

## ***'They must help if the doctor gives them to you': A qualitative study of the older person's lived experience of medication-related problems***

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### **Abstract**

#### **Objective**

Medication related problems (MRP) are common for older adults and can lead to harm. The older person's perspective on MRP has been seldom reported in published literature. This study explored the lived experience of MRP in older adults with varying functional levels, focussing on the hospital discharge period.

#### **Design, setting, participants**

This qualitative study was conducted in Brighton and Hove, UK. A purposive sample of 20 older people with experience of MRP, involving carers, took part in focus groups and semi-structured interviews. Data were thematically analysed using a 'framework' approach.

#### **Results**

Four major themes associated with MRP were identified; (1) experience of the healthcare system, (2) practicalities of using medicines, (3) management of medication problems, and, (4) participant beliefs. Participants encountered problems in communication with healthcare professionals such as passive listening and paternalistic consultations. A conflict was acknowledged between participants' implicit trust in the healthcare system and their negative experience of MRP. Participants felt vulnerable around hospital discharge, describing reduced capacity to comprehend information, pressured discharge circumstances, and lack of integrated care in the community. Drug formulations, packaging and information leaflets were felt to be poorly tailored to the needs of older people.

#### **Conclusions**

The lived experience of older people with MRP in this study was multifaceted and complex. Participants felt communication was poor around hospital discharge, and insufficient support with medicines was offered in the community when problems arose. Harm due to MRP might be reduced if the contributory factors described by patients inform clinical and policy-level intervention.

## **Introduction**

Polypharmacy and medication-related harm are increasing in England. [1,2] The period following hospital discharge is a time when older people are at highest risk; one in three experience medication-related harm within eight weeks post-discharge.[3]

Although medication-related problems (MRP) are an important cause of harm, there has been little research to understand its impact from the older person's view point. The patient perspective is crucial in effectively translating clinical research to 'real-world' settings [4,5]. For instance, in the Canadian EMPOWER trial of patient education to support withdrawal of benzodiazepines in older users[6], the patient perspective was pivotal to understand the patient-provider context necessary for successful deprescribing [7].

The aim of this study was to explore the lived experience of MRP amongst older adults in a UK community setting. Given the increased risk of MRP following hospital discharge, we designed the study to elicit participant views around this critical time.

## **Methods**

Full methods are described in appendix 1 online. Three focus groups and eight semi-structured interviews were conducted using topic guides with a purposive sample including both independent and housebound older adults in Brighton and Hove, UK. Participants were recruited through Age-UK Brighton and Hove (AUKBH). Data collection took place between October 2016 and January 2017 until data saturation (defined as no new themes being elicited).[8] Data were analysed thematically using a Framework approach, developed by the National Centre for Social Research, particularly suited to multidisciplinary research teams. [9,10] This approach involves five processes: data familiarisation, coding, indexing, charting, and interpretation.

## **Results**

### **Participants**

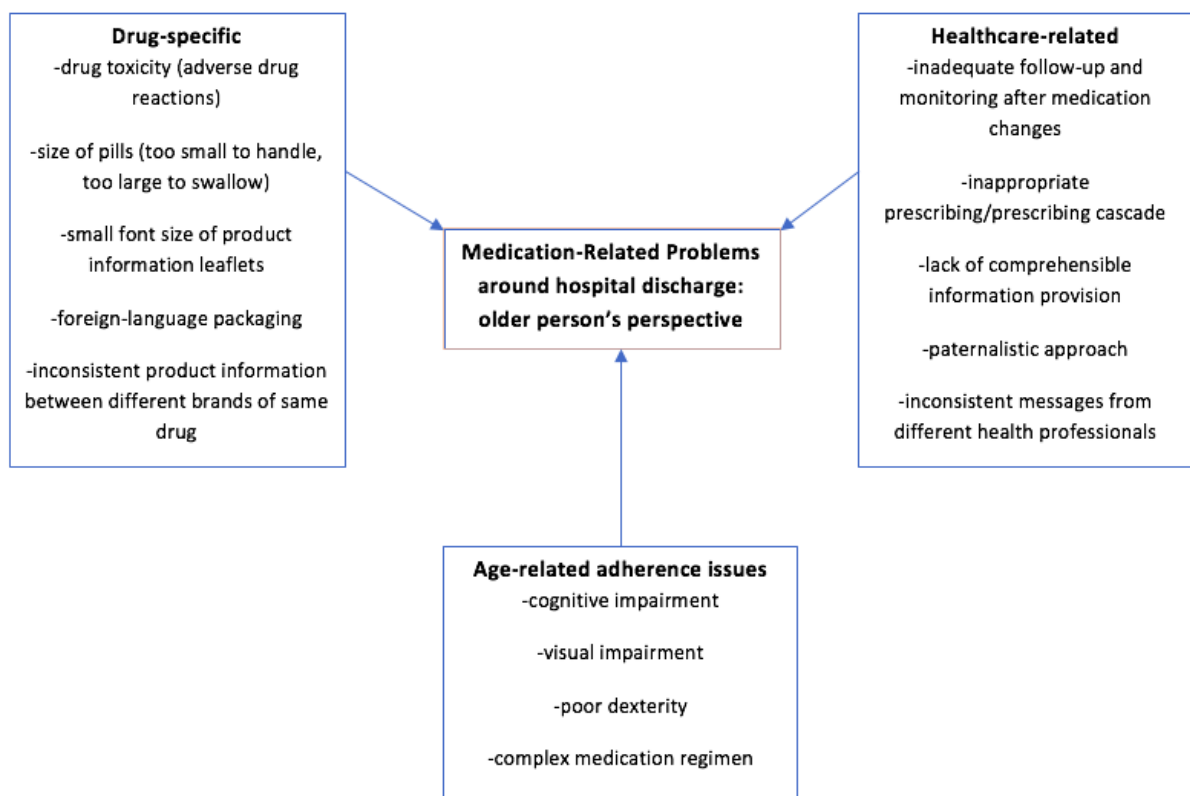
Twenty participants were included (see appendix 2 online), 14 females, median age 78 years (range 65 to 98 years), all Caucasian. Twelve independent older adults, recruited from AUKBH activity groups, participated in three focus groups. The remaining eight participants (six housebound individuals and two informal carers) were recruited from a support service offered by AUKBH for recently discharged patients and interviewed at home.

The mean number of prescribed medicines amongst all participants was 5 (SD  $\pm$ 3.6, range 0-12). However the mean was 8 medicines amongst housebound individuals. Nine participants had a hospital admission in the past year.

## Key findings

Participants' experience of MRP around hospital discharge is summarised in Figure 1. The range of 'side-effects' described can be seen in appendix 3 online.

**Figure 1. Experiences of MRP amongst participants**



Four major themes associated with MRP were identified: experience of the healthcare system, practicalities of using medicines, management of medication problems, and participant beliefs (see Table 2).

### Experience of the healthcare system

Participants reported poor communication with health professionals and between professionals. In some cases, participants described passive listening and failure of doctors to respond when harm was reported. Discussion about MRP with General Practitioners (GP) often took place over the telephone due to lack of face-to-face appointments, limiting the quality of communication and capacity of GPs to fully address the

problem. None of the participants felt involved in medication-related decisions. In response to adverse events, some participants reported changes in their own behaviour (e.g. asking a standard set of questions about any new medicine), to ensure they understand the rationale for medication-related decisions.

The transition from hospital to home was considered a particularly vulnerable time due to ongoing recovery from illness, a reduced capacity to retain information provided at the point of discharge, and a lack of community follow-up. Changes made to regular medicines whilst in hospital contributed to participants' confusion and poor adherence when back in their own homes. Pharmacists were mentioned as a valuable support in the community, offering more time compared to GPs about medication-related concerns, and, identifying prescribing errors.

### **Practicalities of using medicines**

Many participants experienced difficulties with medicine formulation, packaging and/or instructions. They felt that medicines themselves were not tailored to meet the needs of an older person, with tablets such as aspirin being too small to handle and other medicines such as calcium/vitamin D combinations being too large to swallow. These problems were especially noted in the context of visual impairment or manual dexterity. One participant made the analogy between such difficulties in older people and that seen in children, '*...imagine giving a big pill like that to a kid*'.

Medication compliance aids (MCA) e.g. blister packs, were broadly felt to be helpful despite difficulties removing tablets which sometimes necessitated use of sharp instruments to cut into each pocket. A major concern was the inconsistency in the colour and shape of medicines placed in the MCAs from one week to another. Other challenges included packaging in foreign languages and discrepancies in the listed drug interactions for the same drug by different manufacturers.

### **Management of medication problems**

Whilst some participants sought medical attention for MRP, many chose not to due to perceived lack of time of the GP, or, fear of being a '*nuisance*'. Self-management of MRP was attempted using medical books, the online British National Formulary, newspapers articles, and the advice of friends or family. 'Trial and error' adjustment of medicines to overcome adverse effects, without consulting prescribers, was a common approach. One lady expressed the need to suffer side-effects as her '*body had to get used to it*'.

### **Participant beliefs**

A prominent sub-theme was the older person's misinformed risk to benefit calculations, with several participants describing a poorer quality of life due to MRP as a necessary trade-off for additional life years.

There was a tension between the participants' expectations of medical treatment, based on implicit trust in their doctors, and their adverse lived experiences. One participant said '*they must help if the doctor gives*

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them to you...but they're not, not in my body'.

**Table 2. Illustrative data extracts by thematic categories and key sub-themes**

<b>Categories</b>	<b>Sub-themes</b>	<b>Illustrative extracts</b>
<b>Experience of the healthcare system</b>	Poor communication	<p><i>'I kept telling her (General Practitioner) I was getting more and more suicidal, I told her, and then all she said was "oh well, you've had these depressive states before", which was nothing at all to do with these tablets (steroids), this was something different' [P20, female, 84]</i></p> <p><i>'When you're in hospital and you get prescribed these pills they don't ever tell you what they are and what they're for... they discuss things themselves and the patient is not involved, which is wrong...it's like a secret society' [P17, male, 75]</i></p>
	Inappropriate prescribing	<p><i>'They'll go back to the doctor and maybe see someone different and then say "oh I've got this wrong with me" and they might be given another drug but it's not looked at that it might be the first drug that's causing that problem.'</i> [P4, female, 69]</p>
	Hospital discharge support	<p><i>'I come out and they give me a pile of medicine to take which I didn't know what to do with and I had to get somebody, don't know what it was, come around and sort out medicine for me... that was that, and that's for afternoon and two of them, you know, 'cos I didn't know' [P14, male, 82]</i></p> <p><i>'The pharmacist came around and talked to her about it and explained it and everything, she was going to change one of the medicines, so she had a good story before she came out of hospital' [P10, male, 74]</i></p>
<b>Practicalities of using medicines</b>	Formulation, Packaging and instructions	<p><i>'Sometimes the colour changes or the shape, and that does concern me because you know, I think have they made a mistake. It's written on the side but it's very difficult to work out, especially when your eyes are getting bad' [P9, female, 85]</i></p> <p><i>'Some pills they are huge...imagine giving a big pill like that to a kid' [P17, male, 75]</i></p>
<b>Management of medication problems</b>	Information and Support	<p><i>'I suppose you could go to your doctor if you were worried to ask a few questions, but we're the sort of people that, you know, 'oh I'm afraid to go to the doctor', you know, he's too busy to mess about just answering silly questions like that' [P19, female, 86]</i></p> <p><i>'Got books here, ones on drugs. And the other one, the other one, medical dictionary' [P17, male, 75]</i></p>
	Non-Adherence	<p><i>'They said three a day but see they give me constipation, I know that much, they give me constipation, I take one at maximum a day' [P14,</i></p>

		male, 82]
<b>Participant beliefs</b>	Risk:Benefit analysis	<p><i>'I suffered for a little while and then I made an appointment...I was just thinking that my body had to get used to it.'</i> [P9, female, 85]</p> <p><i>'I'm now awake at night, it's not life and death but it would be nice not to wake up itching all the time... I know I've got to take the tablets, because I'd like to be around for a little bit longer'</i> [P7, female, 72]</p>
	Conflict between expectation and experience	<p><i>'Well you trust your doctor don't you, I mean, you think they're right and you take them but there was no way I felt depressed when I went to the doctors, I was in pain, my back was killing me'</i> [P13, female, 79]</p> <p><i>'They're telling you you know nothing, whereas you're living it (medication problems) and you do know'</i> [P1, female, 79]</p>

## Discussion

To our knowledge, this is the first community-based study in England to explore the lived experience of older people with MRP. This study highlights key challenges associated with MRP that concern patients; poor communication with prescribers, vulnerability during the transition of care at hospital discharge, inconsistency in medicines information and packaging, side-effects, and, difficulties obtaining medical advice. We acknowledge that our findings were based on the views of a Caucasian cohort in one UK city.

Many of the practical problems with medication use highlighted in our study are common to older people in other European countries.[11] The dispensing of medicines packaged in part English and part foreign text, and, inconsistent drug safety information between manufacturers are new insights. 'Parallel imports', where medicines are imported from countries outside of the UK and then sold and dispensed in the UK under a license from the Medicines and Healthcare products Regulatory Agency (MHRA), are used by pharmacies to reduce their purchase costs. [12] Our findings suggest that this is confusing and anxiety-provoking for some older people, and the MHRA should consider how to tighten regulations around re-labelling to increase clarity for consumers. Furthermore, product safety information should be standardised between manufacturers of the same drug.

Participants reflected that doctors did not actively listen to their concerns of MRP, which directly led to harm in some instances. A Dutch study of hospitalised patients found that approximately 80% of patient reports of 'side-effects' are accurate. [13] Thus a passive approach towards patient concerns of MRP is not clinically justifiable. The impact of

medication harm extends beyond the physical discomfort; older people in this study described erosion of their trust in the healthcare system and heightened anxiety about future medicines use. The time taken in the short-term to elicit patient concerns and proactively respond to these could save substantially on time and cost required in the longer term to address poor adherence and medication harm.

The patient-prescriber relationship is a key determinant of safe and effective medicines use[14]. Concordance is a patient-centred approach to consultation which gives primacy to the patient perspective within negotiated medication-related decisions[15]. This approach re-orientates communication from paternalistic consultation, as experienced by our participants, to collaboration and consensus-built decisions which can better meet both the patient and provider's expectations of treatment [15,16].

Adequate information provision is crucial to shared decision making [17] and informed consent to treatment. Doctors struggle with the balance required in providing sufficient information of potential medication risk and causing undue fear. [18–20] Older people in this study sought clear and contextualised information at their level of comprehension of the medicine indication, and an open discussion of the potential risks and benefits for them as individuals. Our findings can generate a wider impact by supporting the case for enhanced medication counselling during pharmacist-led medication reviews at hospital discharge[21]. This would align with related national guidance[14,22], and might lead to reduction in MRP.

## Conclusions

Older people describe a heightened vulnerability to MRP around hospital discharge, and identify inadequate communication, uncoordinated processes, inappropriate prescribing, and poor drug formulation and packaging as important issues to address.

### Key Points

- Comprehension of medicines-related information at hospital discharge is limited amongst older adults
- Medication-related problems can erode the trust of patients in their doctors and the healthcare system
- Non-adherence is used by some older adults as a protective measure to ameliorate medication-related harm
- Medicines formulation and information should be better tailored to the needs of older

**Contributors:** NP and KA conceived of the initial idea. All authors designed the study with support from a PPI group. NP conducted interviews and focus group meetings. All authors contributed to coding transcripts and interpreting data within themes. NP drafted the article, and all authors revised the draft critically for important intellectual content, and approved the final version.

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**Conflicts of Interest:** None

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## References

- [1] Veeren JC, Weiss M. Trends in emergency hospital admissions in England due to adverse drug reactions: 2008-2015. *J Pharm Heal Serv Res* 2017;8:5–11.
- [2] Gao L, Maidment I, Matthews FE, Robinson L, Brayne C. Medication usage change in older people (65+) in England over 20 years: Findings from CFAS I and CFAS II. *Age Ageing* 2018;47:220–5.
- [3] Parekh N, Ali K, Stevenson J, Davies JG, Schiff R, Cammen T Van Der, et al. Incidence and cost of medication harm in older adults following hospital discharge: A multicentre prospective study in the UK. *Br J Clin Pharmacol* 2018;(in press).
- [4] Greenhalgh T, Snow R, Ryan S, Rees S, Salisbury H, Osborne R. Six ‘biases’ against patients and carers in evidence-based medicine. *BMC Med* 2015;13:200. doi:10.1186/s12916-015-0437-x.
- [5] Pearce W, Raman S, Turner A. Randomised trials in context: practical problems and social aspects of evidence-based medicine and policy. *Trials* 2015;16:394.
- [6] Tannenbaum C, Martin P, Tamblyn R, Benedetti A, Ahmed S. Reduction of Inappropriate Benzodiazepine Prescriptions Among Older Adults Through Direct Patient Education. *JAMA Intern Med* 2014;174:890.



- [7] Martin P, Tannenbaum C. A realist evaluation of patients' decisions to deprescribe in the EMPOWER trial. *BMJ Open* 2017;7:e015959. doi:10.1136/bmjopen-2017-015959.
- [8] Green J, Thorogood N. *Qualitative methods for health research*. Third ed. London: SAGE Publications Ltd; 2014.
- [9] Ritchie J, Lewis J, Nicholls CM, Ormston R. *Qualitative Research Practice*. Second ed. SAGE Publications; 2014.
- [10] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117. doi:10.1186/1471-2288-13-117.
- [11] Notenboom K, Beers E, van Diana A, Egberts CG, Leufkens GM, Jansen AF, et al. Practical problems with medication use that older people experience: a qualitative study. *J Am Geriatr Soc* 2014;62:2339.
- [12] Gallagher C, O'Neill Richard. Negotiating the parallel imports rules. *Pharm J* 2008. <https://www.pharmaceutical-journal.com/opinion/comment/negotiating-the-parallel-imports-rules/10026643.article> (accessed May 21, 2018).
- [13] Mannesse CK, Derkx FH, de Ridder MA, Man in 't Veld AJ, van der Cammen TJ. Do older hospital patients recognize adverse drug reactions? *Age Ageing* 2000;29:79–81.
- [14] National Institute for Health and Care Excellence. *Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence (CG76)*. NICE; 2009.
- [15] Pollock K. *Concordance in Medical Consultations: a critical review*. Oxford: Radcliffe Publishing Ltd; 2005.
- [16] Horne R, Weinman J, Barber N, Elliott R, Morgan M. *Concordance, adherence and compliance in medicine taking*. 2005.
- [17] Politi MC, Dizon DS, Frosch DL, Kuzemchak MD, Stiggelbout AM. Importance of clarifying patients' desired role in shared decision making to match their level of engagement with their preferences. *BMJ* 2013;347.
- [18] Faasse K, Petrie KJ. The nocebo effect: patient expectations and medication side effects. *Postgrad Med J* 2013;89:540–6.
- [19] Barsky AJ. Nonspecific Medication Side Effects and the Nocebo Phenomenon. *JAMA* 2002;287:622.
- [20] Tan K, Petrie KJ, Faasse K, Bolland MJ, Grey A. Unhelpful information about adverse drug reactions. *BMJ* 2014;349.
- [21] Ensing HT, Stuijt CCM, van den Bemt BJJ, van Dooren AA, Karapinar-Çarkit F, Koster ES, et al. Identifying the Optimal Role for Pharmacists in Care Transitions: A Systematic Review. *J Manag Care Spec Pharm* 2015;21:614–36.
- [22] Public Health England. *Improving Health Literacy to Reduce Health Inequalities*. 2015.

<https://www.gov.uk/government/publications/local-action-on-health-inequalities-improving-health-literacy> (accessed May 21, 2018)

## **Appendix 1. Methods**

This study was approved by the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC reference 16/041/ALI).

This qualitative research using focus groups and semi-structured interviews was undertaken with older adults in the city of Brighton and Hove, UK. This study is reported in accordance with the standards published by O'Brien et al (2014), and patient and public involvement informed its design (see below).[8]

We intentionally did not stipulate a definition of MRP to ensure that we explored MRP from the participant perspective.

### **Patient and public involvement (PPI)**

Five older adults (one male, four females; all aged greater than 65 years) with previous experience of participatory research acted as advisors and supported the conceptualisation and design of this study, and provided input to the protocol, consent forms, participant information sheets and topic guides. We held a round-table meeting in June 2016, and then continued correspondence with the PPI group through telephone meetings, email and letters. The relevance of the study for patient benefit was explored and confirmed, and changes were made to the wording and length of the participant information sheet to improve readability and comprehension.

### **Participants**

A purposive sample of ambulatory older adults, and dependent, housebound older adults were invited to participate in this study. Participants were recruited via a community organisation (Age UK Brighton & Hove) that runs activity groups, and, a 'crisis' service that gives social assistance and supports access to clinical help for older people following hospital discharge. The study was advertised by the organisation's activity group leader using posters (see example poster below), whilst participants recruited through the crisis service were invited to participate by the service manager. Participants were included if they met the following eligibility criteria; (1) age  $\geq 65$  years, (2) has personal experience of taking regular medicines or caring for someone taking regular medicines, (3) has personal experience of MRP or caring for someone that has experienced MRP, (4) has personal experience of hospital discharge or caring for someone that has experienced hospital discharge, (5) does not have severe cognitive impairment as assessed by the service

managers. Participants self-defined themselves as having experienced MRP as the research team intentionally did not specify an MRP definition (see participant information sheet below). Written informed consent was taken from each participant.

### **Data collection**

Three focus groups and eight semi-structured home interviews were conducted by the lead author using a topic guide (see topic guides below), lasting approximately 90 and 45 minutes respectively. The focus groups and interviews were audio recorded and transcribed verbatim. Data collection took place between October 2016 and January 2017 until data saturation (defined as no new themes being elicited) was achieved.[9]

### **Framework thematic analysis**

A 'framework' approach to thematic data analysis was chosen due to its highly prescriptive methodology, which is particularly suited to multidisciplinary research teams such as ours.[10,11] The framework approach, developed in the 1980s by the UK National Centre for Social Research, involves five key processes for data analysis; familiarisation, coding, indexing, charting, and interpretation.[10,11] Codes in this study were selected through a mixed deductive and inductive approach.[10] The deductive codes were pre-selected with reference to the interview topic guides used and further themes were generated inductively through an open coding process. Initial codes were suggested by all study authors based on individual familiarisation with two participant transcripts. These were then discussed and consensus was reached on the codes to be adopted. The remaining transcripts were coded based on this consensus, with new codes emerging inductively during the process of indexing the transcripts. New codes were discussed and their relevance explored between the researchers to decide on adopting them.

Codes were categorised into four meta-constructs of themes in relation to MRP, (1) experience of the healthcare system, (2) practicalities of using medicines, (3) managing MRP (4) participant beliefs. Themes were then extracted from interrogating the data within the context of these categories and codes, after charting the data by participants and codes in a spreadsheet. This matrix was then analysed by comparison within and between cases under columns of codes, in conjunction with brief field notes made immediately post-interviews, to extract meaning and data interpretation.

## Appendix 2. Table of sample characteristics

Participant number*	Gender	Age	Ethnicity	Last hospital admission	Regular medicines (n)
P1	Female	79	White British	> 12 months ago	3
P2	Female	68	White British	> 12 months ago	0
P3	Female	76	White British	> 12 months ago	1
P4	Female	69	White British	> 12 months ago	0
P5	Female	65	White British	N/A	N/A
P6	Female	72	White British	last 5-8 months	3
P7	Female	72	White British	> 12 months ago	3
P8	Female	74	White British	unknown	7
P9	Female	85	White British	last 9-12 months	6
P10	Male	74	White British	in last month	5
P11	Male	74	White British	last 9-12 months	2
P12	Female	75	White British	> 12 months ago	3
P13	Female	79	White Irish	in last month	11
P14	Male	82	White British	in last month	3
P15	Female	79	White British	> 12 months ago	8
P16	Male	85	White British	in last month	9
P17	Male	75	White British	> 12 months ago	7
P18	Male	98	White British	last 9-12 months	4
P19	Female	86	White British	N/A	N/A
P20	Female	84	White British	last 1-4 months	12

\*P1 to P12 participated in focus groups. P13 to P20 were interviewed in their homes; P5 and P19 were interviewed as informal carers of older people with medication-related problems; P15 was interviewed in a dual role as an informal carer and individual that met eligibility for participation.

**Appendix 3. Selected examples of medication ‘side-effects’ in the words of participants**

<b>Medicine</b>	<b>Participants experiences</b>
<b>Alzheimer’s tablet</b>	<i>‘rather loose to the toilet’</i>
<b>Beta-blocker</b>	<i>‘they paralysed me. I couldn’t move my arms more than that in about two weeks’</i>
<b>Citalopram</b>	<i>‘made my head fuzzy’ ‘I hear myself talking’</i>
<b>Codeine</b>	<i>‘upsets my stomach’</i>
<b>Gabapentin</b>	<i>‘they give me constipation’</i>
<b>Prednisolone</b>	<i>‘they made me very, very depressed’</i>
<b>Statin</b>	<i>‘pain in my thigh and numbness of the digits’ ‘pains in my calves and leg muscles’</i>
<b>Tegretol</b>	<i>‘tiredness and the awful slothfulness’</i>