery expected. Any information on this aspect was gratefully received but participants felt clarity about timescales was unlikely due to the complex nature of their injury and individual recovery paths.

> …if they hadn't shown me the pictures and explained how long it takes I would have thought after three months I would be back at work but after seeing the pictures there's no chance I would be back at work at three months but it's nice to know that I can inform my boss and everything and get all of that out of the way, yes it's really helped with planning for future jobs and things, it's useful, very useful. *Participant 11*

Participants with more sedentary jobs could imagine getting back to work but those with physical jobs had difficulty knowing what they would do. For some participants the accident had provided an opportunity to re-evaluate their life and reconsider what they would like to happen in the future.

Discussion

The three themes, being 'emotionally fragile', 'being injured' and 'living with injury' represent a collective narrative of 20 patients sampled within a larger randomized control trial which has demonstrated some resonance with patient groups and trauma staff. In addition the sample was purposive in relation to gender, age, severity of injury and a range of experience however it was not selected to be ethnically diverse. The research achieved saturation in the themes which occurs when no new themes can be found in the transcripts. However the sample reflects the population within the trial and more diverse methods of sampling may have provided different perspectives.

The study supports research that suggests this type of injury is life changing and patients struggle to recover. The results of this study identify that patients experience strong emotions, immobility, dependency, anxiety, pain and disruption to their body image during hospitalisation. Later on during recovery, similar concerns and a lack of return to their pre injury state have been noted [4]. Studies with more diverse samples of lower limb injury [7, 9] and general traumatic injury [10] suggest patients require increased support for pain control and psychological distress; which can be present 5-10 years post injury [11]. Nurses and allied health professionals are well placed to provide support in hospital and emotional support in daily trauma care on a ward is evident [12]. However staff identify that comforting and talking to patients in fast pace environments is often, care left undone, at the end of a shift [13]. This suggests other strategies are required to help patients through the recovery period. Supportive strategies presented as useful for trauma survivors are holistic strategies, coping, mindfulness, peer support and education [14]. A tool kit of activities supporting recovery that includes psychological distress could be developed and facilitated by appropriately qualified specialist practitioners. This however would need testing in practice to ascertain the benefits for whom and under what circumstances. In addition research is required to identify if experience in the early phase of recovery is indicative of, or can be used to predict the degree of recovery.

Conclusion

This study, adds to current evidence through the identification of the concept of vulnerability which conveys the emotional and physical work undertaken by participants whilst in hospital. Surgeons and other staff have a vital role to play in supporting this activity. Recovery activities need to encompass an increased focus on emotional well-being, and surgeons have a key part to play in this recovery. While improved access to professional psychological support is required following major trauma, surgeons will still be best-placed to both acknowledge the impact of vulnerability and to manage expectations of body image and return to both home and work after major trauma. Surgeons can

help their patients greatly in this regard. They have a key role to play in the patients' emotional as well as physical recovery following serious injury.

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