Living with frailty and falls

A qualitative study exploring the experiences of patients with end-stage renal disease receiving haemodialysis.

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End Stage Renal Disease and Haemodialysis (HD)

Haemodialysis second most common form of renal replacement therapy in the UK (*Macneil et al, Nephron, 2018*)

- Standard treatment 4 hours thrice weekly
- Cannot replace all functions of kidney
- Requires significant diet and lifestyle change
- Associated with constellation of health and wellbeing issues
Frailty and falls in HD

Frailty is highly prevalent in HD patients, **35% of whom are under 65** (Bao, Arch Int Med, 2012, Johansen, Am J Soc Neph, 2007)

- **1.4 fold increased risk of hospitalisation**
- **Two-fold increased risk of mortality** (McAdams-DeMarco, J Am Ger Soc, 2013)
- Falls increased up to three times in frail HD patients (McAdams-DeMarco, BMC Neph, 2013)
- Less likely to receive a transplant
- Those who do more susceptible to poor post-transplant outcomes and graft failure
Care for frail, falling HD patients

Frail HD patients are ‘shoe-horned’ into specialist renal services originally designed for younger patients with single organ disorders

Renal rehabilitation and specialist physiotherapy for renal patients not widely available (Greenwood, Neph Clin Pract, 2014)

Accessing services designed for frail, falling older people may not be possible or appropriate for the HD group

Numerous national drivers to improve the care of this patient group
- NHS Long term plan (TBA Autumn 2018)
- NICE multimorbidity guidance (2017)
- NICE dementia, disability and frailty in later life (2015)

How services should be tailored to the needs of frail and falling HD patients is unclear, little prior research in this area
To explore haemodialysis patients’ experiences of living with frailty and falls
Study design

Screening

Recruitment

Analysis

Eligibility criteria

- Prevalent, adult HD patients
- Able to provide informed consent
- Able to speak English
- History of at least one fall within the last six months
- Clinical Frailty Scale Score 4-8

Recruitment

- Across 2 NHS and 1 Fresenius run HD unit
- All shifts approached
- Maximum variation sampling used initially, followed by more focused theoretical sampling

Analysis

- Informed by constant comparative approach
- Reflexive diary used help reveal preconceptions
- NVivo software used to facilitate coding
- Multiple researchers undertook analysis
<table>
<thead>
<tr>
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<th>(n= 18)</th>
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<td>Age (Years)</td>
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<tr>
<td>Gender</td>
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<tr>
<td>Female</td>
<td>10 (56%)</td>
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<td>Atypical HUS</td>
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<td>Minimal change nephropathy</td>
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<tr>
<td>Charlston Co-morbidity Index</td>
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<td>HD Vintage (months)</td>
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<tr>
<td>Clinical Frailty Scale score</td>
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<tr>
<td>Vulnerable</td>
<td>8 (44%)</td>
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<tr>
<td>Mildly frail</td>
<td>3 (17%)</td>
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<td>Moderately frail</td>
<td>5 (28%)</td>
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<tr>
<td>Severely frail</td>
<td>2 (11%) 15-75</td>
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<tr>
<td>No. falls in last six months</td>
<td>3 (2-4)</td>
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“I get home and I do feel exhausted, really tired. Thursday, I had [HD] Wednesday, I was just like a zombie, I just couldn’t do anything. I hardly did anything, I couldn’t even concentrate to read a newspaper”

[Male, 75, mildly frail]

“Since I started dialysis my legs don’t seem to have the same strength. Before dialysis I was walking with a stick, but now I can only do a few steps and mostly I am in a wheelchair”

[Male, 70, moderately frail]

“You think I can’t do that now because you’re getting older and I can’t do much exercising while you’ve got this [haemodialysis]”

[Female, 86, moderately frail]

“I have always been a bit of a quick walker so when these things have happened I am like OK time to slow down.”

[Female, 69, vulnerable]
Experiences of healthcare

“This was all new to me and I hadn’t met anyone that knew about it. I did have a brochure about what they do, it says you will be shown the unit to explain what’s happening...but no-one bothered”

[Male, 75, mild frailty]

“[Dialysis] was all new to me and I hadn’t met anyone that knew about it. I did have a brochure about what they do, it says you will be shown the unit to explain what’s happening...but no-one bothered”

[Male, 75, mild frailty]

“They said as long as I could use the equipment I was alright, I could go home. I would have liked to have done a bit more towards walking.”

[Female, 86, moderately frail]

“When I was at the hospital I told them I had a fall they don't want to know. They said ‘you are perfect, your levels are perfect and everything’.”

[Male, 55, vulnerable]

“Today I went to the diabetic foot clinic. The doctor is referring me to the vascular clinic. Then it’s dialysis in the afternoon. Is there no part of my body that is functioning properly? Eye, heart, back, kidney, even my foot has an ulcer on it. My medical needs seem to be taking over my life”

[Female, 77, mildly frail]
Falls: perceptions of contributing factors

“My medication has actually got better since I was in hospital....when I went in there I was on about 17 tablets a day.”

[Female, 48, vulnerable]

 “[After HD] you feel extra, extra weakness, right. So then you move like you are in the middle of the wind. I sit outside for 5, 10 minutes. When I feel I’m ok then I start moving.”

[Male, 64, severely frail]

“We get the transport and sometimes [you are waiting]...hours... I have fallen down two or three times. As soon as you get up...you are not stable. Your blood pressure has been dropping all the time while you have been waiting.”

[Male, 70, moderately frail]

“I fell down because I didn't have enough power in my legs. You can fall automatically, you don't know yourself if you have got no strength”

[Male, 55, vulnerable]

“Very often I have got up and gone back down on the chair because I have lost my balance. I don't go giddy, I don't go light headed.”

[Female, 69 severely frail]

“It just goes like black out, like something going around, around, around you know. And I tell my son now just bring anything, because he feels like that sometimes too, he is a diabetic as well”

[Female, 80, mildly frail]

“[After HD] you feel extra, extra weakness, right. So then you move like you are in the middle of the wind. I sit outside for 5, 10 minutes. When I feel I’m ok then I start moving.”

[Male, 64, severely frail]

“Once I was out there and then it was dark and I fell down. After that I was frightened to go out. And even now I don't feel like going out at night. Tomorrow we have to go out somewhere but I am not going because it’s late.”

[Male, 69, moderately frail]

“Environmental hazards
Once I was out there and then it was dark and I fell down. After that I was frightened to go out. And even now I don't feel like going out at night. Tomorrow we have to go out somewhere but I am not going because it’s late.”

[Male, 69, moderately frail]
Consequences of falls

“I had a little stumble that day when I broke both my hands and my leg, it wasn't a big fall, it was just a little stumble, but the bones are so weak. I couldn't eat, you know I couldn't even brush my teeth. [The hand is] still broken. It looks ugly, but because it’s a fistula arm we are told not to use that arm anyway you know.”
[Female, 54, vulnerable]

“I had a permacath put in, that was in...for a few months... I can't do anything about it you know...I can't use that arm [for HD] because they plastered me right up to here”
[Female, 69, severely frail]

“I ruptured all the muscles in my shoulder, the first time I fell. It’s a continuous pain and you don’t know where to put it, you don’t know how to get. When I want to get dressed I have to hold my arm up while [the carers] put my bra on and such like.”
[Female, 86, moderately frail]

“If I have to go somewhere with my family it’s embarrassing, when I say I can't walk. Then I need something to lean on and other people keep looking at you as if you are drunk. It’s embarrassing.”
[Male, 70, moderately frail]
Coping with frailty and falls

Problem-focused coping

Focuses upon addressing the difficult situation. Used when the individual feels an element of control over the situation.

Adapting tasks

“I have fallen down the stairs a few times...which is why I have stairlift. When it didn't work...it really scared me because I thought what if I just take a tumble down.”

[Female, 48, vulnerable]

Family/friend support

“My friend brought me some daffodils. We discussed our ailments. She always cheers me up”

[Female, 77, mildly frail]
Coping with frailty and falls

**Emotion-focused coping**
Focuses upon alleviating emotions associated with the difficult situation. Used when the situation feels beyond control.

**Avoidance**
“I stay on the bed because I don’t want to do any experiment and put myself in trouble or put [my family] in trouble. So better if you’re happy with sitting on the bed.”
[Male, 64, severely frail]

**Gratitude**
“I have lived long enough, I find this is extra life so I am happy with that...Every day is extra and I can see my children, grandchildren growing up.”
[Male, 69, moderately frail]

**Acceptance**
“Unfortunately there are things that you cannot help ...these falls and that. And there is nothing I can do about it.”
[Male, 70, moderately frail]
Conclusions

Current healthcare services are:
- Difficult for frail HD patients to navigate
- Not consistently meeting their needs

The coping strategies patients employ are not always helpful or effective

Care can be enhanced by:
• Routinely screening for frailty and asking patients about falls
• Referring to existing rehab services in the absence of specific ones
• Increasing awareness of renal specific impairments and symptoms amongst rehab providers
• Involving family in care decisions
• Utilising empathetic communication and seeing the whole person

In the longer term redesign of services and increased access to tailored rehab is required
Thank you

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