

Qualitative synthesis themes

Theme	Sub-theme	Codes	Quotations
<i>Theme one</i>			
A stark decision- Do or Die	No alternative Decision has been made	Life or death Take it or leave it Perception of decision making Lifeline	<p>“If I don’t have the [HPN], I won’t be here. There’s no other way, is there?” (69)</p> <p>It’s either die with food or [HPN] for the rest of your days and I’d sooner live and be on [HPN]” (69)</p> <p>No, why would I do that?” Asked about stopping HPN (69)</p> <p>“when I get to the point where I’ve got to say, oh, enough is enough, it won’t matter then, but until that point comes then I just have to fight, keep going” (69)</p> <p>“there was no choice really, it was one of those take it or leave it, they didn’t say that, but it’s a take it or leave it, isn’t it?” (73)</p> <p>“Well, to me it was a no option thing. I don’t think they could have done anything else, bar starve me . . . if that’s what’s keeping me alive, it’s what I have to have isn’t it. So I don’t think [there was] a decision as such, if there was no other . . . if I can’t eat, it will be next best thing” (73)</p> <p>“Hobson’s choice” (73)</p>

			“Certainly yes, I mean what’s the alternative...you just have to go with what the doctors recommend, I think. (75)
Theme two			
Realities of the intervention.	Benefits	Improved quantity and quality of life Valuing activities of daily living Increased energy/strength Symptoms	<p>“spending time with family when you get to, like, my stage, is the most important for everybody” (69)</p> <p>“it’s given me, yes, more energy” (69)</p> <p>“I think I’ve put a little bit of weight on” (69)</p> <p>“It’s keeping her alive really. That’s the big advantage.” (Husband). (69)</p> <p>“it’s going to help her do what she wants to do” (Husband). (69)</p> <p>“I’m looking forward to her being able to come out of hospital and go home and have the [HPN] at home and, sort of, have some sort of normality to life” (Daughter) (69)</p> <p>“Well they explained that it would be helpful for the sickness...stopping the sickness, which it did. I was so grateful for that because it was just projectile all the time. (75)</p> <p>“I hated that up my nose (NGT) it was so uncomfortable. It hurt me...it was horrible and uncomfortable in my throat, but this (referring to her PVG tube) isn’t uncomfortable. (75)</p>
	Burdens	Hospitalising home Role of carers Complexity of treatment Loss of normality Emotional loss Lack of information	<p>“initially when this was being discussed with us ... I thought it was probably less medical than what it is” (Daughter). (69)</p> <p>“It wasn’t as easy as it was made out to be” (69)</p>

		Recommendations from HCP	<p>“It just becomes a way of life really, you know what I mean, this is how your day goes and this is what it is. A nurse comes and takes it off in a morning and then a nurse comes at night and puts it back on” (Belinda). (69)</p> <p>“I’ve tried creeping, ‘cause I don’t want to wake him up” (Penny). “I’m awake most of the night listening for her, but she tells me not to help her” (Husband). (69)</p> <p>“I am physically falling to bits” (Daughter). (69)</p> <p>“what you sign on for when you get married” (Husband) (at the end of the second interview, he reported feeling like a “prisoner”) (69)</p> <p>“It would be wonderful if I could have even 5 h sleep without a break” (Marilyn). (69)</p> <p>“It’s difficult, yeah, especially going upstairs, because I’ve not got much energy, so usually my husband ... has to take it for me” (69)</p> <p>“when I go in the shower and everything, I can ... take both tubes off, and I’m a different person” (69)</p> <p>“a ball and chain” (Husband). (69)</p> <p>“I’ve done things for him. He can do things for me” (69)</p> <p>“as for going out and taking a contract on or something. It’s just not feasible” (Husband). (69)</p> <p>“(are you able to walk up and down the stairs?) ...not when carrying my bags (referring to her PVG, PN and syringe pump), but X (partner) carries those either behind or in front of me.” (75)</p>
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			<p>“My husband has been in a lot of discomfort, it has been leaking all the time, he’s being changed numerous times a day, the beds have to be changed and now his skin is all sore.” (75)</p> <p>“You can smell it though, even if it’s not leaking. I feel like...it smells like sewage, it’s not faecal, it’s worse than that, it’s a sewage smell and I feel like I can smell it all the time and anyone who is anywhere near me can smell it. It is making me quite paranoid, I am constantly asking my husband if he can smell it...I don’t get embarrassed too easily, but I do find that quite difficult to deal with)” (75)</p> <p>when I got down to radiology, Dr X (Consultant IR) came and explained it all to me and I was even more anxious then because I sort of then understood what was happening... (not given any written information pre-PVG)” (75)</p> <p>“(Referring to ward nurses): ...one nurse who was giving it a clean said, you don’t rotate this one...that other nurse, she said something about I’ll rotate it and I said oh well I’ve been told not to rotate mine.” (75)</p>
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