

Experience of hospital-initiated medication changes in older people with multimorbidity: a multicentre mixed-methods study embedded in the OPtimising thERapy to prevent Avoidable hospital admissions in Multimorbid older people (OPERAM) trial

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#### ABSTRACT

**Background** A patient-centred approach to medicines optimisation is considered essential. The OPtimising thERapy to prevent Avoidable hospital admissions in Multimorbid older people (OPERAM) trial evaluated the effectiveness of medication review with shared decisionmaking (SDM) in older people with multimorbidity. Beyond evaluating the clinical effectiveness, exploring the patient experience facilitates a better understanding of contextual factors and mechanisms affecting medication review effectiveness.

**Objective** To explore experiences of hospital-initiated medication changes in older people with multimorbidity. **Methods** We conducted a multicentre mixed-methods study, embedded in the OPERAM trial, combining semi-structured interviews and the Beliefs about Medicines Questionnaire (BMQ) with a purposive sample of 48 patients (70–94 years) from four European countries. Interviews were analysed using the Framework approach. Trial implementation data on SDM were collected and the 9-item SDM questionnaire was conducted with 17 clinicians.

**Results** Patients generally displayed positive attitudes towards medication review, yet emphasised the importance of long-term, trusting relationships such as with their general practitioners for medication review. Many patients reported a lack of information and communication about medication changes and predominantly experienced paternalistic decision-making. Patients' beliefs that 'doctors know best', 'blind trust', having limited opportunities for questions, use of jargon terms by clinicians, 'feeling too ill', dismissive clinicians, etc highlight the powerlessness some patients felt during hospitalisation, all representing barriers to SDM.

#### Key messages

#### What is already known on this topic

⇒ A patient-centred approach to medicines optimisation is considered essential.

#### What this study adds

⇒ This multicentre mixed-methods study, embedded in the OPERAM trial, provides an in-depth understanding of experiences of hospital-initiated medication changes in older people with multimorbidity and identified barriers, facilitators and patients' needs in relation to medication review.

## How this study might affect research, practice or policy

⇒ To meet patients' needs, medicines optimisation services should enhance information exchange, better prepare patients and clinicians for partnership in care and foster collaborative medication reviews across care settings.

Conversely, involvement of companions, health literacy, empathetic and trusting patient-doctor relationships, facilitated SDM. Paradoxical to patients' experiential accounts, clinicians reported high levels of SDM. The

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BMQ showed that most patients had high necessity and low concern beliefs about medicines. Beliefs about medicines, experiencing benefits or harms from medication changes, illness perception, trust and balancing advice between different healthcare professionals all affected acceptance of medication changes.

**Conclusion** To meet patients' needs, future medicines optimisation interventions should enhance information exchange, better prepare patients and clinicians for partnership in care and foster collaborative medication reviews across care settings.

## INTRODUCTION

A patient-centred approach to medicines optimisation, incorporating patient preferences in treatment decisions through shared decision-making (SDM), is advocated as pivotal to improving quality of care and reducing harms of overtreatment in patients with multimorbidity.<sup>1-6</sup> Recently, the European OPERAM trial has evaluated the impact of a complex intervention of medication review and SDM on drug-related readmissions in older people with multimorbidity. Inappropriate prescribing was reduced through the OPERAM intervention, but without a significant effect on drug-related hospital admissions.<sup>7 8</sup> Beyond evaluating the clinical effectiveness of the OPERAM intervention, exploring patients' experiences facilitates a more comprehensive understanding of contextual factors and mechanisms affecting intervention effectiveness. There is lack of a universally agreedupon definition of patient experience but core aspects associated with a positive patient experience include involvement of patients and companions in decisionmaking, respect for patient preferences, clear information and communication, emotional support, physical comfort, transparency, care coordination, continuity and access to care.9-12 A positive patient experience is correlated with clinical effectiveness and safety including reduced readmission rates.<sup>9 13</sup> Few qualitative studies have explored the experiences of hospitalinitiated medication changes in older people with multimorbidity.<sup>14–18</sup> Most studies focus on the patient experience of medication-related information and communication and do not evaluate the wider range of aspects associated with patient experience according to the NHS Patient Experience Framework.<sup>10</sup> This study, embedded in the OPERAM trial, explored experiences of hospital-initiated medication changes in older people with multimorbidity.

#### **METHODS**

#### Study design and setting

We conducted a multicentre mixed-methods study combining qualitative and quantitative data. Semistructured interviews were performed with patients to gain an in-depth understanding of patient experience of hospital-initiated medication changes. The NHS Patient Experience Framework was used to underpin the interviews.<sup>10</sup> Qualitative data were triangulated with quantitative data from the Beliefs about Medicines Questionnaire (BMQ) completed by all interviewed patients.<sup>19</sup> Furthermore, trial implementation data on SDM were collected and the 9-item SDM questionnaire was conducted with a subsample of clinicians.<sup>20</sup> Participants were recruited in teaching hospitals in urban settings in Belgium, Ireland, Switzerland and The Netherlands.

#### **Participant selection**

Patients enrolled in the OPERAM intervention or control arms, who met the mixed-methods study inclusion criteria (table 1) were eligible to participate. Patients were approached face-to-face during their hospitalisation by OPERAM researchers. We selected a purposive sample by screening medical records to ensure heterogeneity in terms of age, gender, study arm, hospital ward, education and living situation (at home/nursing home) (online supplemental file S1). We estimated a priori to recruit 10–15 participants per country to have a sample with diversity in several patient characteristics, yet the final sample size depended on the quality of data obtained and was

Table 1         Inclusion and exclusion criteria of the OPERAM trial and the embedded mixed-methods study (created by the authors)				
OPERAM trial	Mixed-methods study embedded in OPERAM			
<ul> <li>Inclusion criteria:</li> <li>70 years or older.</li> <li>Multimorbidity (≥3 chronic conditions ≥6 months).</li> <li>Polypharmacy (≥5 chronic medications).</li> <li>Exclusion criteria:</li> <li>Direct admission to palliative care.</li> <li>Report of a structured medication review within the last 2 months.</li> <li>The OPERAM intervention consisted of the Structured Method to Reduce Inappropriate Prescribing including structured history taking of medication use, a CDSS-assisted medication review based on the STOPP/START V.2 criteria, discussion of medication optimisation recommendations with the attending physician and the patient and generation of a discharge report with recommendations for the GP.</li> <li>The control arm received usual care.</li> </ul>	<ul> <li>Inclusion criteria:</li> <li>≥1 change in chronic medication proposed during hospitalisation, for example, the addition, discontinuation or modification of a medicine. The medication change could be a result of the OPERAM intervention or usual care.</li> <li>Informative patients willing to share their experience.</li> <li>Exclusion criteria:</li> <li>Inability to provide informed consent.</li> <li>Patients with confusion, dementia or severe cognitive impairment.</li> <li>Unacceptable living distance from the clinical sites (for pragmatic reasons).</li> </ul>			
CDSS, Clinical Decision Support System; GP, general practitioner; START, Screening Prescriptions.	g Tool to Alert to Right Treatment; STOPP, Screening Tool of Older People's			

determined during data analysis when data saturation was reached.  $^{\rm 21}$ 

A subsample of clinicians (the physician/pharmacist who proposed medication changes to the patient as part of the intervention or usual care) from the Belgian and Swiss study sites were invited to complete the physician version of the SDM questionnaire (SDM-Q-DOC).<sup>20</sup>

The present study started after the OPERAM trial had been running for 12 months; hence researchers had become experienced in delivering the intervention. Prior to the start of the OPERAM trial, all researchers delivering the intervention were trained in intervention delivery, including a 45 min webinar training on the principles of SDM based on the collaborative deliberation model.<sup>6 22 23</sup>

#### Qualitative data collection and analysis

Semi-structured interviews were conducted in each site in the local language (French (Belgium), Dutch (The Netherlands), English (Ireland), Swiss-German (Switzerland)) between January 2018 and February 2019. Interviewers (ST, CP, BM, AVH, KM) were researchers and/or healthcare professionals with backgrounds in pharmacy, public health/nursing, psychology and geriatric medicine; were trained in qualitative interviewing and had no clinical relationship with patients. The interview was preferably scheduled within 1 month (median (P25-P75): 21 (13-30) days) after discharge to avoid recall bias and took place at the patient's home or at the hospital before or after an outpatient consultation. The patient was invited to have a companion present if this reflected the usual situation. Interviews lasted on average 36 min (range: 19-80 min).

A topic guide (online supplemental file S2) was developed in English based on the NHS Patient Experience Framework and the OPERAM intervention components.<sup>10</sup> The topic guide consisted of eight open-ended questions with follow-up prompts covering the following aspects: information about medication changes, involvement in decision-making, involvement of companions, perspectives on medication review in general, patient experience of and acceptance of hospital-initiated medication changes, transition to primary care and related barriers, facilitators and patients' needs. The topic guide was translated into the local languages and piloted with at least three patients in each study site. A webinar training session and standard operating procedures were provided to train the interviewers. Interviewers took field notes during the interview to document contextual aspects, interviewees' behaviour and reflections about the interview.

Interviews were recorded and transcribed verbatim in the local language. Data collection and analysis occurred simultaneously to allow incorporation of interesting findings in the topic guide for the next interviews. Thematic analysis was performed using

the Framework approach by three researchers (ST, CP, BM) combining pharmacy, nursing/public health and psychology perspectives. The Framework approach is a systematic approach for categorising and organising the data and involves familiarisation with the interviews, developing a thematic framework, coding, charting the data into the framework and interpreting the data (online supplemental file S3).<sup>24 25</sup> We combined inductive and deductive thematic analysis; major themes were partly predefined by the NHS Patient Experience Framework, but mainly arose inductively from the data to dictate themes and categories. QSR International's NVivo V.11 software was used to facilitate data analysis. Qualitative results were triangulated with the quantitative data collected during the interpretation stage. A summary of the qualitative findings was sent to the interviewers from each site and to nine Belgian OPERAM patients for validation. We used the consolidated criteria for reporting qualitative research for designing and reporting this study.<sup>26</sup> Rigour was addressed throughout the various stages of the research process as described in online supplemental file S4.<sup>26–28</sup>

#### Quantitative data collection and analysis

#### Beliefs about Medicines Questionnaire

To complement the findings from the interviews, patients' beliefs about medicines were assessed quantitatively using the BMQ at the end of the interview.<sup>19</sup> Understanding patients' beliefs about medicines is important because they may influence the acceptance of medication changes and adherence.<sup>29–31</sup>

## Clinicians' perspective on patient participation in decision-making about medication changes

For the patients enrolled to the intervention arm, we collected the following trial implementation data on patient participation, as perceived by the research clinician who delivered the intervention:

- Whether medication changes were discussed with the patient (yes/no).
- Whether SDM was performed (yes/no) (according to the OPERAM standard operating procedure on SDM).

Furthermore, a subsample of clinicians (the physician/pharmacist who proposed medication changes as part of the intervention or usual care) were invited to complete the SDM-Q-DOC, a validated 9-item questionnaire assessing the level of SDM as perceived by the physician during a consultation.<sup>20</sup> The SDM-Q-DOC was administered as soon as possible after discharge of the patient. For pragmatic reasons, only clinicians from the OPERAM sites in Belgium and Switzerland were invited to complete the SDM-Q-DOC. Quantitative data obtained were summarised using descriptive statistics. In online supplemental file S5, details on data analysis of the BMQ and SDM-Q-DOC are provided.

Table 2         Patient characteristics (n=48) (creation of the sector)	ited by the authors)				
Variable	Value				
Age (years; median (P25–P75))	76 (72–81)				
≥70-≤80 years (n, (%))	34 (71)				
>80-≤90 years (n, (%))	13 (27)				
>90 years (n, (%))	1 (2)				
Sex (n, (%))					
Female	23 (48)				
Male	25 (52)				
No. of medications on admission (median (P25– P75))	10 (7–14)				
Total no. of medication changes proposed during admission (median (P25–P75); (range))	4 (2–6; 1–13)				
n (%) of patients with $\geq 1-\leq 4$ changes	29 (60)				
n (%) of patients with $\geq$ 5–<10 changes	17 (35)				
n (%) of patients with $\geq 10 - \leq 13$ changes	2 (4)				
Proposed medication stops					
(median (P25–P75); (range))	1 (0-2; 0-10)				
Proposed medication starts					
(median (P25–P75); (range))	1 (1-2; 0-10)				
Proposed medication modifications					
(median (P25–P75); (range))	0 (0-1; 0-3)				
Country (local language, n, (%))					
Belgium (French)	15 (31)				
Ireland (English)	7 (15)				
Switzerland (Swiss-German)	11 (23)				
The Netherlands (Dutch)	15 (31)				
OPERAM study arm (n, (%))					
Control arm	21 (44)				
Intervention arm	27 (56)				
Ward specialty (n, (%))					
Medical ward	36 (75)				
Surgical ward	12 (25)				
Length of stay (days; median (P25–P75))	9 (7–11)				
Educational level (n, (%))					
Less than high school completed	7 (15)				
High school degree	23 (48)				
Postsecondary degree	18 (37)				
Place of residence (n, (%))					
Home 45 (94)					
Nursing home 3 (6)					
Interview with (n, (%))					
Patient	31 (65)				
Patient and companion	17 (35)				

## RESULTS

## Description of participants

Of the 73 patients approached with a view to enrolment, 57 patients agreed to participate (acceptance rate=78%). Sixteen patients declined to participate (reasons: not interested, not comfortable talking about doctors to researchers, feeling 'too old'). Nine dropped out of the study (died, too ill, no longer interested, could not be contacted after discharge, not within time limit) resulting in a sample of 48 patients (table 2).

## Semi-structured interviews

Thematic analysis resulted in 6 themes and 24 categories, organised according to the process of medication review and SDM (online supplemental file S6). We aimed to describe patient experience across a diverse sample, rather than reporting countryspecific or study arm-specific findings. However, when comparing themes and categories between countries or study arms, major themes did not differ.

## Theme I: lack of information and communication about medication changes

Patients' satisfaction with information received about medication changes was mixed. Many patients reported a lack of information, in particular on the indication of medicines, reason for changing or side effects. Some patients said they received no information at all and others said they had to ask for information themselves.

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. (ID-0358)

Inadequate information resulted for some patients in lacking understanding of medication changes, confusion or anxiety. Other patients were satisfied because they were well-informed and some were satisfied, although reporting having received very limited information.

It was clear. I felt that they granted me that I'd understand them, that I knew what they'd be talking about. (ID-0416)

Some patients had problems recalling the medication changes or the information received. Others stated that information was provided hurriedly with limited opportunities for questions. Some patients had difficulties with jargon terms used by clinicians or the fact that the information was not provided in their native language.

And when you start asking why, sometimes I think they find it hard to explain things. They all have their drug lingo. And that's what's difficult to grasp at times. (ID-0562)

They [the doctors] would just come along in a hurry, they come and 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. (ID-0978)

Many patients emphasised the need for more information and medication counselling, a written

medication list, providing information in lay language at a moment when the patient feels well and taking more time for providing information.

## Theme II: paternalistic decision-making predominates, variable satisfaction

Patients predominantly experienced paternalistic decision-making, in which decisions to change medicines were taken by the clinician and patients were informed afterwards. A minority of patients reported active participation in decision-making, varying from patients being asked for their approval, decision shared or patients deciding autonomously after being informed. Some patients participated by proposing medication changes themselves.

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. (ID-0438)

I made the decision [decision to not commence a statin proposed as part of the OPERAM intervention in a SDM process] 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. (ID-0528)

One participant had open discussion about preferences in the context of medication-related decisions. Several patients commented that "You go to the doctor to be healed, not to discuss preferences". Others assumed that clinicians know their preferences, whereas a minority of patients would like to have preference discussions.

Patients' satisfaction with participation in decision-making was mixed. Most patients were satisfied with paternalistic decision-making and preferred to be informed rather than actively involved, whereas others were dissatisfied with paternalistic decision-making and preferred to be more involved. All patients with patient-centred decision-making were satisfied.

## Perceptual differences between patients and clinicians in relation to patient participation in decision-making

Paradoxical to patients' experiential accounts reported in the interviews, quantitative data on SDM from clinicians' perspectives revealed high levels of patient participation (table 3). According to trial implementation data, for 85% of the interviewed intervention patients, medication changes were discussed and for 70% of intervention patients formal SDM was performed. Eleven Belgian and six Swiss clinicians completed the SDM-Q-DOC (response rate=65%) and reported a median score of 76. Patients however displayed mixed perceptions about participation in decision-making with 77% of all patients in the study reporting 
 Table 3
 Perceptual differences between prescribing clinicians and their patients in relation to patient participation in decision-making about medication changes (created by the authors)

#### Clinicians' perspective on patient participation in decision-making

		•		•	2	
	l implementation data on ERAM intervention for inte					
	n (%) of intervention patie were discussed	nts for w	hom m	edication changes	23 (85)	
	n (%) of intervention patie performed	nts for w	hom fo	rmal SDM was	19 (70)	
SDI	M-Q-DOC score (median (I	P25-P75)	))†			
T	Fotal participating prescrib	ing clinic	ians (n=	=17)	76 (69–82)	
F	Prescribing clinicians' inter	vention g	jroup (r	n=10)	77 (74–81)	
F	Prescribing clinicians' cont	rol group	(n=7)		69 (53–81)	
n (9	%) of patients reporting pa	articipatio	on in de	cision-making‡		
A	All patients (n=48)				11 (23)	
	ntervention patients (n=2	7)			8 (30)	
(	Control patients (n=21)				3 (14)	

\*Implementation of SDM as perceived by the research clinician who performed the OPERAM intervention. Formal SDM was defined according to the standard operating procedure on SDM used in the OPERAM trial, based on the collaborative deliberation model.

tSDM-Q-DOC scores were available for 17/48 interviewed patients' clinicians (from both intervention and control groups). The SDM-Q-DOC was completed by the research clinician (intervention group) or the patients' prescribing clinician (control group) who proposed the medication changes to the patient. Scores on the SDM-Q-DOC range between 0 and 100 with 0 representing the lowest possible level of SDM and 100 the highest possible level.

\*As reported by patients in the semi-structured interviews. Decision-making was classified as 'patient participation in decision-making' if the patient reported some extent of patient participation, varying from patients reporting having been asked for their approval on medication changes (patient consultation), decision shared or having decided autonomously after being informed. Decision-making was classified as 'paternalistic decision-making' if the patient reported that the decision was taken by the clinician and the patient was informed afterwards.

SDM, shared decision-making; SDM-Q-DOC, physician version of the 9-item SDM questionnaire.

paternalistic decision-making compared with 23% patients reporting participation.

## Theme III: barriers and facilitators to information and patient participation

#### Beliefs about patient role

Overwhelmingly patients believe 'doctors know best' and considered themselves lacking competence to be involved in medication-related decision-making. This belief was closely linked with trust in doctors, a passive attitude and not asking for information, a barrier to be well-informed and to patient participation. Some patients specifically referred to this passive role while in hospital: "In hospital you just take medications, you don't ask questions".

I assume the doctor knows more about it than I do, so I have to accept it. (ID-0608)

Others described a more active role in decisionmaking varying from sharing experiences with medications, to questioning what doctors propose to some strongly believing that 'the patient has the last word' about treatment.

#### Health literacy and personal resources

Knowledge and understanding of medications acted as facilitators to patient participation. Patients with unmet information needs described various ways in which they independently gained access to additional information, for example, by searching on the internet, by consulting a companion or a (primary) care provider.

#### Involvement of companions

Whereas for most patients, companions were not involved in their care, some patients perceived involvement of companions as a facilitator for being well-informed, for example, by helping to remember the information received, by obtaining extra information from the clinician or for language support. For one patient, involvement of a companion facilitated patient participation in decision-making.

So if my grandson hadn't intervened, maybe they wouldn't have given me Lyrica and wouldn't have discussed things with me more. (ID-0365)

#### Interpersonal characteristics of the clinician

Patients valued being treated as individuals and appreciated clinicians listening to them, reassuring them, being understanding, being cordial, acting as facilitators to patient participation. In contrast, others reported negative experiences with dismissive clinicians neglecting their needs and focusing solely on treating a disease, acting as barriers to patient participation.

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. I think that's really nice because all too often in hospitals you feel a bit like a number. (ID-0528)

Oh they just more or less dismissed. I don't think they were listening at all. And I'll be quite honest with you. (ID-0408)

### Trust and the patient-clinician relationship

Trust in doctors was for some patients a barrier to patient participation because it reinforces a passive attitude ('doctors know best'). On the other hand, one patient reported that a long hospitalisation allowed him to build a relationship with clinicians, which was a facilitator for patient participation.

What prevented you from being involved in the decision yourself? (Interviewer) I trusted them blindly. (P-0907)

### Feeling too ill or too fatigued

Several patients reported that hospitalisation was not the right time to discuss medication changes because they were too ill or too fatigued, acting as a barrier to patient participation.

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. (ID-0583)

### Overwhelmed by multiple clinicians involved in care

The fact that multiple clinicians were involved in care, was for some patients a barrier to asking questions and being involved.

## Theme IV: positive attitudes towards medication review and acceptance of medication changes

Patient perspectives on medication review were generally very positive. Patients acknowledged the importance of checking the appropriateness of their medication and stopping unnecessary medicines. Many patients expressed a desire to take less medicines. Several patients considered medication review desirable in hospital because specialists were around or they felt closely monitored, whereas others emphasised the need for more involvement of their GP. Several patients considered the GP or the community pharmacist to be the more appropriate person for medication review because of trust, having a good and long-standing doctor-patient relationship and the medical overview that they have. One patient enrolled to the intervention arm had a very strong opinion about this and considered the proposed medication changes in hospital as critical of the GP and did not accept any of the proposed medication changes.

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. (ID-0904)

There should be another person there, the GP. (ID-0355)

The majority of patients reported having accepted and implemented the hospital-initiated medication changes, compared with a minority of patients that did not, following the GP's advice or on their own initiative. Some patients implemented on their own initiative additional strategies to cope with medication changes including dose reduction because of side effects, self-medication, 'grandmothers' remedies' or self-monitoring blood pressure.

#### Theme V: barriers and facilitators to acceptance of medication changes *Beliefs about medicines*

Necessity and concern beliefs were identified as key barriers or facilitators to acceptance of medication changes. Most patients accepted the medication changes and acknowledged the necessity for a

## Original research

change (eg, physical need, usual treatment perceived as burdensome or ineffective) or believed in a longterm effect (facilitators).

Well, generally speaking, all these medicines are pretty essential for me, you know, so it's very important. (ID-0333)

Conversely, low necessity beliefs about medicines (eg, usual treatment perceived as important) or concerns about medicines (eg, fear of side effects), acted as barriers or facilitators to acceptance of medication changes.

I mean, they're using a sledgehammer to crack a nut. With a whole host of side-effects, it's just not necessary. (ID-0528)

#### Medication changes perceived as minor

Medication changes that were perceived as minor ('it is only a small change') were easily accepted. Several patients considered a medication change as a minor issue in relation to their illness perception, for example, a decision to start a proton pump inhibitor for symptomatic oesophagitis considered as minor compared with cancer they suffer from.

#### Experiencing a benefit or harm from a medication change

Patients described the impact of a medication change on symptom control and side effects as attributes affecting the definite implementation of medication changes. Practical effects (eg, fewer medicines, smaller pills) were cited as facilitators to accept medication changes.

I do feel in the short, the short time that I'm on them. I feel possibly that my chest is a little freer. (ID-0443)

#### Trust and balancing advice between different healthcare professionals

Trust in doctors was a facilitator to accept the medication changes. Several patients reported receiving conflicting advice from different healthcare professionals, which may act as a barrier to accepting medication changes. Patients explained how they choose to either follow the GP's or the specialist physician's recommendations, depending on whom they trusted more. In contrast, when the GP confirmed the medication change or the medication change had been previously proposed by a specialist physician, it facilitated acceptance and reassured patients. Many patients reported that their GPs approved the medication changes and some patients explained that their GPs did not question decisions from the specialist physician.

Because anyway with all the changes they suggested, I went to see my GP. I have a lot of confidence in her, she's known me for years. 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 
 Table 4
 Patients' beliefs about medicines (n=48) (created by the authors)

BMQ subscale	Median score (P25–P75)	<i>N</i> (%) of patients above the scale midpoint
General-overuse*	13 (10–15)	25 (52)
General-harm*	11 (8–12)	10 (21)
Specific-necessity†	21 (17–24)	40 (83)
Specific-concerns†	12 (10–14)	11 (23)
Necessity-concern differential‡	8 (4–12)	43 (90)

\*Scale ranges from 4 to 20, where high scores indicate negative beliefs about medicines.

+Scale ranges from 5 to 25, higher scores indicate stronger necessity or concern beliefs.

 $\pm$ Ccale ranges from -20 to 20, positive scores indicate that the patient perceives necessity outweighs concerns.

BMQ, Beliefs about Medicines Questionnaire.

not at all in favour of using statins, I didn't pursue the matter. (ID-0528)

Theme VI: importance of coordination between secondary and primary care

Many patients reported having received good follow-up support from their GP and appreciated the fact that the GP was updated about the medication changes. However, some patients experienced a lack of follow-up support. One patient experienced severe psychological distress because of the withdrawal of his antidepressant. He felt abandoned by the hospital physician and by the GP, neither of whom provided adequate psychological support. A few days later, the patient was readmitted with a panic attack. Some patients had problems with a lack of prescription refills after discharge and others were confused because of the generics received in hospital and branded medication received at home. Several patients highlighted the need for better preparation for discharge, good follow-up support and better communication between primary and secondary care.

That's the problem: when they change something, they do it at the hospital and there's no follow-up outside. (ID-0358)

#### Beliefs about Medicines Questionnaire

Results from the BMQ are shown in table 4. For 90% of patients, the necessity-concerns differential was positive, indicating that necessity beliefs outweighed concerns. When participants were categorised by attitudinal group, 71% of patients were accepting, 21% were ambivalent, 6% were indifferent and 2% were sceptical.

#### DISCUSSION

This study provides an in-depth understanding of experiences of hospital-initiated medication changes

in older people with multimorbidity in the OPERAM trial and identified barriers, facilitators and patients' needs in relation to medication review. Patients generally displayed positive attitudes towards medication review and hospital-initiated medication changes, but an interplay of deficient information and communication, paternalism, patients' beliefs, clinicians' attitudes, trust and doctor-patient relationships highlight the complexity of implementing medication review and SDM in hospital and may affect its effectiveness.

Several patients lacked information regarding their medication changes or had problems recalling the information received, which has been previously reported.<sup>14–16 32–35</sup> In the intervention arm, OPERAM researchers discussed medication changes with the patient during their hospitalisation, but patients did not receive written information and there was no direct involvement of OPERAM researchers in discharge counselling. This might explain the lack of information reported in both study arms.

Paternalistic decision-making was predominantly both study arms, suggesting that SDM was not largely used in the OPERAM trial. Inadequate information is an evident barrier to SDM but is not sufficient; patients need both knowledge and power for SDM.<sup>36-39</sup> Patients' accounts of having limited opportunities for questions, poor understanding of jargon terms, feeling too ill or too fatigued to participate, being overwhelmed by multiple clinicians involved in care, dismissive clinicians, etc highlight the powerlessness some patients felt during hospitalisation, all representing barriers to SDM.<sup>37 39-44</sup> Conversely, health literacy, involvement of companions, being listened to, empathetic and trusting patient-doctor relationships facilitated SDM. Furthermore, while some patients recognised their experiential role in medication-related decisionmaking, many patients retained paternalistic views on decision-making ('doctors know best' and 'blind trust'). Paternalistic views are especially engrained in older people, acting as a barrier to SDM.<sup>37–39</sup> Heterogeneity in older patients' preferences for participation has been consistently demonstrated and the patient's preferred role in decision-making should therefore be explicitly elicited and respected.<sup>15 45 46</sup> Even if a patient prefers to defer decision-making to a trusted person, but is involved in information exchange and preference discussions, this can still be considered SDM.<sup>47</sup>

Interestingly, we found discordance between patients' accounts of paternalistic decision-making and clinicians reporting high levels of SDM according to quantitative measures. Despite observations demonstrating the contrary, "we are already doing SDM" is a frequently reported attitude of clinicians, which might be due to a lack of understanding of what real SDM is about.<sup>38 48</sup> The webinar training provided to clinicians delivering the intervention was likely not sufficient to equip them with the full range of skills to perform highly effective SDM.

Despite limited patient participation, patients' attitudes towards medication review and hospitalinitiated medication changes were generally positive, with the majority of patients reporting having accepted the medication changes. Acceptance of medication changes is likely to drive adherence and persistence.<sup>31</sup> Beliefs about medicines reported in the interviews were in line with results from the BMO, showing that the majority of patients had high necessity and low concern beliefs and were categorised in the attitudinal group 'accepting'.<sup>19</sup> An interplay of beliefs about medicines, illness perception, experience with medication changes, trust and balancing advice between different providers affected acceptance of medication changes, which echoes findings from previous studies.<sup>31 49–53</sup> Given limited patient participation in decision-making, patient beliefs about medicines and preferences were unlikely to have been sufficiently addressed.

Patients emphasised the importance of a long-term, trusting relationships (relational continuity of care) such as with the GP for discussions about medicines and the need for good coordination between primary and secondary care. In OPERAM, GPs were not directly involved in medication review and received a letter with the proposed medication changes after the patient's discharge. To overcome some of the patientreported barriers to medication review in hospital (eg, lack of GP involvement, conflicting advice between healthcare professionals), involving GPs earlier in the medication review process seems essential.

Major themes did not differ between countries or study arms, suggesting that the study site did not substantially affect patient experience, nor did the OPERAM intervention. This might be due to the fact that patients were all involved in the OPERAM trial and all were hospitalised. Moreover, no major differences in standard practice regarding medication review exist across the four countries. However, given a limited number of interviews undertaken in each country, it is difficult to make a definitive statement about country-specific differences.

#### Implications for practice

To meet patients' needs, medication review services should enhance information exchange, foster collaborative medication reviews across care settings and better prepare patients and clinicians for partnership in care. Reinforcing medication-related information at discharge using the teach-back technique, providing written information or reinforcing postdischarge follow-up (eg, follow-up calls) are effective strategies for improving patients' understanding of medications.<sup>54–56</sup> Involvement of companions also helped patients to be better informed. Furthermore, compared with unidirectional communication, consensus and close collaboration between hospital specialists and follow-up care providers in medication reviews may lead to higher acceptance rates of medication plans

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postdischarge.<sup>57 58</sup> Especially for older patients with multimorbidity, SDM and medicines optimisation should not be restricted to one patient and one clinician in one consultation, rather integrated and interprofessional approaches are needed.<sup>38 48</sup> With deeply engrained paternalistic practices in many countries, implementing medication review with SDM requires significant behaviour change of both clinicians and patients. Neither patients nor clinicians might have been adequately prepared for or skilled in SDM in the OPERAM trial. A combination of interventions at the macrolevel, mesolevel and microlevel are needed to foster cultural and attitudinal changes to SDM including training healthcare professionals in SDM, preparing patients and companions to engage in SDM, SDM tools and a patient-centred culture.<sup>5</sup>

#### **Strengths and limitations**

Transferability of our findings was enhanced by interviewing a relatively large sample of patients from multiple European countries with diversity in several patient characteristics. However, the views expressed in this study represent those of cognitive fit, educated older people with multimorbidity enrolled in the OPERAM trial, rather than the oldest old or patients with low educational levels, impaired cognition or functional status. We did not analyse the potential link between various patient characteristics and the experiences of medication changes, which might be an interesting future research question.

We did not perform a formal process evaluation of the OPERAM trial, rather we focused on the patient experience and triangulated our qualitative results with quantitative measures on patient participation for a subsample of patients and clinicians.<sup>61</sup> The extent of participation in decision-making from the patient perspective was only evaluated qualitatively using an open-ended question in the interviews. Concordance between patients and clinicians on patient participation would likely have been higher if we would have used a patient-reported SDM questionnaire.<sup>62</sup> Selfreport SDM measures broadly indicate satisfaction with decision-making rather than the quality of the interaction and are susceptible to social desirability and response biases, which may also explain the high SDM ratings by clinicians.<sup>63</sup> <sup>64</sup> We conducted the SDM-Q-DOC for only a proportion of clinicians and cannot rule out that some of the questionnaires were completed with a delay, which may lead to recall errors. Integrating observations or interviews with the involved clinicians might have provided a deeper understanding of the patient-clinician dyad.<sup>63</sup>

Not all interviewers were blinded to the intervention or control arm allocation of the patients because of their role in the OPERAM trial, which might have influenced data collection. Credibility of our findings was enhanced by respondent validation and by integrating perspectives from different backgrounds in protocol development, data collection and analysis.

#### CONCLUSION

To meet patients' needs, medicines optimisation services should enhance information exchange, better prepare patients and clinicians for partnership in care and foster collaborative medication reviews across care settings.

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### SUPPLEMENT S1 – PARTICIPANT SELECTION: PURPOSIVE SAMPLE

For patients meeting the inclusion criteria, we aimed to ensure diversity in patient characteristics that may influence patient experience in order to enhance transferability of our findings. A purposive sample was selected by screening patients' medical records to ensure heterogeneity in terms of country, study arm, gender, age, hospital ward, education and living situation (at home/nursing home).

We estimated *a priori* that we would need to include 10-15 patients in each study site based on the following reasons: (a) we wanted to have a similar number of patients recruited from each site, as the research team considered that country and site (and implementation of intervention at each site) could influence patient's experience and (b) At each study site, we aimed to ensure diversity in the following patients characteristics in order to enhance the transferability of our findings:

- Study arm: e.g. 7-8 patients from the intervention arm and 7-8 patients from the control arm
- ▶ Gender: e.g.  $\geq$  3 men and  $\geq$  3 women per study arm
- Age: e.g. ≥2 patients >70 & ≤80 years, ≥2 patients >80 & ≤90 years and ≥2 patients
   ≥90 years per study arm
- ➤ Hospital ward : e.g. ≥ 3 patients from a surgical ward and ≥ 3 from a medical ward per study arm
- ➤ Education : e.g. ≥ 2 patients with less than high school education, ≥ 2 patients with a high school degree and ≥2 patients with a post-secondary degree (diploma from a university or equivalent institution) per study arm
- ➤ Living situation: e.g. ≥ 3 patients living in a nursing home and ≥ 3 patients living at home per study arm

The final purposive sample of 48 patients is shown in Table 1.

Study arm	Intervention arm					Control arm					
n of patients		2	27			21					
Gender	Fema	e	Male			Female				Ma	ale
n of patients	15		12			8				13	
Age	>70 & ≤80 year	s >80 & ≤	90 years		≥90 years	>70 & ≤80 ye	ears	>80 & ≤	90 years		≥90 years
n of patients	21		6 0		13		7		1		
Hospital ward	Medical	vard	Surgical ward			Medical ward		Surgical ward			
n of patients	18			9	1	18		3			
Education	Less than high school education	-	school Post-secondary gree degree		Less than hig school educat	-	-		Po	ost-secondary degree	
n of patients	3	1	6		8	4		7		10	
Living situation	Nursing ł	ome	At hom		ome	Nursing home		At home			
n of patients	2		25		1		20				
Country	Belgium	Ireland	Switzerla	Switzerland		Belgium	I	reland	Switzerla	and	The Netherlands
n of patients	8	3	8 8		8	7		4 3			7

## Tabel 1: Purposive sample (n=48)

## SUPPLEMENTS S2 – TOPIC GUIDE

## Introduction

Thank you for agreeing to participate in this interview. Like many seniors, you take multiple medications for different diseases. Some medications are prescribed by the GP, some by specialists or following a hospitalization. Sometimes during the hospitalization, the doctor or pharmacist and you, take the time to review all your medications. Together with you they check if there are medications that should be stopped, if medications are missing, if doses are suitable, if all medications work well together and if the treatment is in line with your preferences. This is called a medication review. As you know, at the moment we are undertaking the OPERAM project that compares different methods of medication review in seniors. Therefore, we are interested in your personal experience and thoughts on these medication changes and how it was discussed with you during your recent hospitalisation. As a patient, you know best how these medication review services should be designed to help you.

Our discussion will not take more than 1 hour. Everything you say here will remain strictly anonymous. If you agree, I will record the interview, to transcribe your remarks as accurately as possible. Do you agree?

You don't need to answer questions where you're uncomfortable with and you can withdraw from the interview whenever you wish. There are no right or wrong answers, we are interested in your personal opinion.

Do you have any questions before we begin? Can you confirm that you are happy for the interview to be recorded?

## <u>Icebreaker</u>

- a) What is your general opinion about the fact that the physician or the pharmacist reviews the medication during hospitalisation (stop, start, changes of medication)?
- b) May I ask you to think about your recent hospitalisation, during which some medication changes were proposed. Could you tell me which medication changes were proposed/implemented during your hospitalisation? (*if the patient does not remember, explain the changes*)

If the medication changes are unclear or seem unimplemented: ask to see the medication box or list to ensure you are aware which medications the patient is actually taking.

# Patient experience of and attitudes towards medication changes (perceived utility, barriers, facilitators)

- What do you think about the medication changes (refer to the proposed medication changes) proposed by the physician or the pharmacist?
   <u>Prompts</u>\*:
  - > How do you feel (physically) about these medications changes?
  - > How did you experience these medication changes?
    - What is good about these changes (i.e. satisfaction, advantages, as compared to the situation before hospitalisation)?
    - What is not good about these changes (i.e. fear, difficulties, discomfort, annoyance)?

## Patient experience of and perspectives on decision-making regarding medication changes (shared-decision making)

- 2. During your hospitalization, the following medication changes were proposed (remind the changes). Could you tell me how these medication changes were proposed to you?
  <u>Prompts</u><sup>\*</sup>:
  - > Who presented these changes to you? (physician, pharmacist?)
  - In which context did it happen? (time taken for discussion, location, at discharge, other people involved?)
- **3.** What kind of information did you receive about these medication changes?

- > To what extent have you understood the proposed medication changes?
- > To what extent are you satisfied or not about the information you have received?
- When we propose to start, stop or change a medicine, there are often advantages and disadvantages to consider. To what extent were these advantages and disadvantages of medication changes discussed with you/your family?
- In an ideal world, how would you have liked to be informed about the medication changes?
- **4.** When deciding to change a medication, there are 3 possible ways to proceed. It is either the doctor that decides alone, or it is the patient that takes the decision alone or it is a shared decision. How was the decision of changing your medication taken during your hospitalisation?

### Prompts\*:

- > Was there something that helped you in deciding on medication changes?
- > Was one of your family members or a carer involved in the discussion?
  - If yes: did they help you to make decisions on your treatment? How do you feel about that?
  - If no: would you have preferred someone to be present?
- > To what extent were you satisfied or not with your involvement in decision-making?
  - Would you have liked to participate more? Not participate?
  - If the patient did not participate: what kept you from being involved in the decision?
- In an ideal world, how would you have liked that the decision making on medication changes occurred?
- > How do you see your role as a patient in making decisions about your medications?
- **5.** Taking into account what is important to patients, their preferences and needs is an essential part of reviewing the medication.
  - > For you, what is important that your medications do to you?
  - People like you taking multiple medications, have shown to distinguish between 4 care goals regarding their medications: living as long as possible, reducing/eliminating symptoms and side effects (e.g. dizziness, shortness of breath,

constipation), maintaining independence (e.g. living alone, getting dressed, washing) and reducing/eliminating pain. Could you explain me which care goals you expect from your medications? (*use Outcome Prioritization Tool as visual aid and ask the patient to prioritize the 4 care goals*)

- To what extent were your preferences discussed when the medications changes were proposed?
- To what extend did you feel listened to and understood concerning your preferences for medications?
- To what extent do you think your current medications allow you to reach (*cite the care goals prioritized by the patient*)?

### **Transition and continuity**

- 6. When you are hospitalised, the hospital informs your GP about the medication changes.
  - Since your hospitalisation, did you talk about the changed medications with your GP or pharmacist?
  - > How did it go? What was his/her opinion about the proposed changes?

#### **Suggestions for improvement**

7. As a patient, you know best how these medication review services should be designed to help you. If you should help researchers to improve the medication review service for people like you, what would be your suggestions?

Prompts<sup>\*</sup>:

- > What was good about how the medication review process was delivered?
- > What needs to be improved?
- 8. Would you like to add something else to everything we have discussed here today?

#### Questionnaire: Beliefs about medicines questionnaire (BMQ)

Explain the BMQ questionnaire and let the patient complete it *(if not possible, read the questions out loud).* Invite the patient to comment out if he/she wishes while completing the questionnaire *(keep on recording the interview).* Introduce the questionnaire as follows:

 We would like to ask you questions about your personal opinion regarding medicines in general (BMQ-General) and medicines prescribed for you (BMQ-Specific).

- The following affirmations are opinions of other people about their medication.
- Please, thick to what extend you agree or not to these affirmations.
- There are no correct or wrong answer. We are interested by your personal opinion.

## SUPPLEMENTS S3 – QUALITATIVE DATA ANALYSIS

The Framework approach is a systematic approach for categorising and organising the data and involves familiarisation with the interviews, developing a thematic framework, coding, charting the data into the framework and interpreting the data.<sup>34,35</sup> Firstly, two researchers (ST and CP, combining pharmacy and nursing /public health perspectives) familiarised themselves with a sub-set of interviews by reading and re-reading the transcripts and field notes to identify themes. Themes were compared and discussed between the two researchers to develop an initial coding framework. Codes were partly pre-defined by the study objectives/interview schedule but mainly arose inductively from the data to dictate themes and categories. Subsequently, the coding framework was applied to the next set of transcripts. To minimise subjectivity, the first 15 interviews from Belgium were coded concurrently by ST and CP. Codes applied for the first 15 interviews were compared and discussed until consensus to refine the coding framework. The coding framework contained definitions for application of each code. After analysis of a first set of interviews, the initial coding framework and illustrative quotes were discussed within the research team, which helped to identify overlap between themes, themes that should be separated and to refine organisation of themes and categories into the coding framework. Next, the Swiss interviews were coded independently by ST and BM (who conducted the Swiss interviews and who has a background in psychology). Agreement on coding across all themes for a set of 3 transcripts was satisfactory, with Cohen's κ scores for of 0.83 and 0.84 between ST and CP and between ST and BM respectively. ST continued with coding independently the interviews from the Netherlands and Ireland, with regular crosschecks with the interviewers if needed. The coding framework was constantly refined during further analysis until no new codes emerged. Data saturation, defined as the point where themes and categories become repetitive between participants, was reached after analysis of the first 15 Belgian interviews.<sup>75</sup> The coding framework did not change considerably following analysis of subsequent interviews from the other sites. Throughout the coding, the researchers created analytical memo's to write down, impressions, ideas and early interpretation of the data. When all data were coded and summarised, the coding framework was reviewed to make connections within and between participants and themes. Barriers and facilitators were identified and linked to the major themes. Interpretation of the findings was supported by the use of the analytical memos, looking for deviant cases, going back to the literature, discussion

within the research team and feedback from the interviewers from all sites on the preliminary results. The qualitative results were validated by sending nine Belgian OPERAM participants a summary of the findings. Patients were asked to what extent the findings corresponded to their experience and to report any disagreement. None disagreed with the themes reported and some patients stressed themes that they considered as most important.

#### Language issues

Interviews were conducted in four different languages. Transcriptions were performed by local researchers in each site in the native language to avoid that nuances in the data were lost due to translation. The researchers analysing the data had good command of English, French, Dutch and German to reduce the chance of linguistic misinterpretation. Cross-checks with the interviewers were performed in case of uncertainty about meaning. The coding framework was developed in English. A selection of quotes (Table 3) from the Belgian, Swiss and Dutch study participants were translated from French, Swiss German and Dutch into English by a translation agency.

## SUPPLEMENT S4 – RIGOUR AND QUALITY ASSURANCE

Rigour addressed throughout the research process.<sup>1-3</sup>

	• The researchers who drafted the study protocol (ST, OD, AS) have a background
	in pharmacy and had pre-conceptions about the topic by prior literature review
	and because of their involvement in the OPERAM trial. Feedback on the study protocol was provided by a sociologist and a multidisciplinary research team
	members from the four countries involved.
	<ul> <li>Data collection was performed by researchers and/or healthcare professionals</li> </ul>
Reflexivity	
nenexity	from four different countries (ST, KM, CP, AVH, BM) who have backgrounds in pharmacy, nursing/public health, geriatric medicine and psychology respectively.
	All interviewers were trained in qualitative research methods and had no direct
	clinical relationship with the patient to limit the risk of response bias. All
	researchers performed 3 pilot interviews. Not all interviewers were blinded to the
	intervention or control arm allocation of the patients because of their role in the OPERAM trial, which might have influenced data collection.
	Several researchers from different countries and backgrounds were involved in
	data collection and analysis, helping to prevent bias from a single researcher
	excessively influencing data analysis.
	<ul> <li>Respondent validation: The results were validated by sending nine OPERAM</li> </ul>
	patients a summary of the findings. Patients were asked to what extent the
	findings corresponded to their experience and to report any disagreement. None
	disagreed with the themes reported.
	Data analysis was documented in detail (Supplements S2). The coding
	framework contained definitions and rules for application of each code to allow
Credibility	explicit and transparent data analysis.
Credibility	• Transcriptions were performed by local researchers in each site in the native
	language, to avoid losing nuances in the data by translation. To account for the
	chance of linguistic misinterpretation during data analysis, a native speaker was
	involved for analysis of the Belgian (CP), Dutch (ST) and Swiss (BM) interviews.
	Analysis of the Irish interviews was performed by a researcher with a good
	command of the English language (ST) with cross-checks with the native speaker
	who conducted the Irish interviews (KM) in case of uncertainty about meaning.
	A selection of quotes from the Belgian, Swiss and Dutch study participants were
	translated from French, Swiss German and Dutch into English by a translation
	agency.
	• Thick description of setting and participants was performed. Transferability is
Transferability	enhanced by including participants from four different countries and healthcare
······	settings as well as by including a purposive sample to ensure variation in several
	patient characteristics.

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2. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ (Clinical research ed)*. 2000;320(7226):50-2.

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## SUPPLEMENT S5 – QUANTITATIVE DATA ANALYSIS

## **Beliefs about Medicines Questionnaire (BMQ)**

The BMQ consists of the BMQ-General and BMQ-Specific, evaluating beliefs about medicines in general and beliefs about medicines prescribed for personal use respectively. The BMQ-General assesses beliefs that medicines are overused by physicians (*General-Overuse*) and beliefs that medicines are harmful (*General-Harm*). The BMQ-Specific assesses beliefs about the personal need for medicines to maintain health (*Specific-Necessity*) and concerns about the potential adverse effects of medicines (*Specific-Concerns*). Items on the BMQ subscales are scored on a 5-point Likert scale varying from 1="strongly disagree" to 5="strongly agree". Higher scores indicate stronger beliefs in the concepts of the sub-scale. Median scores for the four sub-scales were calculated. For the BMQ-Specific, the necessity-concerns differential was calculated by subtracting the concerns score from the necessity score resulting in four attitudinal groups: accepting (necessity  $\geq$ 15, concerns <15), ambivalent (necessity  $\geq$ 15, concerns  $\geq$ 15), sceptical (necessity <15, concerns  $\geq$ 15) and indifferent (necessity <15; concerns <15).

## Physician version of the 9-item shared-decision making questionnaire (SDM-Q-DOC)

The SDM-Q-DOC is a validated 9-item questionnaire assessing the level of shared-decision making as perceived by the physician during a consultation.<sup>31</sup> The SDM-Q-DOC includes 9 statements that should be scored on a 6-point Likert scale ranging from "0=completely disagree" to 5=completely agree". Scores range between 0 and 100 with 0 representing the lowest possible level of SDM and 100 the highest possible level.<sup>31</sup>

## 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	Satisfaction with information received	<u>ID-0416</u> : 'Well if they mentioned a medication, I wouldn't know what it was for and they would tell me thenor 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 themthat I knew what they'd be talking about.' <u>ID-0704</u> : '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' <u>ID-0358</u> : '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.'
COMMUNICATION ABOUT MEDICATION CHANGES	Lack of recall	<u>ID-0562</u> : '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?'
	Limited opportunities for questions	<u>ID-0978</u> : '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.'
	Use of jargon and language issues	<u>ID-0562</u> : '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.'
II. PATERNALISTIC DECISION-MAKING PREDOMINATES, VARIABLE SATISFACTION	Paternalistic decision-making	<u>ID-0438</u> : '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.' <u>ID-0416</u> : '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!' <u>ID-0511</u> : 'That wasn't discussed with me [stop amlodipine and lisinopril]. I suddenly realised, hey, I'm not being given those [medications] anymore.'
	Patient-centred decision-making	<u>ID-0528</u> : '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.' <u>ID-0992</u> : '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.'
	Discussion of patient preferences	<u>ID-0438</u> : '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.'

		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
	Satisfaction with participation in decision-making	consult me, but I do want to be informed about it.' <u>ID-0557</u> : '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.'
III. BARRIERS AND FACILITATORS TO INFORMATION AND PATIENT PARTICIPATION	Beliefs about patient role [barrier or facilitator]	<u>ID-0522</u> : 'Well, when you're in hospital and you're getting medication, you just take it. You don't ask questions like.' <u>ID-0608</u> : 'I assume the doctor knows more about it than I do, so I have to accept it.' <u>ID-0333</u> : '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.'
	Health literacy and personal resources [facilitator]	<u>ID-0333</u> : '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 <u>Patient, Switzerland</u> : 'But I was on top of the medication situation. And now too. I know what I'm taking and why.'
	Involvement of companions [facilitator]	<u>ID-0365</u> : 'So if my grandson hadn't intervened, maybe they wouldn't have given me Lyrica and wouldn't have discussed things with me more.'
	Interpersonal characteristics of the clinician [barrier or facilitator]	<u>ID-0408</u> : '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 knowOh 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.' <u>ID-0528</u> : '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.'
	Trust and clinician-patient relationship [barrier or facilitator]	<u>Interviewer</u> : 'What prevented you from being involved in the decision yourself?' <u>ID-0907</u> : 'I trusted them blindly.' <u>ID-0333</u> : '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.'
	Feeling too ill or too fatigued [barrier]	<u>ID-0583</u> : '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.'
	Overwhelmed by multiple clinicians involved in care [barrier]	<u>ID-0902</u> : '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.'
IV. Positive attitudes Towards medication	Medication review is 'a good thing' but the GP should be involved	<u>ID-0904</u> : '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.' <u>ID-0355</u> : '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.'
REVIEW AND ACCEPTANCE OF MEDICATION CHANGES	Acceptance of hospital-initiated medication changes	<u>ID-0907</u> : 'I just take what the doctors prescribe, and I do so consistently. It mightn't taste great, but I take them. [laughs]' <u>ID-0704</u> : 'I take it because it's prescribed, and that's that'. <u>ID-0557</u> : '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.'

V. BARRIERS AND FACILITATORS TO ACCEPTANCE OF MEDICATION CHANGES	Beliefs about medicines [barrier or facilitator]	<u>ID-0333</u> : '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.' <u>ID-1089</u> : '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.' <u>ID-0528</u> : 'I mean, they're using a sledgehammer to crack a nut. With a whole host of side-effects, it's just not necessary.'
	Medication changes perceived as minor [facilitator]	<u>ID-0634</u> : 'They are minor changes – that's not hard to decide. Look, they're nothing drastic, so no, it wasn't difficult.' <u>ID-0583</u> : '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'
	Experiencing benefit or harm from a medication change [barrier or facilitator]	<u>ID-0443</u> : 'I do feel in the short, the short time that I'm on them. I feel possibly that my chest is a little freer.' <u>ID-0358</u> : '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]'
	Trust and balancing advice between different healthcare professionals [barrier or facilitator]	<u>ID-1089</u> : 'But when someone says to me, "Your liver results are too high, so we have to change a medication," then I trust them.' <u>ID-0528</u> : '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.' <u>ID-0992</u> : '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.'
	Better preparation for discharge	<u>ID-0365</u> : '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?'
VI. IMPORTANCE OF COORDINATION BETWEEN SECONDARY AND PRIMARY CARE	Follow-up support	<u>ID-0891</u> : '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.' <u>ID-0358</u> : 'That's the problem: when they change something, they do it at the hospital and there's no follow-up outside.'
	Poor communication between primary and secondary care	<u>Id 0511</u> : '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 becauseand 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.'