

SUPPLEMENT S6 – THEMES, CATEGORIES AND ILLUSTRATIVE QUOTES RELATED TO EXPERIENCES OF HOSPITAL-INITIATED MEDICATION CHANGES IN OLDER PEOPLE WITH MULTI-MORBIDITY

Theme	Category	Illustrative quotes
I. LACK OF INFORMATION AND COMMUNICATION ABOUT MEDICATION CHANGES	Satisfaction with information received	<i>ID-0416: 'Well if they mentioned a medication, I wouldn't know what it was for and they would tell me then...or what effect it was going to have. And he'd say "do you understand what I've been saying?" and I'd say "no" and he'd explain it then. And that was fine. It was clear. I felt that they granted me the... that I'd understand them...that I knew what they'd be talking about.'</i> <i>ID-0704: 'If you don't ask about it [for information about medication changes], they don't tell you anything; but if you do ask, then they're quite willing to tell you stuff, but I don't think that's really right. You should do that when you're planning to make those [medication] changes'</i> <i>ID-0358: 'No-one explained anything to me! When I was discharged they just told me, so you've got this and that, and this instead of that. And that's all.. As for the whys and wherefores, I've no idea.'</i>
	Lack of recall	<i>ID-0562: 'Because when the doctor explains things, you understand at the time... but then I start having doubts and feel I have to do some research... I'm not totally lost, but I find myself thinking, ooh, what's that and what about that? Have I understood it right?'</i>
	Limited opportunities for questions	<i>ID-0978: 'But they were all stressed all the time, anyway. And they would just come along in a hurry. They come and they go and that's it, it's done... I could only ask the nurses; the doctor only came around very rarely. And when he came, he asked, how are you, and stuff and stories. It's a case of such and such. And then, goodbye, thanks, and they were gone again already.'</i>
	Use of jargon and language issues	<i>ID-0562: 'And when you start asking why – sometimes, I think they find it hard to explain things. // Yes, they have all their drug lingo. And that's what's difficult to grasp at times – well, for me anyway.'</i>
II. PATERNALISTIC DECISION-MAKING PREDOMINATES, VARIABLE SATISFACTION	Paternalistic decision-making	<i>ID-0438: 'It's sort of due to the system, you know. They're the ones who decide on the treatment and then they pass that on to a head nurse to administer or something like that. And well, you don't get a say in the matter, do you? When it comes down to it, all you have to do is swallow what they put in your mouth.'</i> <i>ID-0416: 'They disregarded the people. And now these weren't people that, you know, had problems taking on board what they were saying. But they just said "we'll do this, this and this" and they'd be gone!'</i> <i>ID-0511: 'That wasn't discussed with me [stop amlodipine and lisinopril]. I suddenly realised, hey, I'm not being given those [medications] anymore.'</i>
	Patient-centred decision-making	<i>ID-0528: 'I don't have anything to say, as I made the decision [decision to not commence a statin proposed as part of the OPERAM intervention in a shared decision-making step] freely. It can't be any other way. I can't imagine another situation where the nurse, pharmacist, doctor or whatever takes on the role of an instructor, telling the patient "you have to do this, you need to do that", etc.'</i> <i>ID-0992: 'So it's up to me to take them. That means I decide myself. I could refuse to take them, after all. I would have the right to do that. So they just proposed them to me and then it would be up to me...// Yes, actually up to me. Because, as I said, he did say that to me: I could also refuse to take them. But the consequences then would be X and Y.'</i>
	Discussion of patient preferences	<i>ID-0438: 'And I told them that my policy was to live for as long as possible because the fact that I'm alive, even if I'm not leading a very active life, also keeps my wife alive and relatively fit. And that's what has always been our guide.'</i>

	Satisfaction with participation in decision-making	<i>ID-0704: 'Well, I didn't have any say in that and I have to say, honestly, that I don't think that's right... No, they don't have to consult me, but I do want to be informed about it.'</i> <i>ID-0557: 'I hadn't [the desire to ask] because they completely ignored me. As if I wasn't there at all. I thought they should have discussed it [decision to commence opioids] with me because I was the person taking them. They were prescribing it to me.' 'I thought it was very bad. The doctor that charged me £400 [Irish currency pre-Euro]. And never even spoke to me.'</i>
III. BARRIERS AND FACILITATORS TO INFORMATION AND PATIENT PARTICIPATION	Beliefs about patient role [barrier or facilitator]	<i>ID-0522: 'Well, when you're in hospital and you're getting medication, you just take it. You don't ask questions like.'</i> <i>ID-0608: 'I assume the doctor knows more about it than I do, so I have to accept it.'</i> <i>ID-0333: 'I just want to understand what's wrong with me and whether there's any chance of improvement.... I need to know and I need to understand.'</i>
	Health literacy and personal resources [facilitator]	<i>ID-0333: 'Yes and especially as I'm really keen on that. I have to know the package leaflets by heart, all the contra-indications. I'm a bit obsessed now. I love knowing exactly what I'm in for. When I take any medication, especially a new medication. Or when the dose is changed too'</i> <i>Patient, Switzerland: 'But I was on top of the medication situation. And now too. I know what I'm taking and why.'</i>
	Involvement of companions [facilitator]	<i>ID-0365: 'So if my grandson hadn't intervened, maybe they wouldn't have given me Lyrica and wouldn't have discussed things with me more.'</i>
	Interpersonal characteristics of the clinician [barrier or facilitator]	<i>ID-0408: 'I was on [loperamide], that transformed my life 30 years ago. This [medication] came along and it transformed me but they seemed to dismiss that like you know....Oh they just, they just more or less dismissed. I don't think they were listening at all. And I'll be quite honest with you.'</i> <i>ID-0528: 'There's a lot of time spent on the patient's experience, their feelings, in a desire – a sincere one, I believe – to help them and not just bombard them with prescriptions that may or may not be helpful. I think that's really nice because all too often in hospitals you feel a bit like a number.'</i>
	Trust and clinician-patient relationship [barrier or facilitator]	<i>Interviewer: 'What prevented you from being involved in the decision yourself?' ID-0907: 'I trusted them blindly.'</i> <i>ID-0333: 'So I might say my breathing isn't great, can I increase my diuretics a little bit? And before you know it, it's done. The initiative usually comes from me, though. Whether or not I complain about my health. And since I was admitted for a month and a half, I had time to talk. I know them [hospital staff] all, you know.'</i>
	Feeling too ill or too fatigued [barrier]	<i>ID-0583: 'For three or four days after the operation you're in a foggy sort of state [laughs], and, as far as I was concerned, the medication problem wasn't important to me at all, not at all. It was just a detail for me.'</i>
	Overwhelmed by multiple clinicians involved in care [barrier]	<i>ID-0902: 'If the same doctor came each time, then you could build up a relationship. And then you might have other questions and things might work differently. Yes, that mightn't be a bad idea.'</i>
IV. POSITIVE ATTITUDES TOWARDS MEDICATION REVIEW AND ACCEPTANCE OF MEDICATION CHANGES	Medication review is 'a good thing' but the GP should be involved	<i>ID-0904: 'Yes, I do think it's a good idea to review things. What had built up, too, over a lifetime and over the whole period. And situations and illnesses change too.'</i> <i>ID-0355: 'So at that point there should be another person there, the GP. It's a good idea for them to be involved in the discussion.'</i>
	Acceptance of hospital-initiated medication changes	<i>ID-0907: 'I just take what the doctors prescribe, and I do so consistently. It mightn't taste great, but I take them. [laughs]'</i> <i>ID-0704: 'I take it because it's prescribed, and that's that.'</i> <i>ID-0557: 'I'm only taking one [instead of the prescribed oxycodone 10mg BD] going to bed at night. Because if I took one during the day when I come down here, I'd be sleepy all day.'</i>

V. BARRIERS AND FACILITATORS TO ACCEPTANCE OF MEDICATION CHANGES	Beliefs about medicines [barrier or facilitator]	<i>ID-0333: 'Well, generally speaking, all these medicines are pretty essential for me, you know, so it's very important. Especially the latest ones – I now take Zyrtec and Imodium to help me make it through the day. I have to take them, you see. Otherwise, I just wouldn't be able to cope.'</i> <i>ID-1089: 'And then I changed that again and took my old painkillers. And now I have them again. I just find they help me. When I take one of those three times a day, then I can feel pretty good.'</i> <i>ID-0528: 'I mean, they're using a sledgehammer to crack a nut. With a whole host of side-effects, it's just not necessary.'</i>
	Medication changes perceived as minor [facilitator]	<i>ID-0634: 'They are minor changes – that's not hard to decide. Look, they're nothing drastic, so no, it wasn't difficult.'</i> <i>ID-0583: 'It's no big deal for me. Because I feel like my oesophagitis isn't very serious after what I've been through. As soon as they tell you you've got cancer, and not a minor cancer, mind you – it's the pancreas after all, which is a serious matter – anything to do with my oesophagitis is not a priority for me, it's just not in the same league...'</i>
	Experiencing benefit or harm from a medication change [barrier or facilitator]	<i>ID-0443: 'I do feel in the short, the short time that I'm on them. I feel possibly that my chest is a little freer.'</i> <i>ID-0358: 'With an anxiety attack you feel like you're going to explode! When you have an attack like that. It's really... it like something's got you by the throat. You can't escape from it [voice breaks, pause]. No, without Seroxat, things aren't good at all. [silence]'</i>
	Trust and balancing advice between different healthcare professionals [barrier or facilitator]	<i>ID-1089: 'But when someone says to me, "Your liver results are too high, so we have to change a medication," then I trust them.'</i> <i>ID-0528: 'Because anyway with all the changes they suggested, I went to see my GP – I have a lot of confidence in her, she's obviously known me for years, keeps an eye on me... And as for the statins [prescribed as part of the OPERAM intervention], I said that I wouldn't take them. Since she [the GP] was not at all in favour of using statins, I didn't pursue the matter.'</i> <i>ID-0992: 'From three sides, more or less, the GP, the hospital, and you (OPERAM Study), you were all agreed. Everybody came to the same conclusion, except for one medication. And that reassured me.'</i>
VI. IMPORTANCE OF COORDINATION BETWEEN SECONDARY AND PRIMARY CARE	Better preparation for discharge	<i>ID-0365: 'But I think that someone who's getting sent home needs more in the way of interaction. I knew I was going home and my daughters were waiting for me and all that. So my case is a bit special, but I suppose when you're old and alone, the situation has to be reviewed at a time like that. Because once you're home, are you in a position to take your medication properly?'</i>
	Follow-up support	<i>ID-0891: 'Afterwards, I asked her [the GP], "Why don't I have to take those brown ones [tablets] anymore?" And she said it was because of my blood pressure. That had changed. So she explained why. And then I was reassured.'</i> <i>ID-0358: 'That's the problem: when they change something, they do it at the hospital and there's no follow-up outside.'</i>
	Poor communication between primary and secondary care	<i>ID 0511: 'But I've noticed that sometimes there's a time lag. One day, the specialist tells you that this and that have to be doubled because...and so on. And a week later you go along and ask for the medication at the pharmacy and they still aren't in the picture. So they give you the old box again. So there's always some problem at the pharmacy. And I find that annoying – surely it doesn't have to be like that in this digital day and age.'</i>