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**A qualitative study of patients’ experience of recovery after a distal femur fracture**

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**Highlights**

* After a distal femoral fracture, patients need support from others to manage at home and undertake their daily activities
* Once discharged from hospital, patients may struggle with limited mobility
* For some patients, their rehabilitation is hindered by a lack of confidence and support

**Abstract**

**Purpose:** This qualitative study was conducted as part of a feasibility study for TrAFFix, (ISRCTN92089567), a randomised controlled trial that will compare two surgical interventions used to fix distal femoral fractures. Our aim was to understand patients’ experiences of treatment and the early phase of recovery after a distal femoral fracture. While, much is known about the experience of recovery from hip fracture, little is known about whether patients with other lower limb fragility fractures experience the same concerns and challenges.

**Materials and Methods**: Semi-structured interviews were conducted with 11 patients participating in TrAFFix or their relative. Interviews were conducted face to face or by telephone. With agreement from participants, interviews were audio recorded and transcribed. Transcripts were analysed inductively using thematic analysis. As part of the user involvement for TrAFFix, we held a focus group with PPI representatives who had experience or knowledge of lower limb fractures, to learn about factors that might influence patients’ recovery after a fragility facture. Data from the focus group relevant to themes from our thematic analysis are also presented.

**Results:** Three themes were identified within patients’ accounts of their experience. Our data revealed that: i) being informed about treatment and recovery was important to patients; ii) patients muddled through and found ways to manage at home, often needing the support of others; and iii) rehabilitation was arduous for patients who received limited rehabilitative support and at times lacked confidence to follow the instructions that they were given.

**Conclusions:**

Our findings highlight the struggle patients endure while recovering after a distal femoral fracture and the limited rehabilitative support they receive after discharge from hospital. They reinforce the need to ensure a patient feels informed about their treatment and recovery and the need for greater support for patients to manage at home and move with confidence.

**Keywords:**

Fragility fracture, qualitative research, recovery, older people, distal femoral fracture

**Introduction**

Fragility fractures are significant injuries that occur in a vulnerable group of patients, causing considerable morbidity and mortality [1]. The incidence of fragility fractures is increasing and the spectrum of fractures presenting in the older population is changing [2]. An increase in fractures around the knee is evident and predicted to continue [3]. Distal femoral fractures (just above the knee) account for between 4 to 6% of all fractures of the femur [4]. Occurring predominantly in older people with osteoporotic bone [2], these fractures can be devastating with a high rate of mortality (18 – 30% mortality at one year [5-7]).

Patients’ experience of recovery from hip fracture, the most common fragility fracture leading to inpatient admission, has been explored through a range of qualitative studies [8-13]. These studies reveal that the experience is individual, depending on the patients’ specific circumstances [8, 13]. Different recovery trajectories have been identified which highlight that while some patients make a gradual recovery and develop a ‘new normal’, others experience an ongoing decline in their health after sustaining a fragility fracture [8, 13]. Common aspects of patients experience have been identified within these studies, including: limited mobility [8, 10, 11], difficulty performing daily activities [8, 11], loss of confidence [10], fear of falling [8] and feelings of seclusion or confinement [10, 11]. Despite these challenges, some patients are able to adapt to their injury, for example by devising strategies to allow them to carry out their everyday activities and maintain their independence [8, 10].

After surgery, patients with other lower limb fragility fractures are often treated in the same way as hip fracture patients as they are a similar cohort of patients [6]. While, much is known about the experience of recovery from hip fracture, little is known about whether patients with other lower limb fragility fractures experience the same concerns and challenges.

Within the TrAFFix study [14], a feasibility study for a randomised controlled trial (RCT) that will compare two surgical methods used to fix distal femoral fractures, we examined patients’ experiences during treatment and the early stages of recovery.

**Patients and Methods**

This study was part of a process evaluation for the TrAFFix study [14].The study was registered with the International Standard Randomised Controlled Trials Number Registry (ISRCTN92089567). Seven centres from across England (United Kingdom) participated in TrAFFix and 23 participants were included during the 10 month recruitment period. The process evaluation used a mixed methodology approach and a variety of data sources. These included interviews with participants or their personal consultee (a person, typically a relative, who was consulted about research participation on behalf of a patient with diminished capacity), interviews with staff from the participating centres, clinical reporting forms (CRFs), which comprised data collected from participants and their medical notes, screening logs from the study and a focus group with patient and public involvement (PPI) representatives. TrAFFix and the embedded process evaluation from which these data were generated was approved by the Wales Research Ethics Committee (REC reference 16/WA/0225). This study draws upon data from the participant interviews and a focus group with PPI representatives.

Interviews aimed to understand participants’ experience of the early phase of recovery after a distal femoral fracture. We asked all patients who were invited to participate in TrAFFix if they could be approached by a researcher about taking part in an interview. Interviews were semi-structured and used a brief topic guide, covering participants experience of i) injury, ii) recovery and iii) taking part in TrAFFix and were conducted up to five months post-surgery. As we were interested in participants’ experience of consenting to TrAFFix and their experience of recovery, we planned to interview them at two time points. The first interview, to take place in the early weeks after surgery would aim to learn about their experience of the study and the second interview, at approximately four months post-surgery would aim to learn about their experience of recovery. Interviews were conducted face to face or by telephone, by an experienced qualitative researcher, who had no prior relationship with the interviewees. Where participants agreed, interviews were audio-recorded and transcribed verbatim.

As part of the user involvement for TrAFFix, we also held a focus group with PPI representatives, who had experience or knowledge of lower limb fractures, to learn about the factors other than surgery that influence patients’ recovery after a distal femoral fracture. The patient pathway, from before the fracture to returning home from hospital, was used as a guide to discuss what might be important for patients at each stage. The focus group was audio-recorded and transcribed with consent from the attendees.

We used Nvivo 10 to manage the data. Interview transcripts were analysed using thematic analysis (as described by Taylor and Bogdan)[15]. This method involved grouping sentences or paragraphs of similar meaning into codes. By comparing within and across the codes, similar codes were grouped together into categories. Three themes were developed by comparing within and across the emerging categories. The study management group met regularly, throughout analysis, to discuss the emerging themes. Themes relating to patients experience of treatment and recovery are presented here. Data from the focus group with PPI representatives, which relate to these themes, are also presented.

**Results**

Seventeen participants agreed to be approached about participating in an interview. One participant died and another withdrew from the study prior to being contacted. Two participants declined to be interviewed when they were contacted by the researcher and two could not be reached. This left 11 participants from five of the seven centres participating in TrAFFix who took part in 14 interviews. Table 1 presents the characteristics of the participants. Due to the difficulty in contacting patients in the first few weeks following surgery, only three participants were interviewed twice. The remaining participants were interviewed once at the earliest opportunity after discharge from hospital, with this interview covering their experience of the study and recovery. Interviews lasted up to thirty minutes. The sample of participants interviewed included two consultees who provided consent for their relative to participate in the study and one patient/consultee dyad who answered the interview questions together. Of the patients who were interviewed or whose relative was interviewed on their behalf, two were male and nine were female. All were of white ethnicity and aged between 54 and 93 (mean age = 76.3). Two participants were able to move about freely without aids prior to their fracture and five participants were classified as frail (either mildly (n=1), moderately (n=1), severely (n=2), or very severely (n=1)) using the Rockwood fragility scale [16]. One participant, whose consultee was interviewed on his behalf, had dementia.

Six PPI representatives and four members of the study team participated in the focus group. Two members of the study team facilitated the discussion, one took field notes and one answered clinical questions. Focus group participants had experience of lower limb fractures either personally, through their family or through their work.

Three themes were identified from the participants’ data: i) being informed, ii) muddling through and iii) struggling to move. Each theme is presented in turn with illustrative quotes. Data from our focus group with PPI representatives that complement or contradict these themes are presented alongside patients accounts.

***Being informed***

Patients valued being informed throughout treatment and recovery despite their frailty and the trauma that they had endured. Seeing their X-rays and knowing who to contact could help patients feel informed while being uninformed could cause distress.

After injury, patients needed fixing and trusted their surgeon to do this for them. Some experienced confusion or delirium and had little memory of their time in hospital prior to surgery. Despite their frailty and their initial reliance on their surgeon to fix them, participants appreciated being informed about the treatment they had received.

No, I don’t really know what happened [while in hospital] to be honest with you. I was just full of drugs and it was just the last couple of days before I got out I remember things then... They phoned my wife because they thought I was a bit confused, well I was. Participant 8

You know they don’t treat you as an idiot you know; they consider that you have got some intelligence left. Participant 3

Several participants described being shown X-rays of their fracture. Knowing what has been done to fix their fracture could help them to understand their pain and discomfort or the reason for the exercises they are given.

They have shown me photographs of it…. they just thought and I agree with them, the fact that I know what they have done and I know why my knee is the worst part of it because it is the part that I have to keep moving so that I don’t have a stiff leg for life. Participant 3

 Knowing their surgeon was happy with how the bones were healing and seeing their X-rays could give patients a degree of confidence during rehabilitation. One patient for example, explained she wanted to hear from her surgeon and see in the x-rays that her bone was healing before trying to weight bear.

I am going to see the doctor for the third time now so to see whether it has made more bone and that will tell me in my head that I can put more weight on it. If he says ‘Oh it’s made a lot more bone this time and it looks good’, I think that will tell me I can try harder with putting the weight on it. Participant 9

 Information was easier for some patients to access than others, after discharge from hospital. Having the contact details of social workers who could answer questions could be helpful for patients and their families.

 I mean there is always someone that is able to help you on the other end of the phone. My daughter has numbers for the social worker people and everything if we have got questions to ask we always know we can phone a number and get an answer from somebody at least. Participant 9

 Not all patients felt informed throughout their treatment and being uninformed could be distressing for patients. One patient, for example, described the impact of being moved from one hospital to another without warning in the days following surgery.

 They took me from [one hospital to another] because they wanted my bed again because there were people waiting for my bed. So I had to come out of that hospital and go to the [4]… it was horrendous feeling for my daughter, feeling for me, not knowing where we were going. And they just came on the wards and started packing my stuff up and said we want this bed, you have got to go to the [other hospital] and there was no warning, no nothing, no it was awful. Participant 9

During the focus group, PPI representatives highlighted the importance of clear and honest communication throughout treatment and recovery. Being kept informed was considered empowering for patients. Avoiding jargon or giving conflicting advice, understanding that patients will not have the same knowledge as clinical staff when discussing injury and treatment, and being mindful that elderly patients are often not inclined to ask questions when an explanation is unclear were also raised as important.

I think communication is really important…If somebody sits with you and even if it’s bad news, if it’s explained and you understand it and things are pointed out to you then you come to terms and you can deal with something but you can’t if you really don’t know. If people think ‘Oh, she doesn’t need to know this… but it’s empowering and there is something disempowering about being a patient isn’t there. PPI Representative

***Muddling through***

Patients were eager to return home after their fracture but once home, managing could be a struggle. Patients talked of ‘muddling through’ at home with the support of their family or carers and developed new ways to undertake their daily activities.

After surgery, patients endured a slow and difficult period of recovery and many were still adjusting to their injury at the time of their interview. Several participants described spending a long time in hospitals, rehabilitation units or care homes before returning to their pre-fracture residence. Four participants were discharged to their own home or sheltered housing; six were discharged to rehabilitation units and one to a residential care home. While patients were eager to return to their pre-fracture residence, they were not all able to.

Since it was agreed that it was not feasible for me (participants’ daughter) to look after her in her own home or in mine as she needed round the clock care and two people to help her to stand with the turner, she had to move into full-time self-funded nursing care and sell her house to pay for this. This has been detrimental to her mental health and well-being. Participant 10

Once home, participants described trying to ‘muddle through’ with support from their family, carers or cleaners. There was a sense of determination to manage at home but participants needed help from others to achieve this. Household chores and daily activities became challenging for the majority of participants, while a minority of patients also needed help with self-care.

My daughter comes in regularly to help me, my sister comes over and my husband’s here but he is not in good health anyway so, he has got osteoarthritis but we will muddle through as I say my daughter comes over quite regularly. Participant 7

Yes, not too bad. I have got carers; they come in three times a day. They bath me and dress me and that in the morning. I do what I can and then if I can’t do it then they, you know, do it and then they come in at tea time and if my husband’s not here, they’ll cook me a tea and a cup of tea and like that and then they come and help me get to bed at night. Participant 2

However, with help from others or by making adaptations, some participants were able to manage and overcome the restrictions imposed by their injury. For example, they ironed sitting down, washed dishes from a stool or hoovered from their wheel chair, as standing for long without support was a struggle. Their ability to adapt to their impaired mobility suggests a degree of resilience.

I have got a cleaner that comes in three times a week for an hour Monday and Tuesday and Thursday and she does the house cleaning because I can’t bend down and get up again. I do my own washing but I am going to try and do my own ironing. It’s the fact that I can’t stand for a long time but my daughter has given me one of those table tops that you can sit down on a chair and iron on it so I am going to try that. Participant 3

 Furthermore, some participants spoke about their future with optimism and hoped that they would get back to how they were before their fracture. Others seemed to be content, accepting that reduced mobility and activities are part of ageing.

Before I was walking with a stick not far because I was in pain but the hospital say it will be four to six months if to get back the way I was, if I ever got it back to the way it was, so I am hoping I can get it back to the way I was. Participant 7

When you consider my age I think I do quite well. I should be 90 at the end of September and I can still do lots of things you know that people younger than me can’t do. Participant 3

Participants could also experience feelings of isolation and depression after their fracture. Their loss of independence could be frustrating and they did not like to be reliant on others or ask for help.

Well she was actually getting quite depressed because obviously she can’t get to the front door and I used to take her round in her wheelchair to see her sister and things like that and she wouldn’t do it because she is frightened of… You know she has not had anybody since she got home. She was doing quite well to start with but then as I say we were expecting a physiotherapist to come round but then gradually because nobody has come to assess her or… she was getting quite depressed about not being able to get up and things like that and not being able to move round like she could before. Participant 4

While the majority of participants were muddling through and finding ways to manage, two participants, in contrast, experienced a decline in their health after the fracture, one of which was already living in a care home prior to the fracture and another who moved into a care home after the fracture.

It has been really hard to see his decline from before but they do say that with older people… a fall does… it does really affect them. Participant 11

PPI representatives emphasised the difficulty of returning home after a fracture and the struggle to readjust. Patients may feel isolated once they return home and may struggle without the support they received while in hospital. The group believed that having information or knowing who to contact could be helpful post-discharge when patients may be alone in their own homes and need support or are unsure about what activities they can undertake. Follow-up appointments were described as milestones patients could work towards to help them cope. The group felt patients need someone to advocate for them while in hospital and once discharged to ensure they could access support and resources. They acknowledged this could be burdensome for family members who often have other responsibilities.

You just have lots of questions when you’re sent home and there isn’t really anybody to talk to. PPI representative

***Struggling to move***

Rehabilitation was slow and arduous for patients who at times struggled to follow the instructions that they were given. Patients often needed support to move and valued the support they received in hospital. However, they received limited rehabilitative support once home.

At the time of their interview, many participants were not fully weight bearing and were trying to walk or stand with frames, crutches or walking sticks. For some, a lack of confidence, often after several falls, or pain prevented them from weight bearing despite being told they could or should.

Yes, I have got a sheet of exercises to do while lying on my bed and standing up with a frame and rocking from side to side trying to be able to put more weight on that leg... The bed ones come natural now, I mean they don’t even hurt anymore when I am lying on the bed and I am showing you with my feet now doing my legs and bringing my knees up and pushing my knees back down into the bed. But it’s the standing, the standing and putting the weight on that side and I am just no confidence in myself at all. Participant 9

Participants described receiving support from physiotherapists while in hospital, several of whom spoke with enthusiasm of the exercises and support they were given to walk and found they built their confidence.

They gave me the confidence to do it. I don’t know what I would have done if they didn’t... If I hadn’t had a good team of physios, they were really great, as I say, I was shaking from head to foot because I knew I had got, that this bad leg was going to have to be the leg that I was going to have to use to support me… I was terrified to go on a normal Zimmer… But eventually they got me on to a Zimmer frame, they gave me the confidence; they were absolutely great. Participant 7

Once they were discharged from hospital, however, participants described receiving delayed or no support from physiotherapists. Lack of support with rehabilitation could impair some patients’ confidence who were reluctant to move on their own. Two personal consultees who were interviewed described advocating for their relative to ensure they received physiotherapy.

No. They haven’t done nothing to be honest. Because they were supposed to send me for therapy but I never had nothing. Participant 8

She was doing very well while she was in hospital but as soon as she came home I think she felt quite isolated and she wasn’t getting the help she was getting in hospital to walk so she just lost confidence. Participant 4

During the focus group with PPI representatives, rehabilitation was described as essential for recovery but it was noted that provision varied. While support from physiotherapists was present in hospitals, it was thought of as lacking in the community. Patients may sometimes have a delay between discharge from hospital and receiving physiotherapy and the group argued that this could impede their recovery. The group emphasised that physiotherapy was not just about exercises but also encourages patients to get better and helps them to develop confidence.

Rehabilitation is not just about physio and showing you how to do an exercise, a physio, a good physio will encourage you to get better. On the days you are in absolute pain and you can’t magic the pain away straightaway, on the days that you’ve given up or don’t want to and let’s be honest with an elderly group… It’s about having confidence that they’re not going to fall. And a good physio will actually more than anything else click into the mind set of that person, and give them the confidence that they need to say this happened, it was a sheer accident, it’s not going to happen again, you can get up there, you’re not too old, you’re not too frail, you can do this and it’s that confidence. Once you’ve got the confidence to put that foot to the floor, you’re up and going and it’s that person that gives you the confidence. PPI representative

**Discussion**

We found recovering after a distal femoral fracture was slow and arduous for patients who, once discharged from hospital, needed support from others such as family or carers to manage and were cautious about walking again. Three themes were evident within participants’ accounts of their experience. First, participants valued being informed during their treatment and recovery. Second, to manage at home, participants needed support from family or carers and developed new ways to go about their daily activities. Third, participants struggled with limited mobility. For some, a lack of confidence hindered their rehabilitation and the majority received little if any rehabilitative support to help them stay mobile at home. The adaptations patients described to allow them to perform daily activities highlight their reluctance to weight bear. These findings suggest there are two key challenges for the clinical team, i) how best to support patients and families to maximise their recovery and ii) how best to communicate information that helps them to make sense of their injury and move forward.

Our findings contribute to existing understanding of patients’ experience of recovery after a fragility fracture. We found similarities between the experience of our sample of patients with distal femoral fractures and the experience of patients recovering from hip fractures. Similar to the studies by Griffiths and Fox, we found that the majority of participants found ways to manage despite struggling with limited mobility or a lack of confidence, while a minority of participants’ health deteriorated after their fracture. Previous qualitative studies have highlighted that mobility and a return to normal activities are important outcomes for patients [8, 9]. These outcomes were evident within our participants’ accounts of their experience and are reflected through the themes ‘struggling to move’ and ‘muddling through’. Our findings emphasise patients’ need for greater support to achieve these outcomes. Participants described benefiting from the physiotherapy they received while in hospital but tended to report limited support after discharge. Several participants reported lacking confidence, which hindered their rehabilitation. Support from physiotherapy after discharge from hospital could enable patients to gain confidence and to increase their mobility at home [17]. Furthermore, we found participants valued being informed about their treatment by healthcare professionals and wanted to know how their fracture was healing. Being informed has been highlighted as important by McMillian [19] who found that after hip fracture older people could miscalculate risks when they did not receive or understand the information that they were provided with and this could lead to further falls or could damage their confidence [18].

These findings emphasise the importance of rehabilitation to maximise recovery. Many participants were not fully weight-bearing, had a high requirement for support with activities of daily living and reduced confidence. Mean scores from the sample (n=23) in the TrAFFix feasibility study show that Quality of Life (EQ-5D-5L) had not returned to the pre-injury level at 4 months [14]. Self-efficacy, a measure of an individual’s confidence in their ability to accomplish tasks and overcome problems may be an important factor in patients’ recovery. Low levels of self-efficacy are associated with less optimal health behaviours such as poorer adherence to medicine[19, 20], unhealthy food intake [21] and poorer vaccine uptake [22]. Low levels of self-efficacy may result in patients being reluctant to mobilise following surgery. Future research examining the relationship between self-efficacy and mobilisation post-surgery and self-efficacy and patient outcomes such as quality of life after a fragility fracture may therefore be valuable. Identifying patients with low levels of self-efficacy may enable healthcare professionals to determine which patients may need more rehabilitative support and could guide rehabilitative prescription.

considering patient characteristics such as their frailty and self-efficacy when making decisions about treatment and rehabilitation

***Strengths and limitations***

We used qualitative methods to elicit patients’ experience of the treatment and the early phase of recovery after a distal femoral fracture. Qualitative research has the potential to influence clinical practice by identifying issues of importance to patients and can provide a useful contribution to the trauma literature [23].

We asked all patients who were approached to participate in TrAFFix, including two patients who declined participation prior to surgery, if they could be approached about taking part in an interview. However, fewer patients with distal femoral fractures than anticipated were deemed eligible by surgeons within the recruiting centres to participate in TrAFFix. As a result of this and the degree of frailty within this patient group, our sample was small. A larger sample size and the inclusion of patients with a distal femoral fracture who were considered ineligible to participate in the TrAFFix study may have provided a useful contribution to our understanding of treatment and recovery after a distal femoral fracture. However our sample, although small, is similar to other qualitative studies and considered sufficient for meaningful interpretation [24]. Other studies examining patients’ experience of fragility fractures [9, 13] and patients’ experience of participation in a surgical trial [25, 26] have similar sample sizes.

Interviews with participants were conducted at different time points during recovery at the convenience of participants. Although, it may have been beneficial to interview participants at set intervals during recovery as we initially intended, the consistency of issues raised during these interviews suggest that the timing did not matter. In addition to data from patients and their consultee, we used data from additional informants namely PPI representatives, allowing corroboration of ideas.

***Rigour***

We adopted several strategies to ensure rigour and trustworthiness of our findings [27]. Throughout analysis, emerging themes were discussed by four researchers, from different disciplines, to ensure that our interpretation of the data reflected the experience and ideas of our participants. We have included verbatim quotes to illustrate our interpretation of participants’ accounts. To enable transferability of findings, detailed descriptions of the participants and of our methods are provided. Due to the frailty of this patient group, we did not attempt to confirm the interpretation of our findings with them.

***Conclusion***

Our findings reveal that patients’ experience of treatment and recovery after a distal femoral fracture is similar to that of a hip fracture, with limited mobility and difficulty completing day-to-day activities prominent within patients’ accounts of their experience. We also found that the majority of participants reported limited physiotherapy once they were discharged from hospital and some participants experienced a lack of confidence and a reluctance to mobilise. Our findings reinforce: i) the importance of engaging with patients and helping them to understand what is happening to their body and the impact of their injury on their daily life, and ii) the need for greater support, including community physiotherapy, to help patients regain confidence, stay mobile and maintain their independence after a fragility fracture. Further research is required to i) identify whether patient characteristics such as self-efficacy, which may not currently be factored into treatment decision-making, are important predictors of patient outcomes and ii) investigate the most appropriate interventions to foster patients’ confidence after a fragility fracture.

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Table 1. A table to show the characteristics of the participants[[1]](#footnote-1)

|  |  |
| --- | --- |
| Participant characteristics | Number |
| **Age**<6060-6970-7980-89≥ 90 Unknown | 131321 |
| **Pre-fracture mobility**Freely mobile without aidsMobile outdoors with one aidSome indoor mobility but never outside without help | 263 |
| **Gender**MaleFemale | 29 |
| I**nterviewed**PatientConsulteePatient with help of consultee | 821 |

1. Where consultees were interviewed, the participants characteristics reported relate to their injured relative [↑](#footnote-ref-1)