# HCP08 ‘Nancy’ - Interview Transcript 07th December 2023 by Teams

0:0:0.0 --> 0:0:4.680  
Catherine Beresford  
Make it so that we don't have to watch the transcription at the same time, because that can be a bit off-putting.

0:0:4.240 --> 0:0:10.120  
HCP08

Oh, so you don't have to get. You don't have to do that yourself or get someone to like type it all off. It just does it. Oh, excellent.

0:0:7.840 --> 0:0:14.880  
Catherine Beresford  
Yeah, yeah, it it. It does make some mistakes. So, you do have to go through it.

0:0:22.670 --> 0:0:22.750  
HCP08  
Oh.

0:0:16.280 --> 0:0:24.480  
Catherine Beresford  
But it's much quicker than doing the whole transcription yourself. I have to say, because I've done that in the past as well. OK, so let me start recording.

0:0:23.720 --> 0:0:25.440  
HCP08  
So OK.

0:0:26.540 --> 0:0:27.740  
Catherine Beresford  
Yeah. What were you going to say?

0:0:30.310 --> 0:0:32.750  
Catherine Beresford  
So can you did you get a message to say it's recording?

0:0:36.460 --> 0:0:38.940  
HCP08  
Recording. Yes, recording and transcription.

0:0:39.350 --> 0:0:40.550  
Catherine Beresford  
Brilliant. OK.

0:0:41.730 --> 0:0:41.810  
Catherine Beresford  
So.

0:0:41.340 --> 0:0:44.380  
HCP08  
Yeah, you wouldn't want to get to the end of it and then realise it wasn't working.

0:0:46.840 --> 0:0:47.520  
HCP08  
I bet.

0:0:43.540 --> 0:0:50.300  
Catherine Beresford  
No, that is one of my biggest fears actually doing this research, OK.

0:0:51.560 --> 0:0:59.240  
Catherine Beresford  
Just to start off with then and again all information I'm asking for is completely voluntary, but if you're happy to, can you just confirm your age?

0:1:0.590 --> 0:1:6.430  
HCP08  
I am [states age]. I really have to think about that. Then that's bad, isn't it? Yeah, [repeats age].

0:1:6.540 --> 0:1:12.660  
Catherine Beresford  
and what ethnicity do you consider yourself to be?

[she stated ethnicity – but it was not picked up by the transcription]

0:1:14.350 --> 0:1:15.870  
Catherine Beresford  
OK. Thank you.

0:1:16.930 --> 0:1:32.290  
Catherine Beresford  
All right. So, the first question I'd like to ask then is to start off with please, can you just tell me about your role in working with individuals who've got advanced liver disease? And I'm particularly interested in the decompensated stage.

0:1:34.740 --> 0:1:39.380  
HCP08  
OK, so I'm an advanced clinical practitioner in hepatology.  
And we generally follow the patients. So, we run a service for patients that require large volume paracentesis. So, in essence if they've got ascites, they are decompensated.

0:1:55.580 --> 0:1:56.220  
Catherine Beresford  
Yes.

0:1:56.980 --> 0:1:58.980  
HCP08  
Many of them like require regular drainage and we offer that as we can as a day case.  
It's really. So that they don't have to remain in hospital. It's a better experience for them. We also run like an ascites and liver decompensation clinic. So maybe patients that have ascites, we’ll have them into clinic to monitor their diuretics. And then I think part of our like advanced practice role really is not just like the monitoring of the medications, but really working with patients so that they understand like the severity of their liver disease.

0:2:40.720 --> 0:2:41.40  
Catherine Beresford  
Yes.

0:2:55.650 --> 0:2:55.850  
Catherine Beresford  
Mm hmm.

0:2:42.480 --> 0:3:6.200  
HCP08  
Because I think although you know, evidence tells us that, you know, liver disease is a progressive disease and that should be made clear to patients. Like at the point of diagnosis of cirrhosis, I think for for, for a lot of them it's it still does come is quite a surprise. So, we will like often use like the Child-Pugh score -

0:3:6.770 --> 0:3:6.970  
Catherine Beresford  
Mm hmm.

0:3:11.370 --> 0:3:12.130  
Catherine Beresford  
I see.

0:3:6.920 --> 0:3:13.640  
HCP08  
- to evidence to them, you know that their liver is struggling. Work with them and their families.

0:3:24.270 --> 0:3:24.950  
Catherine Beresford  
Yes.

0:3:32.720 --> 0:3:33.160  
Catherine Beresford  
Yeah.

0:3:15.40 --> 0:3:35.0  
HCP08

And I think that the the benefit that our role really offers, and that the patients really value, is like that consistency that they get to know us very well. We get to know them and their families. It gives us an opportunity to revisit things like advanced care planning, their liver disease trajectory.

0:3:35.610 --> 0:3:35.970  
Catherine Beresford  
Yeah.

0:3:36.520 --> 0:3:36.720  
HCP08  
I think I think that consistency is really important, and it doesn't like always happen.

0:3:44.870 --> 0:3:45.350  
Catherine Beresford  
Yeah.

0:3:45.730 --> 0:3:47.450  
HCP08  
In my role, we also have.

0:3:52.630 --> 0:3:53.350  
Catherine Beresford  
OK.

0:3:48.970 --> 0:4:1.810  
HCP08  
Like a place on the ward as well. So, we have a ward presence and I think again, our advanced practice skills come in with that, that higher level of communication with patients. That difficult conversations to have when someone's decompensated it's a sign of advanced liver disease.

0:4:7.760 --> 0:4:8.360  
Catherine Beresford  
Yes.

0:4:9.170 --> 0:4:10.450  
HCP08  
And I think again, we we can offer them that time, that explanation -

0:4:27.590 --> 0:4:27.990  
Catherine Beresford  
Yeah.

0:4:18.410 --> 0:4:42.170  
HCP08  
- to to support their understanding really. And that really improves like the quality of like the inpatient care that they receive. They also get an opportunity to meet us and then we'll we'll follow them up in in clinic as well. So, it it really covers like a broad like spectrum, it's it's not just like based on the ward or or based - we we tend to follow the clinic - the patients sorry [i.e., they follow the patient wherever they are].

0:4:44.250 --> 0:4:45.210  
HCP08  
But our role -

0:4:41.370 --> 0:4:45.450  
Catherine Beresford  
I see. Oh, yeah. OK. How long have you been in that role?

0:4:48.70 --> 0:4:48.350  
Catherine Beresford  
Yeah.

0:4:46.920 --> 0:4:57.640  
HCP08

So, I've been in this role… I started as a trainee advanced clinical practitioner in 2017, qualified in 2020 with my Masters in advanced clinical practice.

0:5:8.770 --> 0:5:9.210  
Catherine Beresford  
Yeah.

0:4:58.960 --> 0:5:14.120  
HCP08

Prior to that, like well, so I qualified in 2000 and started working on the Gastro-hepatology medical ward as a D grade staff nurse back then got my E grade and F grade on the ward, and then I was the senior sister there for six years.

0:5:15.720 --> 0:5:24.600  
HCP08  
Then I moved on and did some corporate work and then trained to be an nurse endoscopist and then came back to hepatology with the -

0:5:28.520 --> 0:5:29.200  
Catherine Beresford  
Yes.

0:5:26.530 --> 0:5:31.970  
HCP08  
- for the masters, really. So, all my career is kind of been gastro-hat [i.e., she wears a gastroenterology specialist hat]

0:5:31.940 --> 0:5:35.820  
Catherine Beresford  
Yeah. Yeah, you've obviously got a lot of experience in the field, yeah.

0:5:40.350 --> 0:5:41.150  
Catherine Beresford  
Yes.

0:5:34.790 --> 0:5:42.870  
HCP08  
And I think again that you know that's what our role, what what advanced practice [advanced practitioners] we can we can bring like you know as nurses that experience.

0:5:45.520 --> 0:5:48.640  
HCP08

And that that communication to to the patient really.

0:5:49.40 --> 0:5:56.560  
Catherine Beresford  
Yeah. No, it's interesting hearing what you're saying because am I right in understanding that your role - it doesn't exist everywhere?

0:5:59.850 --> 0:6:3.450  
HCP08  
The Advanced clinical practitioners that they are growing [in numbers].

0:6:4.770 --> 0:6:19.90  
HCP08  
I think I think sometimes the defined role for them, I mean I think like for example, in like the emergency department, you know they've got like an Ark M portfolio that they they have to like reach whereas I think like advanced practice in hepatology requires different skills. I,t's not just like procedural skills.

0:6:24.380 --> 0:6:25.180  
Catherine Beresford  
Yes.

0:6:26.90 --> 0:6:36.250  
HCP08  
It is that higher advanced level communication and thinking a bit more like kind of outside the box on the like needs of the patient.

0:6:36.670 --> 0:6:37.790  
Catherine Beresford  
Yeah, yeah.

0:6:37.450 --> 0:6:41.930  
HCP08  
And often working with people that have difficult lives.

0:6:42.140 --> 0:6:52.940  
Catherine Beresford  
Yeah. Yeah. So, thinking about the area where you work, and the services that people with advanced liver disease typically access, from your point of view what works well at the moment?

0:6:56.620 --> 0:6:58.860  
HCP08  
What for decompensated patients?

0:6:59.50 --> 0:7:2.210  
Catherine Beresford  
Yes, I would focus on on those individuals.

0:7:1.660 --> 0:7:7.460  
HCP08  
OK, so I think what what works well is if they're keyed into the -

0:7:11.60 --> 0:7:11.260  
Catherine Beresford  
Mm hmm.

0:7:8.900 --> 0:7:11.260  
HCP08  
Advanced practice team really. We -

0:7:30.250 --> 0:7:30.450  
Catherine Beresford  
Mm hmm.

0:7:14.190 --> 0:7:32.630  
HCP08  
We're just able to follow them better, you know, for example, if if you've got someone that that that's still drinking, you know they may not turn up to clinic, we will will be a bit more like assertive with our follow-up like we'll we'll give them a call. It's not just a dna [did not attend] letter and off you go.

0:7:32.320 --> 0:7:32.920  
Catherine Beresford  
Yes.

0:7:34.190 --> 0:7:45.230  
HCP08

What we'll do like we'll we'll work with them to to try and see what works best for them like. So maybe like some remote or virtual monitoring of bloods. Working with them -

0:7:50.760 --> 0:7:51.320  
Catherine Beresford  
Yeah.

0:8:3.40 --> 0:8:6.960  
Catherine Beresford  
Yeah. OK. And what do you think? Oh, go on, carry on.

0:7:45.660 --> 0:8:14.900

HCP08  
- you know, regular call backs to see what their weight's doing, what they're, it's that regular contact I think and that they then they've got a point of contact. They they always leave with our contact details and are really actively encouraged to to contact us. That works well. I think the day case paracentesis service that that that does work really well. I think that that's not to say that there aren't challenges without that I think. Capacity, access to -

0:8:30.370 --> 0:8:30.970  
Catherine Beresford  
OK.

0:8:19.0 --> 0:8:42.440  
HCP08  
- a [hospital] bed, a flat space to to to to perform a drain. You know what we try to do it in a planned approach, but the patients also have like what we call SOS contact for us. So, you know if they're concerned that their tummy's getting bigger or or something's not going might that you know that they can contact us. And then sometimes it can be a challenge to get them in in a timely fashion to review them, really. And so that's not to say that, you know, you don't see emergency presentations and to the emergency.

0:8:50.0 --> 0:8:50.600  
Catherine Beresford  
Yes.

0:8:55.870 --> 0:8:56.870  
Catherine Beresford  
Yeah, yeah.

0:8:59.530 --> 0:9:0.450  
Catherine Beresford  
Yeah, yeah.

0:8:51.180 --> 0:9:3.20  
HCP08  
But again, that that's like, you know, the purpose of our role as well to try and like reduce that really. So, we also use like the the same day emergency care area -

0:9:3.370 --> 0:9:3.810  
Catherine Beresford  
Yeah.

0:9:4.560 --> 0:9:8.640  
HCP08  
- that we can generally bring patients to the next day.

0:9:9.440 --> 0:9:16.280  
Catherine Beresford  
I see. So, I mean, you've given me a bit of insight into it already really, but is there anything else that you think doesn't work well?

0:9:20.690 --> 0:9:22.10  
HCP08  
How can I put this? I think sometimes like the the the lack of joined up services. Like like for example, nutrition is really important for patients with decompensated disease.

0:9:45.420 --> 0:9:45.540  
Catherine Beresford  
Hmm.

0:9:39.580 --> 0:9:46.860  
HCP08  
So you know, we can see them in clinic, but then often like access to the Dietetic service can be difficult. It it's like joining up all those like add-ons.

0:9:50.690 --> 0:9:51.250  
Catherine Beresford  
Yeah.

0:9:56.420 --> 0:9:57.180  
Catherine Beresford  
Yes.

0:9:49.320 --> 0:9:59.200  
HCP08  
I think you know psychological support could be. I mean, but beyond what we offer. Sorry my dog's barking beyond what we can offer -

0:10:9.150 --> 0:10:9.790  
Catherine Beresford  
OK.

0:10:0.810 --> 0:10:10.610  
HCP08

-would be beneficial, but again the the the capacity or that service isn't there. So, I think things could could be improved in that sense.

0:10:11.150 --> 0:10:23.470  
Catherine Beresford  
Yeah. And so, you've already given me some indication, but what other professionals are involved in care for people with the decompensated liver disease in your area?

0:10:27.160 --> 0:10:28.40  
Catherine Beresford  
Yeah, yeah.

0:10:25.30 --> 0:10:37.710  
HCP08  
Well, dieticians, when we can get them, you know we have like a hepatology MDT every week where we will talk about our decompensated patients.

0:10:44.740 --> 0:10:45.700  
Catherine Beresford  
Oh yeah, yeah.

0:10:49.770 --> 0:10:49.890  
Catherine Beresford  
Hmm.

0:10:39.70 --> 0:10:59.270  
HCP08

Research is also involved. We're, you know, we're quite heavily involved in the Reduce-2 [research] study at the moment. So, our decompensated patients will be discussed every week to see if they would be suitable for Reduce-2. We also have like an advanced care planning section within our hepatology MDT so,

0:10:59.80 --> 0:10:59.720  
Catherine Beresford  
OK.

0:11:0.10 --> 0:11:13.410  
HCP08  
patients that are decompensated, we've got like a form that we fill in where we use like the SPICT [Supportive & Palliative Care Indicators Tool] tool to to try and identify those with advanced liver disease that we should be thinking, you know about advanced care planning and end of life.

0:11:20.520 --> 0:11:21.200  
Catherine Beresford  
Yes.

0:11:14.610 --> 0:11:24.730  
HCP08  
Who else is involved? So, we're more involved in the decompensated side of of the patient. So, and although that does crossover sometimes with transplants,

0:11:25.150 --> 0:11:25.270  
Catherine Beresford  
Hmm.

0:11:26.770 --> 0:11:30.10  
HCP08  
-they they're kind of on a different pathway really.

0:11:29.340 --> 0:11:32.460  
Catherine Beresford  
Yeah, I thought that. Yeah, yeah.

0:11:34.40 --> 0:11:35.320  
Catherine Beresford  
Hmm hmm.

0:11:47.210 --> 0:11:47.890  
Catherine Beresford  
Sure, sure.

0:11:30.390 --> 0:11:57.910  
HCP08

Can be very difficult because they're they're like kind of on a parallel pathway, really, they're, you know, they can be hoping for transplant and essentially curative treatment, but also walking hand in hand with like, a palliative pathway that actually they, you know, they may not get to transplant, they, you know in that. So, we we do have a psychologist with a few hours that that's generally for the transplant patients really.

0:12:4.940 --> 0:12:5.380  
Catherine Beresford  
Yeah.

0:11:59.960 --> 0:12:6.720  
HCP08  
Yeah. I mean, we will refer on to, you know, social services, community palliative care.

0:12:7.230 --> 0:12:7.630  
Catherine Beresford  
Yeah.

0:12:10.40 --> 0:12:11.760  
HCP08  
Trying to think what else really.

0:12:13.390 --> 0:12:14.350  
Catherine Beresford  
That's OK.

0:12:16.150 --> 0:12:23.150  
Catherine Beresford  
So if people with advanced liver disease or their carers require support, advice or information, where do they go?

0:12:25.450 --> 0:12:27.650  
HCP08  
What sort of support or information?

0:12:28.170 --> 0:12:32.10  
Catherine Beresford  
Anything really. You know any-anything that's sort of relevant to them.

0:12:37.770 --> 0:12:38.250  
Catherine Beresford  
Yeah.

0:12:30.390 --> 0:12:40.470  
HCP08  
I think we, I think we provide a lot of that in terms of like of, of the understanding of the liver disease. I think we will signpost them, you know British Liver Trust, you know.

0:12:47.340 --> 0:12:47.380  
Catherine Beresford  
M.

0:12:46.70 --> 0:12:55.150  
HCP08  
Marie Curie, palliative care, alcohol support services. I think, services like to support relatives is limited. Very limited.

0:12:59.750 --> 0:13:0.390  
Catherine Beresford  
OK.

0:13:0.860 --> 0:13:7.140  
HCP08

And I think again, that's where our consistency really adds the value to the care of these patients.

0:13:10.50 --> 0:13:11.570  
Catherine Beresford  
How do they get hold of you?

0:13:12.180 --> 0:13:19.140  
HCP08  
So, they they will always have our contact details. They're they, they are informed. It is not like an emergency response.

0:13:18.290 --> 0:13:19.730  
Catherine Beresford  
Sure. Yeah.

0:13:30.80 --> 0:13:30.400  
Catherine Beresford  
Is.

0:13:20.420 --> 0:13:31.380  
HCP08  
And they they have a phone number, and they can always leave a message. And you know, we're we're we're very good at getting back to them and it's frequently used to be honest also like the district nurses, like someone with a long-term abdominal drain for ascites drainage in the community. You know, because they're [i.e., the drains] often not familiar with dealing with them and particularly like for troubleshooting that they will have access to us. They've got our bleep numbers, they've got the telephone number. Yeah, we we try to make sure we're available and contactable.

0:13:57.40 --> 0:14:10.40  
Catherine Beresford  
Yeah. OK. Thank you. So, have you got any like, are there any specific examples that spring to mind when you think that care provided for an individual with advanced decompensated liver disease was particularly positive?

0:14:35.920 --> 0:14:36.520  
Catherine Beresford  
Yeah.

0:14:13.470 --> 0:14:37.390  
HCP08  
So we've got quite an elderly gentleman and his wife that we've had in the decompensated clinic for quite a while now. We've, you know, had very meaningful discussions, done some advanced care planning. We've completed the treatment escalation form. They feedback that they really value just having that regular contact. So, they come along to clinic and recently, we, although he wasn't showing overt signs for encephalopathy -

0:14:55.830 --> 0:14:55.950  
Catherine Beresford  
Hmm.

0:15:7.10 --> 0:15:7.890  
Catherine Beresford  
Yes.

0:15:9.130 --> 0:15:9.810  
Catherine Beresford  
Yes.

0:14:44.710 --> 0:15:14.230  
HCP08

-that there was some mild signs there and his EEG was like possibly suggestive of hepatic encephalopathy. And we started some Rifaximin and it was absolutely transformative for him in the sense of his quality of life. You know, they're very aware that we're symptom focused, really, we will treat reversible causes, but it's symptom focused. And every time they come to clinic, they're just so, so grateful really. But that, I mean, not just having that with Rifaxmin, really.

0:15:24.800 --> 0:15:24.920  
Catherine Beresford  
Hmm.

0:15:28.0 --> 0:15:28.560  
Catherine Beresford  
Yeah.

0:15:19.150 --> 0:15:37.790  
HCP08  
He was just so much more like you could visibly see it in him and that, you know, they are hugely grateful. They've had like, a two-day stay away in a hotel, which is the first they've done in three years. And you know that that's made a significant a significant difference to his quality of life. It's those sort of things that stand out for me.

0:15:36.430 --> 0:15:38.550  
Catherine Beresford  
Yes, yeah, yeah.

0:15:39.570 --> 0:15:40.610  
HCP08  
I think again, you know, our availability to contact us, I think.

0:15:52.180 --> 0:15:52.900  
Catherine Beresford  
Yeah.

0:16:10.530 --> 0:16:10.570  
Catherine Beresford  
M.

0:16:13.180 --> 0:16:13.700  
Catherine Beresford  
Yeah.

0:15:50.200 --> 0:16:19.360  
HCP08  
They know us on all first name terms, so I think that's the beauty of and it's then you know, you once you've done some like in more intense work with them and and built up so that they know how to contact us and you know we've educated them as well on the importance of like weighing themselves and signs and symptoms to look out for and what to let us know you know that they will pick up the phone and I mean and then we'll you know we'll act accordingly get them in where we can or give advice or,

0:16:22.30 --> 0:16:23.550  
Catherine Beresford  
Yeah, yeah.

0:16:21.770 --> 0:16:33.330  
HCP08  
Yeah, it's those things that work work well. Really. I mean, we've come in this morning. There was a message from palliative care about one of our patients at end of life. So, you know, I think like other specialist services -

0:16:38.740 --> 0:16:38.860  
Catherine Beresford  
Hmm.

0:16:34.810 --> 0:16:41.370  
HCP08  
-do use us as well. I think that's where our advantage or value sits, I think really.

0:16:41.430 --> 0:16:43.350  
Catherine Beresford  
Yeah, this is.

0:16:42.850 --> 0:16:46.770  
HCP08  
That's really actually sometimes difficult to job plan or to quantify because it can, it can be a bit ad hoc. We we do a lot of background work for like sorting and organising.

0:16:58.90 --> 0:16:58.730  
Catherine Beresford  
Yes.

0:16:59.570 --> 0:17:2.730  
HCP08  
Seamless and more seamless pathway for the patients. You know, reminding them to get the bloods done so that when they come in for a drain, we've got them available and and those sort of little things.

0:17:10.940 --> 0:17:11.620  
Catherine Beresford  
Yeah.

0:17:12.530 --> 0:17:13.130  
HCP08  
That make sense?

0:17:13.80 --> 0:17:16.440  
Catherine Beresford  
It does. Yeah, it does make sense.

0:17:16.460 --> 0:17:22.300  
Catherine Beresford  
So on the other side of the coin, then have you got any examples where you think the care provided for an individual was was negative?

0:17:32.310 --> 0:17:39.550  
HCP08  
Yeah, I think it it, it's it's not being able to get people in a in a timely fashion with capacity. I think it it can be incredibly challenging because we are like hospital-based essentially.

0:17:49.260 --> 0:17:49.980  
Catherine Beresford  
Yes.

0:17:50.550 --> 0:17:56.550  
HCP08  
When they're really struggling in the community and those like those services don't line up. That that's when when things tend to go wrong. Yeah, or lack of support services like.

0:18:16.940 --> 0:18:17.460  
Catherine Beresford  
Yeah.

0:18:21.620 --> 0:18:22.100  
Catherine Beresford  
Yeah.

0:18:26.570 --> 0:18:27.210  
Catherine Beresford  
Yeah.

0:18:7.290 --> 0:18:27.890  
HCP08  
For example, I had a gentleman in clinic yesterday, recent hospital admission, decompensated with ascites was, you know, detoxed in hospital. So, he left hospital alcohol free. Unfortunately, he returned to drinking on discharge and when he came to clinic yesterday, he was very sad, you know, very aware - doesn't necessarily want to be drinking, but finds it very difficult. I think sometimes those - we can signpost them to services, I think sometimes that could be a bit more, that's when. And it can - It felt quite desperate, really, just to see such a sad gentleman, you know, ‘I know I'm better when I'm not drinking -

0:19:10.280 --> 0:19:10.520  
Catherine Beresford  
Hmm hmm.

0:18:56.600 --> 0:19:11.400  
HCP08  
-‘but I just can't get there’ and it's difficult because when we bought him into hospital, you know, it was made very clear to him that, you know, he would leave hospital alcohol free, this was a real opportunity for him. But, you know, he he just struggles with that.

0:19:14.330 --> 0:19:14.450  
Catherine Beresford  
Hmm.

0:19:11.520 --> 0:19:15.120  
HCP08  
Social support as well. You know he lives alone. He's not got any family around.

0:19:30.470 --> 0:19:31.190  
Catherine Beresford  
I See.

0:19:36.730 --> 0:19:36.850  
Catherine Beresford  
Hmm.

0:19:15.910 --> 0:19:46.590  
HCP08  
I think we frequently hear that patients find it very difficult to access GP and GP services now and often that can be a bit of a double-edged sword because they [patients] know that we'll pick up the phone and we'll answer them. So, we'll we'll often get like lots of inquiries now that aren't related to the liver disease because they can't get through to their GP or and I think that's across the board, really throughout hepatology. I know all my colleagues certainly have noticed that as well.

0:19:48.80 --> 0:19:59.520  
Catherine Beresford  
Thank you. So, So, reflecting on your own experiences, what advice, if any, would you give to other professionals who are new to working with individuals who've got decompensated liver disease?

0:20:0.710 --> 0:20:1.390  
HCP08  
Be honest with patients. It's their disease, you know, we are always very clear that we're honest with them.

0:20:14.170 --> 0:20:14.290  
Catherine Beresford  
Hmm.

0:20:15.120 --> 0:20:24.800  
HCP08  
And sometimes that can be hard - hard to do - if we're saying to someone you know, we wouldn't be surprised if you're in your last 12 months of life. So, I I would be honest with them.

0:20:25.800 --> 0:20:26.0  
Catherine Beresford  
Mm hmm.

0:20:26.960 --> 0:20:28.80  
HCP08  
Build that Rapport.

0:20:29.40 --> 0:20:29.160  
Catherine Beresford  
Hmm.

0:20:32.40 --> 0:20:35.0  
HCP08  
And so that they understand that livers do take time. The importance of good nutrition. 'Cause it 'cause it can really you know, with abstinence time and good nutrition. It's it's amazing. Like how what a quality of life can change. They need time, they need time, they they need to be given that time as well. Them and their families be available. And I know that's not always easy, but.

0:21:4.920 --> 0:21:18.280  
Catherine Beresford  
Yeah. Yeah. So, I mean, you've already said quite a lot of things that give me answers to this, but maybe you might want to sort of summarise in your opinion, what does good care in advanced liver disease look like?

0:21:20.900 --> 0:21:22.300  
HCP08  
I think good care has ease of access to services. I think good care would have better support for family and caregivers. You know that that the fatigue of of looking after somebody with liver disease and I think that managing of dealing with uncertainty.

0:21:58.920 --> 0:21:59.480  
Catherine Beresford  
Yeah.

0:21:48.650 --> 0:22:0.610  
HCP08  
But I think that that's a really big thing because we're often saying, well, this may happen or you know, we're hoping for this, but it may not go that way we might -

0:22:5.480 --> 0:22:6.120  
Catherine Beresford  
Yeah.

0:22:0.730 --> 0:22:9.90  
HCP08

-I'm not eloquently putting it. I think dealing with uncertainty is really challenging for the patients. Yeah.

0:22:12.390 --> 0:22:13.390  
Catherine Beresford  
Yeah, yeah.

0:22:16.950 --> 0:22:17.230  
HCP08  
Yeah.

0:22:14.770 --> 0:22:27.130  
Catherine Beresford  
From some of the previous interviews, issues around services being under pressure and the impact on staff well-being has emerged and I'm just interested to hear any thoughts you've got on that aspect.

0:22:28.470 --> 0:22:31.470  
HCP08  
I think that’s growing and growing, really, I think you know if - you know, it's very tricky when a patient rings you up to say they've gained 6 kilogrammes in weight, and you know that you've got to try and get them in to assess them. Trying to find space to do that, a) can take up a lot of time, b) can be very stressful because you know you've got a patient at the end of it.

0:22:52.720 --> 0:22:53.120  
Catherine Beresford  
Yeah.

0:22:55.490 --> 0:23:0.850  
HCP08  
I think that the volume and the the acuity of the patients on the ward can be quite harrowing sometimes really. I don't think healthcare professionals are always that good at looking after themselves. I think sometimes it can feel like judging through sand.

0:23:19.720 --> 0:23:26.80  
Catherine Beresford  
And do you think this is there any support for staff if they if they need it themselves?

0:23:28.620 --> 0:23:37.780  
HCP08  
I think that that there are formal routes for support, but when your time pressured, I think they can be difficult to access. I think that the best support and something that I've learned throughout my nursing career really is the people that help the most are your immediate work colleagues and I think if you've got that supportive network between yourselves, that's invaluable. I think like the team dynamics is, is is essential for that. I think you know our nursing team is you know really very close knit.

0:24:6.880 --> 0:24:7.0  
Catherine Beresford  
Hmm.

0:24:15.670 --> 0:24:15.870  
Catherine Beresford  
Mm hmm.

0:24:9.820 --> 0:24:18.180  
HCP08  
If I'm honest, sometimes I think the medical team can feel much further away from that, but maybe that's the difference between nursing and medics.

0:24:20.390 --> 0:24:36.670  
Catherine Beresford  
Thank you. So, while we've been having this conversation, obviously you know you've had a lot of chance to think about different aspects of your role and the work that you do. Is there anything that's that, that you might not have thought about before that's actually occurred to you during the interview?

0:24:44.680 --> 0:24:47.520  
HCP08  
Maybe a bit more about how we look after ourselves. Now I suppose it does prompt you to think. Well, you know, in an ideal world, what would good care look like - like the best that you that could be given. I'm a bit of a reflector, so I'll probably have an answer for that tomorrow.

0:25:8.385 --> 0:25:10.145  
Catherine Beresford  
That's OK, you can e-mail me.

0:25:12.645 --> 0:25:25.485  
Catherine Beresford  
Yeah. No, I understand what you're saying. Yeah. And is there anything else that you think I should know to better understand care experiences for people with advanced decompensated liver disease?

0:25:31.875 --> 0:25:34.35  
HCP08  
I can't think of anything, I’m afraid.

0:25:34.375 --> 0:25:36.255  
Catherine Beresford  
No, that's OK. That's all right.

0:25:38.975 --> 0:25:43.735  
HCP08  
Yeah, nothing springs to mind. I've gone blank.

0:25:40.75 --> 0:25:47.635  
Catherine Beresford  
That's fine. No, no, that's fine. That's fine. You've given me so much information, it's really helpful.

0:25:48.855 --> 0:25:50.335  
Catherine Beresford  
Is there anything you want to ask me?

0:25:54.545 --> 0:25:56.545  
Catherine Beresford  
Yeah, that's a very good question.

0:25:53.15 --> 0:26:0.455  
HCP08  
So what you do with all these interviews and then what's the what? I mean, I take it this is obviously very qualitative.

0:26:0.545 --> 0:26:3.345  
Catherine Beresford  
It is, yeah. It's qualitative research, yeah.

0:26:5.175 --> 0:26:5.615  
Catherine Beresford  
Yes.

0:26:5.15 --> 0:26:6.695  
HCP08  
What are you aiming to?

0:26:7.145 --> 0:26:26.745  
Catherine Beresford  
Yeah. OK. So, well, basically the well the objectives are to get the perspectives and experiences of individuals with the advanced liver disease, the carers and the staff that support them and then out of that, because I'm the type of methodology that I'm using, you generate a theory out of it.

0:26:29.185 --> 0:26:32.505  
Catherine Beresford  
As well, as an example you know you mentioned uncertainty?

0:26:32.855 --> 0:26:33.295  
HCP08  
Yeah.

0:26:36.105 --> 0:26:41.625  
HCP08

I do. Yeah. It's so true, Kimbell. So true.

0:26:34.25 --> 0:26:56.545  
Catherine Beresford  
You might know of some research that's been done in the past where. Yeah. OK. But Barbara Kimbell - Yeah. And she Gen. Yeah. Exactly. So, she generated this theory of uncertainty, and she used the same sort of methodology that I'm using. So, I'm sort of, but I'm focusing specifically on care experiences where she was looking at the experiences of people with advanced liver disease more generally.

0:27:21.135 --> 0:27:22.775  
HCP08  
You're to my mind that there expect.

0:26:57.735 --> 0:27:23.295  
Catherine Beresford  
So it will be interesting to see what comes out of that. But what I want to do is obviously make sure that I share the findings as much as possible. You know, I've already started sort of networking going out to things like the, you know, the British Association for the Study of the Liver, you know, they have, like, an end-of-life meeting. And I've been to a couple of those, which is where I think I met one of your colleagues there and. Yeah, and meeting with patient groups to tell them what I'm finding, I've written a paper.

0:27:33.555 --> 0:27:35.35  
HCP08  
Send me. Please do.

0:27:32.65 --> 0:27:53.65  
Catherine Beresford  
Which I also I can send you you know. So, I'm I'm. Yeah. So, I'm. I'm trying to sort of share what I'm finding going to conferences etcetera and then I mean I've still got two years until actually submit my thesis just under two years. So as the project evolves you know I'll see what kind of comes out with it. But it's really about kind of gaining more insight and.

0:27:52.415 --> 0:27:57.95  
HCP08  
So. So why did you choose liver disease then? With your background being diabetes?

0:27:55.575 --> 0:28:17.95  
Catherine Beresford  
That's a good question. Well, I would say the topic chose me rather than the other way round because I was already doing research. I was involved in research, but more a qualitative research with people who've got diabetes and I wanted to do a PhD and I saw this particular PHD advertised at Bournemouth University. It's match funded by Lewis Manning Hospice care.

0:28:18.145 --> 0:28:18.465  
HCP08  
OK.

0:28:24.915 --> 0:28:25.315  
HCP08  
Yeah.

0:28:18.495 --> 0:28:28.15  
Catherine Beresford  
And it just looked, even though it wasn't diabetes. You know, when something just that you have like a light bulb moment of hang on, this looks really interesting because it's about.

0:28:31.595 --> 0:28:31.995  
HCP08  
Yeah.

0:28:37.835 --> 0:28:40.435  
HCP08  
Yes, definitely. Definitely.

0:28:43.605 --> 0:28:43.805  
HCP08  
Good.

0:28:28.665 --> 0:28:44.985  
Catherine Beresford  
You know it's about person centred care. It's about exploring what, what's happening - what are people - giving people a voice. You know, I'm really into that, you know. So, I applied for it and I'm really - yeah, I'm really enjoying it. It's really good and it's great meeting people.

0:28:48.455 --> 0:28:48.775  
HCP08  
OK.

0:28:46.125 --> 0:28:55.85  
Catherine Beresford  
But I'll stop the recording now, unless you've got anything else you want to add. OK, so let me let me stop the recording. Hold on, and then I'll turn my camera back on.