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Manuscripts

A qualitative study of long term recovery after open fracture of the lower limb

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ABSTRACT

Objectives: Treatment of open fractures is complex and patients may require muscle and skin grafts. The aim of this study was to gain a greater understanding of patient experience of recovery from open fracture of the lower limb two to four years post-injury.

Design: A phenomenological approach was used to guide the design of the study. Interviews took place between October 2016 and April 2017 in the participants' own homes or via telephone.

Setting: England, UK.

1
2
3 **Participants:** A purposive sample of 25 patients were interviewed with an age range of 26-80 years (median
4
5 51), 19 were male and six female, and time since injury was 24-49 months (median 35 months).
6

7 **Results:** The findings identified a focus on struggling to recover as participants created a new way of living,
8
9 balancing moving forward with accepting how they are, whilst being uncertain of the future and experiencing
10
11 cycles of progress and setbacks. This was expressed through three themes: i) 'being disempowered' with the
12
13 emotional impact of dependency and uncertainty, ii) 'being changed' and living with being fragile and being
14
15 unable to move freely and iii) 'being myself' with a loss of self, feeling and looking different, alongside
16
17 recreation of self in which they integrated the past, present and future to find meaningful ways of being
18
19 themselves.
20

21 **Conclusion:** This study identified the long-term disruption caused by serious injury, the hidden work of
22
23 integration that is required in order to move forward and maximise potential for recovery. Supportive
24
25 strategies that help people to self-manage their everyday emotional and physical experience of recovery from
26
27 injury are required. Research should focus on developing and testing effective interventions that provide
28
29 support and self-management within a holistic rehabilitation plan.
30

31 32 **ARTICLE SUMMARY**

33 34 **Strengths and limitations of this study**

35
36 Use of in-depth qualitative interviews has provided rich data and new insights into the hidden work
37
38 undertaken by patients as they recover from major lower leg injury.
39

40
41 The variation and patterns within the patients' experience may help healthcare providers focus effective
42
43 strategies to maximise emotional and physical recovery over the longer term.
44
45

46
47 Our study was intentionally exploratory in nature and the resulting framework requires further exploration in
48
49 diverse samples to assess its transferability.
50

51 52 **INTRODUCTION**

53
54 Open fractures of the lower limb (where the bone protrudes through the skin) occur in an estimated 30% of
55
56 fractures of the tibia.^[1] Treatment is complex as the wound requires surgical cleaning before fixation of the
57
58 bone, often followed by muscle and skin grafting. The UK WOLLF Wound management of Open Lower Limb
59
60

1
2
3 Fractures trial compared standard dressings with Negative Pressure Wound Therapy.^[2] Negative Pressure
4
5 Wound Therapy is a type of dressing that applies a gentle suction to the wound removing excess fluid. Two
6
7 qualitative sub-studies of this trial were undertaken to explore the lived experience of patients with an open
8
9 fracture of the lower limb, firstly during hospitalisation, and secondly, this paper presents the findings from
10
11 two to four years post-injury.
12

13
14 There is increasing evidence that the impact of open fracture of the lower limb can be life changing with
15
16 prolonged periods of recovery. Embodied vulnerability conveys how patients with open fractures of the lower
17
18 limb struggled to cope with their emotional distress, their changed body which included their wounds, body
19
20 image, pain and the uncertain nature of their future life.^[3] Recovery can be slow and patients can find it hard
21
22 to return to their pre-injury lives even 2 years after an open fracture.^[4] Studies with a broader sample of
23
24 injured patients identify the ongoing challenge of daily living, being able to work and body image.^[5] There is
25
26 also evidence of persisting psychological distress.^[6] This qualitative study aimed to extend our knowledge of
27
28 patient experience of recovery from an open fracture of the lower limb up to four years post injury to provide
29
30 direction for long term support and rehabilitation.
31

32 33 **METHODS**

34
35 This study was informed by phenomenology and the work of Heidegger^[7] used in other studies of injury.^[8,9]
36
37 This enabled participants to share their experience of everyday life within their social and cultural context. It
38
39 uncovered insights into how they know and understand their world and what is important to them. Immersion
40
41 in the data and interpretation led to an understanding of the meanings inherent in the everyday world of the
42
43 participant. The project was given ethical approval by West Midlands Coventry and Warwickshire Research
44
45 Ethics Committee (REC Reference: 12/WM/0001) in June 2016.
46

47
48 A purposive sample of 25 participants were recruited between October 2016 and April 2017, during routine
49
50 follow up. Interviewees were participants in the UK WOLLF trial^[2] and had received reconstructive surgery for
51
52 an open fracture to the lower limb. Purposive sampling included a range of sex, age and grade of severity of
53
54 injury. Most participants had a Gustilo and Anderson^[10] grade of 3, indicating they were the more severely
55
56 injured, having a greater likelihood of needing skin or muscle grafts. See table I for information on the
57
58 participants sex, age, time since injury, cause of injury and injury severity. Two people approached chose not
59
60

to take part due to personal circumstances and lack of time. Respondents received a patient information sheet and provided written or oral consent to take part in an interview. The interviews focused on the participants' lived experience of recovery from injury and were lightly structured to cover their thoughts, feelings, activities, function and work. Open questions such as 'what has it been like for you since your injury', with prompts such as 'tell me more about that', 'how did that feel', were used to enable participants to share their experience. Two female health researchers with PhDs who did not know the participants undertook the interviews (SR (n=15) and ET (n=10)), either face-to-face (usually at the participant's own home, once at a nearby hospital) or over the telephone. Two participants were accompanied by their partners. Care was taken to support participants and respect their privacy and dignity. One interviewer had experience of interviewing patients with cancer and a background in medical sociology, the other had prior experience of interviewing patients with traumatic orthopaedic injuries. Interviews lasted 25-100 minutes (average 60 minutes) and were digitally audio-recorded and transcribed verbatim. Data was anonymised and held on secure password protected University computers. None of the participants wished to see a copy of their transcript.

Table 1 Information about participants

Table 1 Information about participants	
Characteristics	Number of participants
Sex	
Male	19
Female	6
Age (years) mean 51, range 26-80	
18-29	4
30-49	8
50-69	9
70-80	4
Time since injury (months) mean 31, range 24-49	
24-35 months	14
36-49 months	11

Cause of Injury	
Car collision	8
Motorbike collision	5
Pedestrian-vehicle collision	3
Fall from height/stairs	3
Crush injury at work	3
Low energy fall (from standing)	2
Bicycle-vehicle collision	1
Injury severity, Gustilo and Anderson grade	
2	4
3	18
3+	3

Patient and public involvement (PPI) was integral to the management structure for the UK WOLLF study. Four patients with similar injuries helped the researchers reflect on their interpretations during analysis. The UK Musculoskeletal Trauma (PPI) group are involved in dissemination of the findings.

Analysis was an iterative process involving initial coding of sections of the data to label the underlying meaning or 'what is going on' in the data such as 'feeling sad due to lack of progress'. Codes were collected together with other similar codes to create categories such as 'being uncertain'. Differences and challenges within interviews and across interviews were written up in fieldnotes and memos, and discussed. Categories were collected together to create themes or 'structures of experience'^[11] such as 'being disempowered'. NVivo 11 a qualitative software package was used to manage the data (QSR Warrington, UK). The findings were shared and discussed with the broader research team.

Rigour was demonstrated through trustworthiness.^[12] Both researchers were engaged with the data, held regular discussions and reflected on their positionality throughout analysis. Auditability was demonstrated through the identification of themes and categories (table 2) and use of quotes to illustrate them. Saturation of themes and categories was achieved. Resonance with the findings was identified by four patients with

similar injuries. Additional insights were challenges with intimacy and gratefulness for care provided.

Multidisciplinary staff also found the findings resonated with their experience of clinical practice.

RESULTS

Overarching theme: Struggling to recover

The findings, presented in table 2, convey the overarching theme of 'struggling to recover' as an experiential process in which participants aim to make sense of their injury, balance striving to move forward with accepting how they are, and find meaningful ways of living whilst being uncertain of the future and experiencing cycles of progress and setbacks.

Table 2: Key themes and categories identified from the qualitative interviews

Theme	Category	Definition
Theme 1 Being disempowered		Being disempowered conveyed the emotional and physical impact on participants of loss of personal control over their life and was expressed through the categories 'being dependent on others' and 'being uncertain about the future'.
	Category Being dependent on others	Being dependent on others was a process of accepting help from others whilst striving to maintain a sense of independence through activities that supported their mental and physical wellbeing.
	Category Being uncertain about the future	Being uncertain about the future conveyed the emotional impact of not knowing their potential degree of recovery, and what life would be like in the future.
Theme 2 Being changed		Being changed identified how their body no longer looks, feels or functions in ways it previously had done. Everyday life involved a process of re-negotiating where participants learnt through experience what they could do and how they felt about their body

		whilst striving to regain and retain normal activities. It was expressed through the categories of being fragile and being unable to move freely.
	Category Being fragile	Being fragile conveyed a sense of their body as looking and feeling less robust, less trustworthy, less reliable and active engagement was required to reconnect in a positive way with their changed body.
	Category Being unable to move freely	Being unable to move freely was the loss of ease, fluidity and previously taken-for-granted ways of moving, it affected their ability to use certain geographical spaces and effort was required to improve levels of physical activity.
Theme 3 Being myself		Being myself was an active process of integrating injury into their sense of who they were as a person, bringing together the past, present and future. It was expressed through loss of self and recreating me.
	Category Loss of self	Loss of self was expressed as participants felt and looked different and were unable to fulfil their normal roles and activities as they did prior to their injury.
	Category Recreating me	Recreating me referred to the ways in which participants made sense of their altered selves, worked on their body and mind to find meaningful ways of being and living.

In struggling to recover participants conveyed that their 'taken for granted' ways of living experienced prior to injury were replaced with daily challenge as they endured symptoms such as persistent pain. They often hid the struggle to keep going to maximise participation and maintain a sense of progression.

1
2
3 They can see people walking but there is no light or pain-meter on top of the head that says 'this guy
4
5 is in absolute agony but he's not going to stop walking because he doesn't want to go in a mobility
6
7 scooter'. People look at you and say 'You're getting on great aren't you?' All you really just want to
8
9 say to them is 'Every day I struggle' and some days you just want to sit and cry your eyes out. – P13
10

11 Loss caused by injury led participants to re-negotiate how they live and to integrate their past and present self
12
13 into new ways of being. This was portrayed through the themes of being disempowered, being changed, and
14
15 being myself.
16

17 18 19 Theme 1: Being disempowered

20 The impact on participants' loss of control over their life was expressed through the categories 'being
21
22 dependent on others' and 'being uncertain about the future'.
23

24 25 *Being dependent on others*

26
27
28 Many participants had prolonged periods where they were not able to put weight through their injured leg,
29
30 and some had injuries to both legs. Dependency on others created frustration, boredom, distress, dismay, was
31
32 undignified, lowered their mood and was epitomised by not even being able to perform simple tasks, such as
33
34 to make a cup of tea.
35

36 I don't know if it's a man thing or male thing, I don't know. It's your dignity, I mean the last person
37
38 who wiped my arse was my mum and that's it, or my dad, but being a grown man using a bed pan
39
40 because I couldn't get out of bed was awful. – P06
41

42
43 In this state of profound dependency their body became central to everyday life, its needs and limitations
44
45 explicitly governing every aspect of everyday life.
46

47 You feel a bit like a passenger in it all because you're on the outside looking in and you think you're
48
49 being a bit of a burden on everyone. At the time I found it quite hard to almost tell people that's how
50
51 I felt, I feel this, 'I feel a bit worthless'. – P18
52
53

54 Constant support for daily bodily needs could lower their mood so that they could no longer see the 'light at
55
56 the end of the tunnel' (P17) evident in suicidal thoughts.
57
58
59
60

1
2
3 I thought about topping myself because it's like I've been independent all my life. ... One night I had
4 all the tablets, Tramadol. – P06
5
6
7

8 Dependency on others was a disempowering experience that led to emotional vulnerability. Expressing how
9 they felt was challenging in the context of being grateful for the care they had received and some had suicidal
10 thoughts.
11
12
13

14 *Being uncertain about the future*

15
16
17 Being uncertain about their future added to participants' sense of disempowerment. Participants found it hard
18 to imagine walking properly or returning to pre-injury activities and a 'wait and see' approach added to their
19 sense of uncertainty.
20
21
22

23 I would say that was the toughest part, was just the un-endingness of it, it was just constant and it
24 was horrible. – P19
25
26
27

28 I did think in my mind you know 'it will heal and then I've got rehabilitation' but this whole non-union,
29 it just dragged on and on and on, I couldn't see an end. ... I wished I'd known about the non-union,
30 err, it was almost hidden from me. ... I said 'well I thought that the operation was successful?' then he
31 told me 'well it was because we would've cut your leg off years ago'. – P21
32
33
34
35
36

37 There was a degree of anxiety regarding their future and ability to live and work productively.
38
39

40 You want to live for the future now because that's what you've got in front of you but you worry
41 about what it's going to bring, not only physically but financially as well. You have no idea what your
42 pay-out is going to be and so my life is in somebody else's hands. There is that horrible thought that
43 you may have to go back out to work, force yourself to work because financially you can't exist for the
44 rest of your life. – P13
45
46
47
48
49

50 Their capacity to heal often determined their future; leaving them feeling uncertain, disempowered and
51 anxious. This was exacerbated by setbacks such as non-union (also noted in recreating me) that reduced their
52 ability to sustain recovery.
53
54
55
56
57
58
59
60

1
2
3 Theme 2: Being changed
4

5 Participants felt they were changed from how they were pre-injury expressed in categories 'being fragile' and
6
7 'being unable to move freely'.
8

9
10 *Being fragile*

11 Participants were predominantly young or middle-aged adults, and many had been previously fit and active
12
13 individuals. They now felt their body was older, weaker, and more fragile.
14

15
16 I can't dig. ... I feel like I've got a weakness which has left me feeling like I've got a bit of a disability. –

17
18 P21
19

20
21 Participants felt a need to protect their injured body, or at least the injured limb, including avoiding activities
22
23 due to the fear of experiencing another injury.
24

25
26 You're frightened it's gonna (going to) break again. – P02
27

28
29 The sense of a whole, continuous body which the participants felt they could trust to do the activities they
30
31 wanted to do was disturbed and instead participants could experience their bodies as alien and fragile.
32

33 I do go running and I wear long running trousers because I think if I see it (the muscle graft) it makes
34
35 me feel like there's a weakness there and it makes me very aware, I don't think it is any weaker the
36
37 leg but mentally it makes me think it's a bit weaker and I just find it distracting as well if I exercise it. I
38
39 probably would be over-cautious and not really exercise it properly if I could see it I think. – P14
40

41
42 Some participants described feeling distanced or alienated from the injured part of their body.
43

44
45 I don't look at it as my leg anymore. ... It is like the legs belongs to somebody else they don't
46
47 particularly belong to me. – P19
48

49
50 Their injured body part was no longer fully integrated into their perception of their body. Parts of their body
51
52 had literally shifted places as skin/muscle from other areas of the body had been transplanted to cover the
53
54 defect in the leg. Pain and numbness could increase this sense of alienation.
55
56
57
58
59
60

1
2
3 Participants hid or covered up their injured leg, to avoid others perceiving them as fragile, less capable or
4
5 weak. For some participants the struggle with healing, pain and lack of mobility was so exhausting, that they
6
7 thought amputation might improve their chances of mobility and a better quality of life.
8
9

10 There were a couple of times in it all when I thought, would it be better off to say take it off but I
11
12 knew how hard and how much effort people had put in to make sure that leg was staying where it
13
14 was. – P18
15

16 If you took me back in time and I knew then what I know now I would have said ‘take my leg off now’.
17
18 I’d be four years down the line with a prosthetic and I could probably still be working. – P13
19

20
21 Being fragile highlighted the unreliability of their body and continued vulnerability to further injury. The sense
22
23 of a ‘whole’ body could be disrupted and amputation was considered in an effort to improve chances of
24
25 recovery.
26

27 28 *Being able to move freely* 29

30
31 Despite being between two to four years post injury, participants felt they were not able to move with the
32
33 same fluidity or spontaneity. The way they walked, their pace, gait or balance was different.
34

35 I can’t move fast anymore. – P17
36

37
38 My balance was all over the place, it still is, sometimes I feel like I’m falling to the side, it’s a weird
39
40 feeling. – P01
41

42 I waddle, I walk like a penguin it’s the only way I can balance, sort of putting weight on one foot and
43
44 then going over to the next foot, I can’t stride out anymore. – P02
45

46
47 Specific activities such as being able to kneel prevented them from moving as freely. As did the weight of the
48
49 muscle graft (notable when sleeping), swelling and pain. Persistent pain reduced their ability to move and join
50
51 in activities, it varied in type and duration but sometimes was prolonged and often unpredictable.
52

53
54 I sit down for an hour and I get up, oh the pain you can’t describe it, but I mean it’s for seconds but
55
56 it’s enough to, it’s really, really painful. – P02
57
58
59
60

1
2
3 Participants experienced restrictions on the spaces and places they felt confident occupying. They were
4 worried about falling and injuring themselves again. The terrain underfoot, types of floor or ground could
5 cause pain leading them to be constantly vigilant.
6
7
8
9

10 Participants felt changed, even if they had returned to work, often with an increased sense of fragility, loss of
11 fluidity and pace of movement, combined with specific functional losses. They hid this fragility from others,
12 undertook additional planning for daily activities, limited social participation and changed their work roles in
13 order to cope with their injury.
14
15
16
17

18 Theme 3: Being myself

19 Participants worked to integrate their injury into their lives expressed through 'loss of self' and 'recreating me'.
20
21
22

23 *Loss of self*

24 In loss of self, there was a sense that the body 'restricts me from being me' and participants had to adapt to
25 being different from their pre-injury state.
26
27
28
29

30 It seemed like a part of my life stopped at 6.45 on (date of injury) and a new life started. ... I used to
31 think nothing of walking ten to fifteen miles a day along disused railway lines and things like that, we
32 were avid walkers. – P04
33
34
35
36

37 Participants' current experience contradicted their memories of who they were.
38
39

40 I have 55 years' worth of memories inside my head so you think 'Oh I used to go running on a
41 Saturday morning'. ... You try and be the person you were before and you can't be because you are
42 95% of what you used to be. But it's just that 5% area that causes you 100% of the problems. – P13
43
44
45
46

47 Some days I, I could scream. I wake in the morning and 'cause you forget', you know when you go to
48 sleep, and I wake up in the morning thinking I can just jump out of bed and I can't and then it hits you
49 and you think 'Oh God I can't do this!' – P02
50
51
52
53

54 Their body thwarted their attempts to return to their former selves. Despite regaining their independence and
55 feeling that their healthcare team considered them to be recovered, the participants were continually
56 reminded of their injured bodies.
57
58
59
60

1
2
3 It's very difficult to have a day where you are not conscious of 'that hurts'. ... In an active way you are
4
5 kind of constantly reminded because it's never quite the same day to day. – P22
6
7

8 In contrast to younger patients, older participants located the injury within the context of prior conditions and
9
10 they did not experience the same degree of challenge to their identity.
11

12 The event (which) bears more on how I think about life in general is having been fortunate to survive
13
14 a heart attack ten years ago. ... So that sort of in a way puts things in perspective. I know falling off a
15
16 roof can initially be thought of as a life-threatening event but a cardiac arrest is definitely a life-
17
18 threatening event! – P08
19

20
21 Participants struggled with the loss of their pre-injured self and the activities that defined them. Despite
22
23 attempts to move forward and integrate with the present they found their unreliable body provided sensory
24
25 reminders of their loss and their injury.
26

27 *Recreating me*

28
29
30 In making sense of their injury they reflected on how life had been and tried to reconcile this with how they
31
32 felt now.
33

34
35 It did come as a revelation about three weeks ago, just you know, I can't carry on doing this, I can't
36
37 keep pushing to get my life back, it's got you know, I've got to change, you know it is a bit of a shock!
38
39 – P19
40

41
42 I used to think 'I wished the thing had never fallen on me!' but now I think I've got to that stage where
43
44 I've passed that and I think I have just slipped, probably slipped back into normality if, um, I, I sort of
45
46 lived with this problem and that's then become me, so maybe you adapt. – P21
47

48
49 Participants tried to return to usual activities but recovery was characterised by ups and downs. Injuries
50
51 occurred from stress fractures to snapped hamstrings (muscles at the back of the thigh) and iliotibial bands
52
53 (connective tissue running from the pelvis to the knee). Only a small number of participants reported receiving
54
55 enough physiotherapy after their injury. Those who received physiotherapy (usually privately), described a
56
57 more purposeful recovery with fewer examples of setbacks and less uncertainty.
58
59
60

1
2
3 I think she took it upon herself to get me back to where I wanted to be and I think she listened to
4
5 what I wanted out of life. – P18
6

7
8 Some participants expressed gratitude to be alive or to have avoided amputation. They tried to locate meaning
9
10 in what happened to them.

11
12 I went back and met another patient and his family and I hope that I gave them a little bit more hope.
13
14 ... It was good for me as well for my rehabilitation to feel that it wasn't all for nothing. – P18
15

16
17 For these participants, they were able to find meaning in their injury, and so to incorporate it into their
18
19 biography, or their story of themselves. Participants engaged in 'body work' in order to convey a sense of
20
21 normality and provide the appearance of a non-injured body. However, often participants described struggling
22
23 with the difference between others' expectations and the reality of their everyday experience.
24

25
26 I think when people think you're doing so well physically they just think 'she's doing really well' and
27
28 you almost don't want to turn around and say 'well actually I'm really struggling with this, that and
29
30 the other' because I just don't want to disappoint people or turn it into a negative thing. – P14,
31

32
33 In recreating me the participants were hindered by their injured body and a lack of supportive therapies but
34
35 tried to integrate their past and present self-identity. New opportunities and meaningful ways of living that
36
37 were beneficial could be found. There was a strong desire to appear normal and participants struggled to be
38
39 themselves.
40
41
42
43
44
45
46

47 **DISCUSSION**

48
49 This qualitative study adds to recent research on the patient experience of open fractures of the lower limb in
50
51 acute care^[3,9] and post injury^[4] by identifying the ongoing recovery undertaken by patients to process the
52
53 impact of injury on their sense of being disempowered, being changed and being myself. We have specifically
54
55 focussed on the longer-term (two to four year post-injury) impact of these injuries and especially in those
56
57 patients who were identified as having injuries on the 'severe' end of the spectrum. We found that the
58
59 concept of embodied vulnerability,^[3,9] and endurance in early recovery^[8], clearly identified in acute care, also
60

1
2
3 extends into the longer-term as participants struggle to recover, processing their loss, working to negotiate
4 how they live and integrate changes within their self-identity. Our findings indicate that longer term clinical
5 support is required to improve outcomes for mental health, function, management of pain and living with
6 disability in patients with major trauma to the lower limbs.
7
8
9

10
11
12 There were some potential limitations to our study. The sample was purposive within the UK WOLLF
13 population and saturation of data was achieved. However, the sample was not ethnically diverse and sampling
14 at specific time points during recovery may have increased the transferability of the study to other
15 populations. Four patients with similar injuries felt their personal experience resonated with the findings of
16 this study however they also highlighted the joy of recovery, gratefulness to staff for their care, the similarity
17 of the findings to, but also the difference from, their individual experience. Despite these limitations, this study
18 provides evidence that patients who suffered the more severe injuries may benefit from enhanced clinical
19 attention that focusses on distress, uncertainty, fragility and body image over a prolonged period of time.
20 Psychological distress^[6,13] is present in this group and may be linked to ongoing disability.^[14] The continued
21 uncertainty that patients feel reflects elements of a chaos narrative (Frank 1995), where loss of control means
22 it is hard to find meaning in daily life. In our study despair, noted in recovery from trauma ^[15] was expressed as
23 suicidal thoughts. Their perceptions of the body as fragile and weak suggest a state of dys-embodiment^[16] ^[17]
24 where dysfunction highlights the loss of normal taken for granted ways of being. Ongoing disruption to body
25 image is noted in studies of stigma and disfigurement^[18] and in societal pressure to appear recovered^[19] and
26 attractive.^[20] In this study, amputation was considered as an alternative solution to continued challenges and
27 dissociation from the body occurred, as in other specialities.^[21] Patients' progression towards integration of
28 physical change and self-identity was hindered by reminders of their injury, such as persistent pain, as their
29 unreliable body^[22] was unable to achieve the intended activity. This process is noted in chronic illness^[23] and
30 major trauma patients three to six months post injury.^[24] Support that enables patients to feel a greater sense
31 of empowerment and integrate bodily changes within their self-identity may be helpful. Research should
32 therefore focus on developing and testing effective interventions that provide longer term support and self-
33 management within a holistic rehabilitation plan.
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56 STATEMENTS

57 Funding statement

1
2
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6
7
8

9 10 **Competing interests**

11
12 No benefits have been received or will be received from a commercial party related directly or indirectly to the
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22

23 24 25 **Author contributions**

26
27 SR and ET contributed equally to this paper. The design, data collection, analysis and drafting of the paper
28 were jointly undertaken by SR and ET. The team JA, JB, CM supported the project, were involved in discussion
29 of the findings and the development of this paper.
30
31
32

33 34 35 **Ethical approval**

36
37 The project was given ethical approval by West Midlands Coventry and Warwickshire Research Ethics
38 Committee (REC Reference: 12/WM/0001) in June 2016.
39
40

41 42 43 **Consent and Confidentiality**

44
45 All participants received an information sheet and at least 24 hours to consider their participation. Written
46 informed consent or verbal consent over the telephone were obtained.
47
48

49 50 51 **Check list**

52
53 The checklist has been completed and submitted.
54

55 56 57 **Data sharing statement**

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59 No additional data are available.
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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Patient experience of long term recovery after open fracture of the lower limb: A qualitative study using interviews in a community setting

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-031261.R1
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Primary Subject Heading:	Qualitative research
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Keywords:	QUALITATIVE RESEARCH, Orthopaedic & trauma surgery < SURGERY, REHABILITATION MEDICINE

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3 **Patient experience of long term recovery after open fracture of the lower limb: A**
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5 **qualitative study using interviews in a community setting**
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7

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44 **Word Count:** 4762
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46 **Keywords:** injury, recovery, open fracture, experience, qualitative, body image, self-identity
47
48

49 **ABSTRACT**
50

51
52 **Objectives:** Treatment of open fractures is complex and patients may require muscle and skin grafts. The aim
53
54 of this study was to gain a greater understanding of patient experience of recovery from open fracture of the
55
56 lower limb two to four years post-injury.
57
58
59
60

1
2
3 **Design:** A phenomenological approach was used to guide the design of the study. Interviews took place
4
5 between October 2016 and April 2017 in the participants' own homes or via telephone.
6

7 **Setting:** England, UK.
8

9 **Participants:** A purposive sample of 25 patients were interviewed with an age range of 26-80 years (median
10
11 51), 19 were male and six female, and time since injury was 24-49 months (median 35 months).
12

13 **Results:** The findings identified a focus on struggling to recover as participants created a new way of living,
14
15 balancing moving forward with accepting how they are, whilst being uncertain of the future and experiencing
16
17 cycles of progress and setbacks. This was expressed through three themes: i) 'being disempowered' with the
18
19 emotional impact of dependency and uncertainty, ii) 'being changed' and living with being fragile and being
20
21 unable to move freely and iii) 'being myself' with a loss of self, feeling and looking different, alongside
22
23 recreation of self in which they integrated the past, present and future to find meaningful ways of being
24
25 themselves.
26

27 **Conclusion:** This study identified the long-term disruption caused by serious injury, the hidden work of
28
29 integration that is required in order to move forward and maximise potential for recovery. Supportive
30
31 strategies that help people to self-manage their everyday emotional and physical experience of recovery from
32
33 injury are required. Research should focus on developing and testing effective interventions that provide
34
35 support and self-management within a holistic rehabilitation plan.
36

37 38 **ARTICLE SUMMARY** 39

40 41 **Strengths and limitations of this study** 42

- 43 • Use of in-depth qualitative interviews has provided rich data and new insights into the hidden work
44 undertaken by patients as they recover from major lower leg injury.
45
- 46 • The variation and patterns within the patients' experience may help healthcare providers focus
47 effective strategies to maximise emotional and physical recovery over the longer term.
48
- 49 • Our study was intentionally exploratory in nature and the resulting framework requires further
50 exploration in diverse samples to assess its transferability.
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INTRODUCTION

Open fractures of the lower limb (where the bone protrudes through the skin) occur in an estimated 30% of fractures of the tibia.^[1] Treatment is complex as the wound requires surgical cleaning before fixation of the bone, often followed by muscle and skin grafting. The UK WOLLF Wound management of Open Lower Limb Fractures trial compared standard dressings with Negative Pressure Wound Therapy (NPWT).^[2] Negative Pressure Wound Therapy is a type of dressing that applies a gentle suction to the wound removing excess fluid. Two qualitative sub-studies of this trial were undertaken to explore the lived experience of patients with an open fracture of the lower limb, firstly during hospitalisation, and secondly, this paper presents the findings from two to four years post-injury.

There is increasing evidence that the impact of open fracture of the lower limb can be life changing with prolonged periods of recovery. Embodied vulnerability conveys how patients with open fractures of the lower limb struggled to cope with their emotional distress, their changed body which included their wounds, body image, pain and the uncertain nature of their future life.^[3] Recovery can be slow and patients can find it hard to return to their pre-injury lives even 2 years after an open fracture.^[4] Studies with a broader sample of injured patients identify the ongoing challenge of daily living, being able to work and body image.^[5] There is also evidence of persisting psychological distress.^[6] In order to provide direction for long term support and rehabilitation this qualitative study develops existing knowledge by exploring the research question, what are patients' experiences of recovery from an open fracture of the lower limb two to four years post injury?

METHODS

This study was informed by phenomenology and the work of Heidegger^[7] used in other studies of injury.^[8,9] This enabled participants to share their experience of everyday life within their social and cultural context. It uncovered insights into how they know and understand their world and what is important to them. Immersion in the data and interpretation led to an understanding of the meanings inherent in the everyday world of the participant. The project was given ethical approval by West Midlands Coventry and Warwickshire Research Ethics Committee (REC Reference: 12/WM/0001) in June 2016.

A purposive sample of 25 participants were recruited between October 2016 and April 2017, during routine follow up. Interviewees were participants in the UK WOLLF trial^[2] and had received reconstructive surgery for

1
2
3 an open fracture to the lower limb. Purposive sampling included a range of sex, age and grade of severity of
4
5 injury. A key eligibility criteria for the UK WOLLF trial was that at the end of the first surgical wound
6
7 debridement the wound could not be closed. This was required for the trial, as the NPWT dressings under
8
9 investigation cannot be applied to closed wounds, but does not fit clearly with the existing classification
10
11 systems. Only patients with a higher grade of open fracture were included where skin or muscle grafts are
12
13 required. Three sub-divisions of the Gustilo and Anderson^[10] classification were used, grade II, grade III or
14
15 grade III with a vascular injury. See table 1 for information on the participants' sex, age, time since injury,
16
17 cause of injury and injury severity. Two people approached chose not to take part due to personal
18
19 circumstances and lack of time. Respondents received a patient information sheet and provided written or oral
20
21 consent to take part in an interview. The interviews focused on the participants' lived experience of recovery
22
23 from injury and were lightly structured to cover their thoughts, feelings, activities, function and work. Open
24
25 questions such as 'what has it been like for you since your injury', with prompts such as 'tell me more about
26
27 that', 'how did that feel', were used to enable participants to share their experience. Two female health
28
29 researchers with PhDs who did not know the participants undertook the interviews (SR (n=15) and ET (n=10)),
30
31 either face-to-face (usually at the participant's own home, once at a nearby hospital) or over the telephone.
32
33 Two participants were accompanied by their partners. Care was taken to support participants and respect
34
35 their privacy and dignity. One interviewer had experience of interviewing patients with cancer and a
36
37 background in medical sociology, the other had prior experience of interviewing patients with traumatic
38
39 orthopaedic injuries. Interviews lasted 25-100 minutes (average 60 minutes) and were digitally audio-recorded
40
41 and transcribed verbatim. Data was anonymised and held on secure password protected University
42
43 computers. None of the participants wished to see a copy of their transcript.
44
45
46
47

48
49 Table 1 Information about the participants

Table 1 Information about participants	
Characteristics	Number of participants
Sex	
Male	19
Female	6

Age (years) mean 51, range 26-80	
18-29	4
30-49	8
50-69	9
70-80	4
Time since injury (months) mean 31, range 24-49	
24-35 months	14
36-49 months	11
Cause of Injury	
Car collision	8
Motorbike collision	5
Pedestrian-vehicle collision	3
Fall from height/stairs	3
Crush injury at work	3
Low energy fall (from standing)	2
Bicycle-vehicle collision	1
Injury severity, Gustilo and Anderson classification	
II	4
III	18
III plus vascular injury	3

Patient and Public Involvement

Patient and public involvement (PPI) was integral to the design and conduct of the UK WOLFF study. Four patients with similar injuries who were members of the UK WOLFF PPI group helped the researchers reflect on their interpretations during analysis. The UK Musculoskeletal Trauma PPI group are involved in dissemination of the findings.

Analysis

1
2
3 Analysis was undertaken by two researchers (SR and ET), was an iterative process involving initial coding of
4 sections of the data to label the underlying meaning or 'what is going on' in the data such as 'feeling sad due
5 to lack of progress'. Codes were collected together with other similar codes to create categories such as 'being
6 uncertain'. Differences and challenges within interviews and across interviews were written up in field notes
7 and memos, and discussed. Categories were collected together to create themes or 'structures of
8 experience'^[11] such as 'being disempowered'. NVivo 11 a qualitative software package was used to manage
9 the data (QSR Warrington, UK). The findings were shared with the broader research team. Differences in
10 interpretation were discussed as part of the process of analysis but in general there was agreement about the
11 nature and content of the three themes.

12
13 Rigour was demonstrated through trustworthiness.^[12] Both researchers were engaged with the data, held
14 regular discussions and reflected on their positionality throughout analysis. Auditability was demonstrated
15 through the identification of themes and categories and use of quotes to illustrate them. Saturation of themes
16 and categories was achieved. This was indicated when no new themes or categories developed after 18
17 patients were interviewed. Interviewing continued to ensure the sample was purposeful and there was a range
18 of codes in each category. Resonance with the findings was identified by four patients from the UK WOLLF PPI
19 group. It was noted that they placed emphasis on existing codes that identified challenges with intimacy and
20 gratefulness for care provided. A workshop including a range of multidisciplinary staff representing nursing,
21 physiotherapy, trauma surgeons, plastic surgeons and psychologists suggested the findings reflected their
22 experience of listening to patients in clinical practice, although they held differing perspectives on the degree
23 of importance of items and labelling of codes. For example they felt some codes could be drawn together
24 under the broader labels of anxiety or depression.

25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 **RESULTS**

48
49 Overarching theme: Struggling to recover

50
51
52 The findings convey the overarching theme of 'struggling to recover' as an experiential process in which
53 participants aim to make sense of their injury, balance striving to move forward with accepting how they are,
54 and find meaningful ways of living whilst being uncertain of the future and experiencing cycles of progress and
55 setbacks.
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6 In struggling to recover participants conveyed that their 'taken for granted' ways of living experienced prior to
7
8 injury were replaced with daily challenge as they endured symptoms such as persistent pain. They often hid
9
10 the struggle to keep going to maximise participation and maintain a sense of progression.

11
12 They can see people walking but there is no light or pain-meter on top of the head that says 'this guy
13
14 is in absolute agony but he's not going to stop walking because he doesn't want to go in a mobility
15
16 scooter'. People look at you and say 'You're getting on great aren't you?' All you really just want to
17
18 say to them is 'Every day I struggle' and some days you just want to sit and cry your eyes out. – P13

19
20
21 Loss caused by injury led participants to re-negotiate how they live and to integrate their past and present self
22
23 into new ways of being. This was portrayed through the themes of being disempowered, being changed, and
24
25 being myself.

26 27 28 Theme 1: Being disempowered

29
30 Being disempowered conveyed the emotional and physical impact on participants of loss of personal control
31
32 over their life and was expressed through the categories 'being dependent on others' and 'being uncertain
33
34 about the future'.

35 36 37 *Being dependent on others*

38
39 Being dependent on others was a process of accepting help from others whilst striving to maintain a sense of
40
41 independence through activities that supported their mental and physical wellbeing. Many participants had
42
43 prolonged periods where they were not able to put weight through their injured leg, and some had injuries to
44
45 both legs. Dependency on others created frustration, boredom, distress, dismay, was undignified, lowered
46
47 their mood and was epitomised by not even being able to perform simple tasks, such as to make a cup of tea.

48
49 I don't know if it's a man thing or male thing, I don't know. It's your dignity, I mean the last person
50
51 who wiped my arse was my mum and that's it, or my dad, but being a grown man using a bed pan
52
53 because I couldn't get out of bed was awful. – P06

54
55
56 In this state of profound dependency their body became central to everyday life, its needs and limitations
57
58 explicitly governing every aspect of everyday life.
59
60

1
2
3 You feel a bit like a passenger in it all because you're on the outside looking in and you think you're
4 being a bit of a burden on everyone. At the time I found it quite hard to almost tell people that's how
5 I felt, I feel this, I feel a bit worthless. – P18
6
7
8
9

10 Constant support for daily bodily needs could lower their mood so that they could no longer see the 'light at
11 the end of the tunnel' (P17) evident in suicidal thoughts.
12
13

14 I thought about topping myself because it's like I've been independent all my life. ... One night I had
15 all the tablets, Tramadol. – P06
16
17
18

19 Dependency on others was a disempowering experience that led to emotional vulnerability. Expressing how
20 they felt was challenging in the context of being grateful for the care they had received and some had suicidal
21 thoughts.
22
23
24

25 *Being uncertain about the future*

26
27

28 Being uncertain about the future conveyed the emotional impact of not knowing their potential degree of
29 recovery, and what life would be like in the future. Being uncertain about their future added to participants'
30 sense of disempowerment. Participants found it hard to imagine walking properly or returning to pre-injury
31 activities and a 'wait and see' approach added to their sense of uncertainty.
32
33
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35

36 I would say that was the toughest part, was just the un-endingness of it, it was just constant and it
37 was horrible. – P19
38
39
40

41 I did think in my mind you know 'it will heal and then I've got rehabilitation' but this whole non-union,
42 it just dragged on and on and on, I couldn't see an end. ... I wished I'd known about the non-union,
43 err, it was almost hidden from me. ... I said 'well I thought that the operation was successful?' then he
44 told me 'well it was because we would've cut your leg off years ago'. – P21
45
46
47
48
49

50 There was a degree of anxiety regarding their future and ability to live and work productively.
51
52

53 You want to live for the future now because that's what you've got in front of you but you worry
54 about what it's going to bring, not only physically but financially as well. You have no idea what your
55 pay-out is going to be and so my life is in somebody else's hands. There is that horrible thought that
56
57
58
59
60

1
2
3 you may have to go back out to work, force yourself to work because financially you can't exist for the
4
5 rest of your life. – P13
6
7

8 Their capacity to heal often determined their future; leaving them feeling uncertain, disempowered and
9
10 anxious. This was exacerbated by setbacks such as non-union (also noted in recreating me) that reduced their
11
12 ability to sustain recovery.
13

14 Theme 2: Being changed

15
16 Being changed identified how their body no longer looks, feels or functions in ways it had previously. Everyday
17
18 life involved a process of re-negotiating where participants learnt through experience what they could do and
19
20 how they felt about their body whilst striving to regain and retain normal activities. It was expressed through
21
22 the categories of being fragile and being unable to move freely.
23

24 *Being fragile*

25
26 Being fragile conveyed a sense of their body as looking and feeling less robust, less trustworthy, less reliable
27
28 and active engagement was required to reconnect in a positive way with their changed body. Participants were
29
30 predominantly young or middle-aged adults, and many had been previously fit and active individuals. They
31
32 now felt their body was older, weaker, and more fragile.
33
34

35
36 I can't dig. ... I feel like I've got a weakness which has left me feeling like I've got a bit of a disability. –
37

38 P21
39

40
41 Participants felt a need to protect their injured body, or at least the injured limb, including avoiding activities
42
43 due to the fear of experiencing another injury.
44

45 You're frightened it's gonna (going to) break again. – P02
46
47

48 The sense of a whole, continuous body which the participants felt they could trust to do the activities they
49
50 wanted to do was disturbed and instead participants could experience their bodies as alien and fragile.
51

52
53 I do go running and I wear long running trousers because I think if I see it (the muscle graft) it makes
54
55 me feel like there's a weakness there and it makes me very aware, I don't think it is any weaker the
56
57 leg but mentally it makes me think it's a bit weaker and I just find it distracting as well if I exercise it. I
58
59 probably would be over-cautious and not really exercise it properly if I could see it I think. – P14
60

1
2
3 Some participants described feeling distanced or alienated from the injured part of their body.
4

5
6 I don't look at it as my leg anymore. ... It is like the legs belongs to somebody else they don't
7
8 particularly belong to me. – P19
9

10 Their injured body part was no longer fully integrated into their perception of their body. Parts of their body
11
12 had literally shifted places as skin/muscle from other areas of the body had been transplanted to cover the
13
14 defect in the leg. Pain and numbness could increase this sense of alienation.
15

16
17 Participants hid or covered up their injured leg, to avoid others perceiving them as fragile, less capable or
18
19 weak. For some participants the struggle with healing, pain and lack of mobility was so exhausting, that they
20
21 thought amputation might improve their chances of mobility and a better quality of life.
22

23
24 There were a couple of times in it all when I thought, would it be better off to say take it off but I
25
26 knew how hard and how much effort people had put in to make sure that leg was staying where it
27
28 was. – P18
29

30
31 If you took me back in time and I knew then what I know now I would have said 'take my leg off now'.
32
33 I'd be four years down the line with a prosthetic and I could probably still be working. – P13
34

35 Being fragile highlighted the unreliability of their body and continued vulnerability to further injury. The sense
36
37 of a 'whole' body could be disrupted and amputation was considered in an effort to improve chances of
38
39 recovery.
40

41 42 *Being unable to move freely* 43

44
45 Being unable to move freely was the loss of ease, fluidity and previously taken-for-granted ways of moving, it
46
47 affected their ability to use certain geographical spaces and effort was required to improve levels of physical
48
49 activity. Despite being between two to four years post injury, participants felt they were not able to move with
50
51 the same fluidity or spontaneity. The way they walked, their pace, gait or balance was different.
52

53
54 I can't move fast anymore. – P17
55

56
57 My balance was all over the place, it still is, sometimes I feel like I'm falling to the side, it's a weird
58
59 feeling. – P01
60

1
2
3 I waddle, I walk like a penguin it's the only way I can balance, sort of putting weight on one foot and
4
5 then going over to the next foot, I can't stride out anymore. – P02
6

7
8 Specific activities such as being able to kneel prevented them from moving as freely. Some participants felt the
9
10 area where they had a soft tissue/muscle flap used in reconstructive surgery was heavy (notable when
11
12 sleeping), or they experienced swelling and pain. Persistent pain reduced their ability to move and join in
13
14 activities, it varied in type and duration but sometimes was prolonged and often unpredictable.
15

16
17 I sit down for an hour and I get up, oh the pain you can't describe it, but I mean it's for seconds but
18
19 it's enough to, it's really, really painful. – P02
20

21
22 Participants experienced restrictions on the spaces and places they felt confident occupying. They were
23
24 worried about falling and injuring themselves again. The terrain underfoot, types of floor or ground could
25
26 cause pain leading them to be constantly vigilant.
27

28
29 Participants felt changed, even if they had returned to work, often with an increased sense of fragility, loss of
30
31 fluidity and pace of movement, combined with specific functional losses. They hid this fragility from others,
32
33 undertook additional planning for daily activities, limited social participation and changed their work roles in
34
35 order to cope with their injury.
36

37 Theme 3: Being myself

38
39 Being myself was an active process of integrating injury into their sense of who they were as a person, bringing
40
41 together the past, present and future. It was expressed through loss of self and 'recreating me'. Participants
42
43 worked to integrate their injury into their lives expressed through 'loss of self' and 'recreating me'.
44

45 *Loss of self*

46
47
48 Loss of self was expressed as participants felt and looked different and were unable to fulfil their normal roles
49
50 and activities as they did prior to their injury. In loss of self, there was a sense that the body 'restricts me from
51
52 being me' and participants had to adapt to being different from their pre-injury state.
53

54
55 It seemed like a part of my life stopped at 6.45 on (date of injury) and a new life started. ... I used to
56
57 think nothing of walking ten to fifteen miles a day along disused railway lines and things like that, we
58
59 were avid walkers. – P04
60

1
2
3 Participants' current experience contradicted their memories of who they were.
4
5

6 I have 55 years' worth of memories inside my head so you think 'Oh I used to go running on a
7
8 Saturday morning'. ... You try and be the person you were before and you can't be because you are
9
10 95% of what you used to be. But it's just that 5% area that causes you 100% of the problems. – P13
11
12 Some days I, I could scream. I wake in the morning and 'cause you forget', you know when you go to
13
14 sleep, and I wake up in the morning thinking I can just jump out of bed and I can't and then it hits you
15
16 and you think 'Oh God I can't do this!' – P02
17
18

19 Their body thwarted their attempts to return to their former selves. Despite regaining their independence and
20
21 feeling that their healthcare team considered them to be recovered, the participants were continually
22
23 reminded of their injured bodies.
24
25

26 It's very difficult to have a day where you are not conscious of 'that hurts'. ... In an active way you are
27
28 kind of constantly reminded because it's never quite the same day to day. – P22
29
30

31 In contrast to younger patients, older participants located the injury within the context of prior conditions and
32
33 they did not experience the same degree of challenge to their identity.
34
35

36 The event (which) bears more on how I think about life in general is having been fortunate to survive
37
38 a heart attack ten years ago. ... So that sort of in a way puts things in perspective. I know falling off a
39
40 roof can initially be thought of as a life-threatening event but a cardiac arrest is definitely a life-
41
42 threatening event! – P08
43
44

45 Participants struggled with the loss of their pre-injured self and the activities that defined them. Despite
46
47 attempts to move forward and integrate with the present they found their unreliable body provided sensory
48
49 reminders of their loss and their injury.
50

51 *Recreating me*

52

53 Recreating me referred to the ways in which participants made sense of their altered selves, worked on their
54
55 body and mind to find meaningful ways of being and living. In making sense of their injury they reflected on
56
57 how life had been and tried to reconcile this with how they felt now.
58
59
60

1
2
3 It did come as a revelation about three weeks ago, just you know, I can't carry on doing this, I can't
4 keep pushing to get my life back, it's got you know, I've got to change, you know it is a bit of a shock!
5
6 – P19
7
8
9

10 I used to think 'I wished the thing had never fallen on me!' but now I think I've got to that stage where
11 I've passed that and I think I have just slipped, probably slipped back into normality if, um, I, I sort of
12 lived with this problem and that's then become me, so maybe you adapt. – P21
13
14
15

16 Participants tried to return to usual activities but recovery was characterised by ups and downs. Some felt
17 their recovery was delayed by further injuries described by participants as stress fractures, snapped (torn)
18 hamstrings (muscles at the back of the thigh), or injury to their iliotibial bands (connective tissue running from
19 the pelvis to the knee). Only a small number of participants reported receiving enough physiotherapy after
20 their injury. Those who received physiotherapy (usually privately), described a more purposeful recovery with
21 fewer examples of setbacks and less uncertainty.
22
23
24
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26
27

28
29 I think she took it upon herself to get me back to where I wanted to be and I think she listened to
30 what I wanted out of life. – P18
31
32
33

34 Some participants expressed gratitude to be alive or to have avoided amputation. They tried to locate meaning
35 in what happened to them.
36
37

38 I went back and met another patient and his family and I hope that I gave them a little bit more hope.
39
40 ... It was good for me as well for my rehabilitation to feel that it wasn't all for nothing. – P18
41
42

43 For these participants, they were able to find meaning in their injury, and so to incorporate it into their
44 biography, or their story of themselves. Participants engaged in 'body work' in order to convey a sense of
45 normality and provide the appearance of a non-injured body. However, often participants described struggling
46 with the difference between others' expectations and the reality of their everyday experience.
47
48
49

50
51 I think when people think you're doing so well physically they just think 'she's doing really well' and
52 you almost don't want to turn around and say 'well actually I'm really struggling with this, that and
53 the other' because I just don't want to disappoint people or turn it into a negative thing. – P14
54
55
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1
2
3 In recreating me the participants were hindered by their injured body and a lack of supportive therapies but
4
5 tried to integrate their past and present self-identity. New opportunities and meaningful ways of living that
6
7 were beneficial could be found. There was a strong desire to appear normal and participants struggled to be
8
9 themselves.

11 **DISCUSSION**

12
13
14 This qualitative study adds to recent research on the patient experience of open fractures of the lower limb in
15
16 acute care^[3,9] and post injury^[4] by identifying the ongoing recovery undertaken by patients to process the
17
18 impact of injury on their sense of being disempowered, being changed and being myself. We have specifically
19
20 focussed on the longer-term (two to four year post-injury) impact of these injuries and especially in those
21
22 patients who were identified as having injuries on the 'severe' end of the spectrum. We found that the
23
24 concept of embodied vulnerability,^[3,9] and endurance in early recovery^[8], clearly identified in acute care, also
25
26 extends into the longer-term as participants struggle to recover, processing their loss, working to negotiate
27
28 how they live and integrate changes within their self-identity. Our findings indicate that longer term clinical
29
30 support is required to improve outcomes for mental health, function, management of pain and living with
31
32 disability in patients with major trauma to the lower limbs.

33
34
35 There were some limitations to our study. The sample was limited to those taking part in the UK WOLLF trial
36
37 and participants may have different attributes to those who decline to take part in a clinical trial and be
38
39 interviewed. Those agreeing to take part in an interview up to four years after injury may be less likely to
40
41 consider themselves as recovered, thus be more representative of those with chronic ongoing problems. The
42
43 sample was also not ethnically diverse and sampling at specific time points during recovery may have
44
45 increased the transferability of the study findings to other populations. However the UK WOLLF sample were
46
47 considered to be representative of the general population with severe open fractures.^[2] Our sample was
48
49 purposive within the UK WOLLF population and saturation of data was achieved. Four patients with similar
50
51 injuries (UK WOLLF PPI group) felt their personal experience resonated with the findings of this study however
52
53 they also highlighted the joy of recovery, gratefulness to staff for their care, the similarity of the findings to,
54
55 but also the difference from, their individual experience. Despite these limitations, this study provides
56
57 evidence that patients who suffered the more severe injuries may benefit from enhanced clinical attention
58
59 that focusses on distress, uncertainty, fragility and body image over a prolonged period of time. Psychological
60

1
2
3 distress^[6,13] is present in this group and may be linked to ongoing disability.^[14] The continued uncertainty that
4 patients feel reflects elements of a chaos narrative (Frank 1995), where loss of control means it is hard to find
5 meaning in daily life. In our study despair, noted in recovery from trauma ^[15] was expressed as suicidal
6 thoughts. Their perceptions of the body as fragile and weak suggest a state of dys-embodiment^[16] ^[17] where
7 dysfunction highlights the loss of normal taken for granted ways of being. Ongoing disruption to body image is
8 noted in studies of stigma and disfigurement^[18] and in societal pressure to appear recovered^[19] and
9 attractive.^[20] In this study, amputation was considered as an alternative solution to continued challenges and
10 dissociation from the body occurred, as in other specialities.^[21] Patients' progression towards integration of
11 physical change and self-identity was hindered by reminders of their injury, such as persistent pain, as their
12 unreliable body^[22] was unable to achieve the intended activity. This process is noted in chronic illness^[23] and
13 major trauma patients three to six months post injury.^[24] Support that enables patients to feel a greater sense
14 of empowerment and integrate bodily changes within their self-identity may be helpful. Research should
15 therefore focus on developing and testing effective interventions that provide longer term support and self-
16 management within a holistic rehabilitation plan.

31 32 **STATEMENTS**

33 34 **Funding statement**

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38 39 **Competing interests**

40 No benefits have been received or will be received from a commercial party related directly or indirectly to the
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Author contributions

SR and ET contributed equally to this paper. The design, data collection, analysis and drafting of the paper were jointly undertaken by SR and ET. The team JA, JB, MC supported the project, were involved in discussion of the findings and the development of this paper.

Ethical approval

The project was given ethical approval by West Midlands Coventry and Warwickshire Research Ethics Committee (REC Reference: 12/WM/0001) in June 2016.

Consent and Confidentiality

All participants received an information sheet and at least 24 hours to consider their participation. Written informed consent or verbal consent over the telephone were obtained.

Check list

The checklist has been completed and submitted.

Data sharing statement

We do not have consent for data sharing from the study participants.

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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46

47 **ABSTRACT**
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52 **Objectives:** Treatment of open fractures is complex and patients may require muscle and skin grafts. The aim
53
54 of this study was to gain a greater understanding of patient experience of recovery from open fracture of the
55
56 lower limb two to four years post-injury.
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3 **Design:** A phenomenological approach was used to guide the design of the study. Interviews took place
4
5 between October 2016 and April 2017 in the participants' own homes or via telephone.
6

7 **Setting:** England, UK.
8

9 **Participants:** A purposive sample of 25 patients were interviewed with an age range of 26-80 years (median
10
11 51), 19 were male and six female, and time since injury was 24-49 months (median 35 months).
12

13 **Results:** The findings identified a focus on struggling to recover as participants created a new way of living,
14
15 balancing moving forward with accepting how they are, whilst being uncertain of the future and experiencing
16
17 cycles of progress and setbacks. This was expressed through three themes: i) 'being disempowered' with the
18
19 emotional impact of dependency and uncertainty, ii) 'being changed' and living with being fragile and being
20
21 unable to move freely and iii) 'being myself' with a loss of self, feeling and looking different, alongside
22
23 recreation of self in which they integrated the past, present and future to find meaningful ways of being
24
25 themselves.
26

27 **Conclusion:** This study identified the long-term disruption caused by serious injury, the hidden work of
28
29 integration that is required in order to move forward and maximise potential for recovery. Supportive
30
31 strategies that help people to self-manage their everyday emotional and physical experience of recovery from
32
33 injury are required. Research should focus on developing and testing effective interventions that provide
34
35 support and self-management within a holistic rehabilitation plan.
36

37 38 **ARTICLE SUMMARY** 39

40 41 **Strengths and limitations of this study** 42

- 43 • Use of in-depth qualitative interviews has provided rich data and new insights into the hidden work
44
45 undertaken by patients as they recover from major lower leg injury.
46
- 47 • The variation and patterns within the patients' experience may help healthcare providers focus
48
49 effective strategies to maximise emotional and physical recovery over the longer term.
50
- 51 • Our study was intentionally exploratory in nature and the resulting framework requires further
52
53 exploration in diverse samples to assess its transferability.
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INTRODUCTION

Open fractures of the lower limb (where the bone protrudes through the skin) occur in an estimated 30% of fractures of the tibia.^[1] Treatment is complex as the wound requires surgical cleaning before fixation of the bone, often followed by muscle and skin grafting. The UK WOLLF Wound management of Open Lower Limb Fractures trial compared standard dressings with Negative Pressure Wound Therapy (NPWT).^[2] Negative Pressure Wound Therapy is a type of dressing that applies a gentle suction to the wound removing excess fluid. Two qualitative sub-studies of this trial were undertaken to explore the lived experience of patients with an open fracture of the lower limb, firstly during hospitalisation, and secondly, this paper presents the findings from two to four years post-injury.

There is increasing evidence that the impact of open fracture of the lower limb can be life changing with prolonged periods of recovery. Embodied vulnerability conveys how patients with open fractures of the lower limb struggled to cope with their emotional distress, their changed body which included their wounds, body image, pain and the uncertain nature of their future life.^[3] Recovery can be slow and patients can find it hard to return to their pre-injury lives even 2 years after an open fracture.^[4] Studies with a broader sample of injured patients identify the ongoing challenge of daily living, being able to work and body image.^[5] There is also evidence of persisting psychological distress.^[6] In order to provide direction for long term support and rehabilitation this qualitative study develops existing knowledge by exploring the research question, what are patients' experiences of recovery from an open fracture of the lower limb two to four years post injury?

METHODS

This study was informed by phenomenology and the work of Heidegger^[7] used in other studies of injury.^[8,9] This enabled participants to share their experience of everyday life within their social and cultural context. It uncovered insights into how they know and understand their world and what is important to them. Immersion in the data and interpretation led to an understanding of the meanings inherent in the everyday world of the participant. The project was given ethical approval by West Midlands Coventry and Warwickshire Research Ethics Committee (REC Reference: 12/WM/0001) in June 2016.

A purposive sample of 25 participants were recruited between October 2016 and April 2017, during routine follow up. Interviewees were participants in the UK WOLLF trial^[2] and had received reconstructive surgery for

1
2
3 an open fracture to the lower limb. Purposive sampling included a range of sex, age and grade of severity of
4
5 injury. A key eligibility criteria for the UK WOLFF trial was that at the end of the first surgical wound
6
7 debridement the wound could not be closed. This was required for the trial, as the NPWT dressings under
8
9 investigation cannot be applied to closed wounds, but does not fit clearly with the existing classification
10
11 systems. Only patients with a higher grade of open fracture were included where skin or muscle grafts are
12
13 required. Three sub-divisions of the Gustilo and Anderson^[10] classification were used, grade II, grade III
14
15 (inclusive of a/b) or grade IIIc with a vascular injury. See table 1 for information on the participants' sex, age,
16
17 time since injury, cause of injury and injury severity. Two people approached chose not to take part due to
18
19 personal circumstances and lack of time. Respondents received a patient information sheet and provided
20
21 written or oral consent to take part in an interview. The interviews focused on the participants' lived
22
23 experience of recovery from injury and were lightly structured to cover their thoughts, feelings, activities,
24
25 function and work. Open questions such as 'what has it been like for you since your injury', with prompts such
26
27 as 'tell me more about that', 'how did that feel', were used to enable participants to share their experience.
28
29 Two female health researchers with PhDs who did not know the participants undertook the interviews (SR
30
31 (n=15) and ET (n=10)), either face-to-face (usually at the participant's own home, once at a nearby hospital) or
32
33 over the telephone. Two participants were accompanied by their partners. Care was taken to support
34
35 participants and respect their privacy and dignity. One interviewer had experience of interviewing patients
36
37 with cancer and a background in medical sociology, the other had prior experience of interviewing patients
38
39 with traumatic orthopaedic injuries. Interviews lasted 25-100 minutes (average 60 minutes) and were digitally
40
41 audio-recorded and transcribed verbatim. Data was anonymised and held on secure password protected
42
43 University computers. None of the participants wished to see a copy of their transcript.
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Table 1 Information about the participants

Table 1 Information about participants	
Characteristics	Number of participants
Sex	
Male	19
Female	6

Age (years) mean 51, range 26-80	
18-29	4
30-49	8
50-69	9
70-80	4
Time since injury (months) mean 31, range 24-49	
24-35 months	14
36-49 months	11
Cause of Injury	
Car collision	8
Motorbike collision	5
Pedestrian-vehicle collision	3
Fall from height/stairs	3
Crush injury at work	3
Low energy fall (from standing)	2
Bicycle-vehicle collision	1
Injury severity, Gustilo and Anderson classification	
II	4
III (inclusive of a/b)	18
IIIc	3

Patient and Public Involvement

Patient and public involvement (PPI) was integral to the design and conduct of the UK WOLLF study. Four patients with similar injuries who were members of the UK WOLLF PPI group helped the researchers reflect on their interpretations during analysis. The UK Musculoskeletal Trauma PPI group are involved in dissemination of the findings.

Analysis

1
2
3 Analysis was undertaken by two researchers (SR and ET), was an iterative process involving initial coding of
4 sections of the data to label the underlying meaning or 'what is going on' in the data such as 'feeling sad due
5 to lack of progress'. Codes were collected together with other similar codes to create categories such as 'being
6 uncertain'. Differences and challenges within interviews and across interviews were written up in field notes
7 and memos, and discussed. Categories were collected together to create themes or 'structures of
8 experience'^[11] such as 'being disempowered'. NVivo 11 a qualitative software package was used to manage
9 the data (QSR Warrington, UK). The findings were shared with the broader research team. Differences in
10 interpretation were discussed as part of the process of analysis but in general there was agreement about the
11 nature and content of the three themes.

12
13 Rigour was demonstrated through trustworthiness.^[12] Both researchers were engaged with the data, held
14 regular discussions and reflected on their positionality throughout analysis. Auditability was demonstrated
15 through the identification of themes and categories and use of quotes to illustrate them. Saturation of themes
16 and categories was achieved. This was indicated when no new themes or categories developed after 18
17 patients were interviewed. Interviewing continued to ensure the sample was purposeful and there was a range
18 of codes in each category. Resonance with the findings was identified by four patients from the UK WOLFF PPI
19 group. It was noted that they placed emphasis on existing codes that identified challenges with intimacy and
20 gratefulness for care provided. A workshop including a range of multidisciplinary staff representing nursing,
21 physiotherapy, trauma surgeons, plastic surgeons and psychologists suggested the findings reflected their
22 experience of listening to patients in clinical practice, although they held differing perspectives on the degree
23 of importance of items and labelling of codes. For example they felt some codes could be drawn together
24 under the broader labels of anxiety or depression.

25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 **RESULTS**

48
49 Overarching theme: Struggling to recover

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51
52 The findings convey the overarching theme of 'struggling to recover' as an experiential process in which
53 participants aim to make sense of their injury, balance striving to move forward with accepting how they are,
54 and find meaningful ways of living whilst being uncertain of the future and experiencing cycles of progress and
55 setbacks.
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6 In struggling to recover participants conveyed that their 'taken for granted' ways of living experienced prior to
7
8 injury were replaced with daily challenge as they endured symptoms such as persistent pain. They often hid
9
10 the struggle to keep going to maximise participation and maintain a sense of progression.

11
12 They can see people walking but there is no light or pain-meter on top of the head that says 'this guy
13
14 is in absolute agony but he's not going to stop walking because he doesn't want to go in a mobility
15
16 scooter'. People look at you and say 'You're getting on great aren't you?' All you really just want to
17
18 say to them is 'Every day I struggle' and some days you just want to sit and cry your eyes out. – P13

19
20
21 Loss caused by injury led participants to re-negotiate how they live and to integrate their past and present self
22
23 into new ways of being. This was portrayed through the themes of being disempowered, being changed, and
24
25 being myself.

26 27 28 Theme 1: Being disempowered

29
30 Being disempowered conveyed the emotional and physical impact on participants of loss of personal control
31
32 over their life and was expressed through the categories 'being dependent on others' and 'being uncertain
33
34 about the future'.

35 36 37 *Being dependent on others*

38
39 Being dependent on others was a process of accepting help from others whilst striving to maintain a sense of
40
41 independence through activities that supported their mental and physical wellbeing. Many participants had
42
43 prolonged periods where they were not able to put weight through their injured leg, and some had injuries to
44
45 both legs. Dependency on others created frustration, boredom, distress, dismay, was undignified, lowered
46
47 their mood and was epitomised by not even being able to perform simple tasks, such as to make a cup of tea.

48
49 I don't know if it's a man thing or male thing, I don't know. It's your dignity, I mean the last person
50
51 who wiped my arse was my mum and that's it, or my dad, but being a grown man using a bed pan
52
53 because I couldn't get out of bed was awful. – P06

54
55
56 In this state of profound dependency their body became central to everyday life, its needs and limitations
57
58 explicitly governing every aspect of everyday life.
59
60

1
2
3 You feel a bit like a passenger in it all because you're on the outside looking in and you think you're
4 being a bit of a burden on everyone. At the time I found it quite hard to almost tell people that's how
5 I felt, I feel this, I feel a bit worthless. – P18
6
7
8
9

10 Constant support for daily bodily needs could lower their mood so that they could no longer see the 'light at
11 the end of the tunnel' (P17) evident in suicidal thoughts.
12
13

14 I thought about topping myself because it's like I've been independent all my life. ... One night I had
15 all the tablets, Tramadol. – P06
16
17
18

19 Dependency on others was a disempowering experience that led to emotional vulnerability. Expressing how
20 they felt was challenging in the context of being grateful for the care they had received and some had suicidal
21 thoughts.
22
23
24
25

26 *Being uncertain about the future*

27

28 Being uncertain about the future conveyed the emotional impact of not knowing their potential degree of
29 recovery, and what life would be like in the future. Being uncertain about their future added to participants'
30 sense of disempowerment. Participants found it hard to imagine walking properly or returning to pre-injury
31 activities and a 'wait and see' approach added to their sense of uncertainty.
32
33
34
35

36 I would say that was the toughest part, was just the un-endingness of it, it was just constant and it
37 was horrible. – P19
38
39
40

41 I did think in my mind you know 'it will heal and then I've got rehabilitation' but this whole non-union,
42 it just dragged on and on and on, I couldn't see an end. ... I wished I'd known about the non-union,
43 err, it was almost hidden from me. ... I said 'well I thought that the operation was successful?' then he
44 told me 'well it was because we would've cut your leg off years ago'. – P21
45
46
47
48
49

50 There was a degree of anxiety regarding their future and ability to live and work productively.
51
52

53 You want to live for the future now because that's what you've got in front of you but you worry
54 about what it's going to bring, not only physically but financially as well. You have no idea what your
55 pay-out is going to be and so my life is in somebody else's hands. There is that horrible thought that
56
57
58
59
60

1
2
3 you may have to go back out to work, force yourself to work because financially you can't exist for the
4
5 rest of your life. – P13
6
7

8 Their capacity to heal often determined their future; leaving them feeling uncertain, disempowered and
9
10 anxious. This was exacerbated by setbacks such as non-union (also noted in recreating me) that reduced their
11
12 ability to sustain recovery.
13

14 Theme 2: Being changed

15
16 Being changed identified how their body no longer looks, feels or functions in ways it had previously. Everyday
17
18 life involved a process of re-negotiating where participants learnt through experience what they could do and
19
20 how they felt about their body whilst striving to regain and retain normal activities. It was expressed through
21
22 the categories of being fragile and being unable to move freely.
23

24 *Being fragile*

25
26 Being fragile conveyed a sense of their body as looking and feeling less robust, less trustworthy, less reliable
27
28 and active engagement was required to reconnect in a positive way with their changed body. Participants were
29
30 predominantly young or middle-aged adults, and many had been previously fit and active individuals. They
31
32 now felt their body was older, weaker, and more fragile.
33
34

35
36 I can't dig. ... I feel like I've got a weakness which has left me feeling like I've got a bit of a disability. –
37

38 P21
39

40
41 Participants felt a need to protect their injured body, or at least the injured limb, including avoiding activities
42
43 due to the fear of experiencing another injury.
44

45
46 You're frightened it's gonna (going to) break again. – P02
47

48
49 The sense of a whole, continuous body which the participants felt they could trust to do the activities they
50
51 wanted to do was disturbed and instead participants could experience their bodies as alien and fragile.
52

53
54 I do go running and I wear long running trousers because I think if I see it (the muscle graft) it makes
55
56 me feel like there's a weakness there and it makes me very aware, I don't think it is any weaker, the
57
58 leg, but mentally it makes me think it's a bit weaker and I just find it distracting as well if I exercise it. I
59
60 probably would be over-cautious and not really exercise it properly if I could see it I think. – P14

1
2
3 Some participants described feeling distanced or alienated from the injured part of their body.
4

5
6 I don't look at it as my leg anymore. ... It is like the legs belongs to somebody else they don't
7
8 particularly belong to me. – P19
9

10 Their injured body part was no longer fully integrated into their perception of their body. Parts of their body
11
12 had literally shifted places as skin/muscle from other areas of the body had been transplanted to cover the
13
14 defect in the leg. Pain and numbness could increase this sense of alienation.
15

16
17 Participants hid or covered up their injured leg, to avoid others perceiving them as fragile, less capable or
18
19 weak. For some participants the struggle with healing, pain and lack of mobility was so exhausting, that they
20
21 thought amputation might improve their chances of mobility and a better quality of life.
22

23
24 There were a couple of times in it all when I thought, would it be better off to say take it off but I
25
26 knew how hard and how much effort people had put in to make sure that leg was staying where it
27
28 was. – P18
29

30
31 If you took me back in time and I knew then what I know now I would have said 'take my leg off now'.
32
33 I'd be four years down the line with a prosthetic and I could probably still be working. – P13
34

35 Being fragile highlighted the unreliability of their body and continued vulnerability to further injury. The sense
36
37 of a 'whole' body could be disrupted and amputation was considered in an effort to improve chances of
38
39 recovery.
40

41 42 *Being unable to move freely* 43

44
45 Being unable to move freely was the loss of ease, fluidity and previously taken-for-granted ways of moving, it
46
47 affected their ability to use certain geographical spaces and effort was required to improve levels of physical
48
49 activity. Despite being between two to four years post injury, participants felt they were not able to move with
50
51 the same fluidity or spontaneity. The way they walked, their pace, gait or balance was different.
52

53
54 I can't move fast anymore. – P17
55

56
57 My balance was all over the place, it still is, sometimes I feel like I'm falling to the side, it's a weird
58
59 feeling. – P01
60

1
2
3 I waddle, I walk like a penguin it's the only way I can balance, sort of putting weight on one foot and
4
5 then going over to the next foot, I can't stride out anymore. – P02
6

7
8 Specific activities such as being able to kneel prevented them from moving as freely. Some participants felt the
9
10 area where they had a soft tissue/muscle flap used in reconstructive surgery was heavy (notable when
11
12 sleeping), or they experienced swelling and pain. Persistent pain reduced their ability to move and join in
13
14 activities, it varied in type and duration but sometimes was prolonged and often unpredictable.
15

16
17 I sit down for an hour and I get up, oh the pain you can't describe it, but I mean it's for seconds but
18
19 it's enough to, it's really, really painful. – P02
20

21
22 Participants experienced restrictions on the spaces and places they felt confident occupying. They were
23
24 worried about falling and injuring themselves again. The terrain underfoot, types of floor or ground could
25
26 cause pain leading them to be constantly vigilant.
27

28
29 Participants felt changed, even if they had returned to work, often with an increased sense of fragility, loss of
30
31 fluidity and pace of movement, combined with specific functional losses. They hid this fragility from others,
32
33 undertook additional planning for daily activities, limited social participation and changed their work roles in
34
35 order to cope with their injury.
36

37 Theme 3: Being myself

38
39 Being myself was an active process of integrating injury into their sense of who they were as a person, bringing
40
41 together the past, present and future. It was expressed through loss of self and 'recreating me'. Participants
42
43 worked to integrate their injury into their lives expressed through 'loss of self' and 'recreating me'.
44

45 *Loss of self*

46
47
48 Loss of self was expressed as participants felt and looked different and were unable to fulfil their normal roles
49
50 and activities as they did prior to their injury. In loss of self, there was a sense that the body 'restricts me from
51
52 being me' and participants had to adapt to being different from their pre-injury state.
53

54
55 It seemed like a part of my life stopped at 6.45 on (date of injury) and a new life started. ... I used to
56
57 think nothing of walking ten to fifteen miles a day along disused railway lines and things like that, we
58
59 were avid walkers. – P04
60

1
2
3 Participants' current experience contradicted their memories of who they were.
4
5

6 I have 55 years' worth of memories inside my head so you think 'Oh I used to go running on a
7
8 Saturday morning'. ... You try and be the person you were before and you can't be because you are
9
10 95% of what you used to be. But it's just that 5% area that causes you 100% of the problems. – P13
11
12 Some days I, I could scream. I wake in the morning and 'cause you forget', you know when you go to
13
14 sleep, and I wake up in the morning thinking I can just jump out of bed and I can't and then it hits you
15
16 and you think 'Oh God I can't do this!' – P02
17
18

19 Their body thwarted their attempts to return to their former selves. Despite regaining their independence and
20
21 feeling that their healthcare team considered them to be recovered, the participants were continually
22
23 reminded of their injured bodies.
24
25

26 It's very difficult to have a day where you are not conscious of 'that hurts'. ... In an active way you are
27
28 kind of constantly reminded because it's never quite the same day to day. – P22
29
30

31 In contrast to younger patients, older participants located the injury within the context of prior conditions and
32
33 they did not experience the same degree of challenge to their identity.
34
35

36 The event (which) bears more on how I think about life in general is having been fortunate to survive
37
38 a heart attack ten years ago. ... So that sort of in a way puts things in perspective. I know falling off a
39
40 roof can initially be thought of as a life-threatening event but a cardiac arrest is definitely a life-
41
42 threatening event! – P08
43
44

45 Participants struggled with the loss of their pre-injured self and the activities that defined them. Despite
46
47 attempts to move forward and integrate with the present they found their unreliable body provided sensory
48
49 reminders of their loss and their injury.
50

51 *Recreating me*

52

53 Recreating me referred to the ways in which participants made sense of their altered selves, worked on their
54
55 body and mind to find meaningful ways of being and living. In making sense of their injury they reflected on
56
57 how life had been and tried to reconcile this with how they felt now.
58
59
60

1
2
3 It did come as a revelation about three weeks ago, just you know, I can't carry on doing this, I can't
4 keep pushing to get my life back, it's got you know, I've got to change, you know it is a bit of a shock!
5
6
7 – P19
8
9

10 I used to think 'I wished the thing had never fallen on me!' but now I think I've got to that stage where
11 I've passed that and I think I have just slipped, probably slipped back into normality if, um, I, I sort of
12 lived with this problem and that's then become me, so maybe you adapt. – P21
13
14
15

16 Participants tried to return to usual activities but recovery was characterised by ups and downs. Some felt
17 their recovery was delayed by further injuries described by participants as 'stress fractures', 'snapped (torn)
18 hamstrings' (muscles at the back of the thigh), or injury to their 'iliotibial bands' (connective tissue running
19 from the pelvis to the knee). Only a small number of participants reported receiving enough physiotherapy
20 after their injury. Those who received physiotherapy (usually privately), described a more purposeful recovery
21 with fewer examples of setbacks and less uncertainty.
22
23
24
25
26
27
28

29 I think she took it upon herself to get me back to where I wanted to be and I think she listened to
30 what I wanted out of life. – P18
31
32
33

34 Some participants expressed gratitude to be alive or to have avoided amputation. They tried to locate meaning
35 in what happened to them.
36
37

38 I went back and met another patient and his family and I hope that I gave them a little bit more hope.
39
40 ... It was good for me as well for my rehabilitation to feel that it wasn't all for nothing. – P18
41
42

43 For these participants, they were able to find meaning in their injury, and so to incorporate it into their
44 biography, or their story of themselves. Participants engaged in 'body work' in order to convey a sense of
45 normality and provide the appearance of a non-injured body. However, often participants described struggling
46 with the difference between others' expectations and the reality of their everyday experience.
47
48
49
50

51 I think when people think you're doing so well physically they just think 'she's doing really well' and
52 you almost don't want to turn around and say 'well actually I'm really struggling with this, that and
53 the other' because I just don't want to disappoint people or turn it into a negative thing. – P14
54
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1
2
3 In recreating me the participants were hindered by their injured body and a lack of supportive therapies but
4
5 tried to integrate their past and present self-identity. New opportunities and meaningful ways of living that
6
7 were beneficial could be found. There was a strong desire to appear normal and participants struggled to be
8
9 themselves.

11 **DISCUSSION**

12
13
14 This qualitative study adds to recent research on the patient experience of open fractures of the lower limb in
15
16 acute care^[3,9] and post injury^[4] by identifying the ongoing recovery undertaken by patients to process the
17
18 impact of injury on their sense of being disempowered, being changed and being myself. We have specifically
19
20 focussed on the longer-term (two to four year post-injury) impact of these injuries and especially in those
21
22 patients who were identified as having injuries on the 'severe' end of the spectrum. We found that the
23
24 concept of embodied vulnerability,^[3,9] and endurance in early recovery^[8], clearly identified in acute care, also
25
26 extends into the longer-term as participants struggle to recover, processing their loss, working to negotiate
27
28 how they live and integrate changes within their self-identity. Our findings indicate that longer term clinical
29
30 support is required to improve outcomes for mental health, function, management of pain and living with
31
32 disability in patients with major trauma to the lower limbs.

33
34
35 There were some limitations to our study. The sample was limited to those taking part in the UK WOLLF trial
36
37 and participants may have different attributes to those who decline to take part in a clinical trial and be
38
39 interviewed. Those agreeing to take part in an interview up to four years after injury may be less likely to
40
41 consider themselves as recovered, thus be more representative of those with chronic ongoing problems. The
42
43 sample was also not ethnically diverse and sampling at specific time points during recovery may have
44
45 increased the transferability of the study findings to other populations. However the UK WOLLF sample were
46
47 considered to be representative of the general population with severe open fractures.^[2] Our sample was
48
49 purposive within the UK WOLLF population and saturation of data was achieved. Four patients with similar
50
51 injuries (UK WOLLF PPI group) felt their personal experience resonated with the findings of this study however
52
53 they also highlighted the joy of recovery, gratefulness to staff for their care, the similarity of the findings to,
54
55 but also the difference from, their individual experience. Despite these limitations, this study provides
56
57 evidence that patients who suffered the more severe injuries may benefit from enhanced clinical attention
58
59 that focusses on distress, uncertainty, fragility and body image over a prolonged period of time. Psychological
60

1
2
3 distress^[6,13] is present in this group and may be linked to ongoing disability.^[14] The continued uncertainty that
4 patients feel reflects elements of a chaos narrative ^[15], where loss of control means it is hard to find meaning
5 in daily life. In our study despair, noted in recovery from trauma ^[16] was expressed as suicidal thoughts. Their
6 perceptions of the body as fragile and weak suggest a state of dys-embodiment^{[17] [18]} where dysfunction
7 highlights the loss of normal taken for granted ways of being. Ongoing disruption to body image is noted in
8 studies of stigma and disfigurement^[19] and in societal pressure to appear recovered^[20] and attractive.^[21] In this
9 study, amputation was considered as an alternative solution to continued challenges and dissociation from the
10 body occurred, as in other specialities.^[22] Patients' progression towards integration of physical change and self-
11 identity was hindered by reminders of their injury, such as persistent pain, as their unreliable body^[23] was
12 unable to achieve the intended activity. This process is noted in chronic illness^[24] and major trauma patients
13 three to six months post injury.^[25] Support that enables patients to feel a greater sense of empowerment and
14 integrate bodily changes within their self-identity may be helpful. Research should therefore focus on
15 developing and testing effective interventions that provide longer term support and self-management within a
16 holistic rehabilitation plan.

31 STATEMENTS

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36 Competing interests

37 No benefits have been received or will be received from a commercial party related directly or indirectly to the
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Author contributions

SR and ET contributed equally to this paper. The design, data collection, analysis and drafting of the paper were jointly undertaken by SR and ET. The team JA, JB, MC supported the project, were involved in discussion of the findings and the development of this paper.

Ethical approval

The project was given ethical approval by West Midlands Coventry and Warwickshire Research Ethics Committee (REC Reference: 12/WM/0001) in June 2016.

Consent and Confidentiality

All participants received an information sheet and at least 24 hours to consider their participation. Written informed consent or verbal consent over the telephone were obtained.

Check list

The checklist has been completed and submitted.

Data sharing statement

We do not have consent for data sharing from the study participants.

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COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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