Family carers' experiences of managing older relative's medications: insights from the MEMORABLE study.

Author Names and Affiliations:

1. Sally Lawson, School of Life and Health Sciences, Aston University, Birmingham, B4 7ET, UK (s.lawson2@aston.ac.uk)
2. Judy Mullan, School of Medicine, University of Wollongong, Wollongong NSW, Australia 2522 (jmullan@uow.edu.au)
3. Geoff Wong, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, OX2 6GG, UK (geoffrey.wong@phc.ox.ac.uk)
4. Hadar Zaman, School of Pharmacy and Medical Sciences, Faculty of Life Sciences, University of Bradford, Richmond Road, Bradford, BD7 1DP, UK (H.Zaman4@bradford.ac.uk)
5. Andrew Booth, School of Health and Related Research (ScHARR), University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, UK (a.booth@sheffield.ac.uk)
6. Anne Watson, Clinical Pharmacist/Pharmacist Independent Prescriber, Bournville & Northfield PCN, Our Health Partnership, UK (annepwatson38@hotmail.com)
7. Ian Maidment, School of Life and Health Sciences, Aston University, Birmingham, B4 7ET, UK (i.maidment@aston.ac.uk)

Corresponding Author

Associate Professor Judy Mullan
School of Medicine
University of Wollongong
Wollongong, New South Wales, 2522
Australia
Email: jmullan@uow.edu.au
Mobile Telephone: +61 2 412175029
Office Telephone: + 61 2 42215980

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insights from the MEMORABLE study.

Highlights

- Family carers often play key medication management roles for their older relatives
- Recognition in policy and practice is required for these medication management roles
- Better information, training and support is needed to mitigate family carer burden

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1. Introduction

The number and proportion of older people in the United Kingdom (UK) population is increasing.[1–4] Many live with multi-morbidity and polypharmacy.[5–8] Medication management and the experiences of older people and practitioners have been addressed in research, policy and practice.[9–12] However, the experiences of family or informal carers are less well understood.[13]

This study re-analyses a family carer subset from the UK medication management study funded by the National Institute for Health Research (NIHR): MEdication Management in Older people: Realist Approaches Based on Literature and Evaluation (MEMORABLE).[14,15,16] MEMORABLE aimed to understand medication management from the perspective of older people living with co-morbidities treated with complex medication regimens, as well as family carers and health and care practitioners. Two aspects of MEMORABLE inform this study.

First, MEMORABLE described a five-stage medication management process, which included formal, time-limited interpersonal contacts with practitioners, where medications were prescribed or reviewed. As part of this process, people and practitioners made individual and shared decisions and acted to control and routinise medication work and get the best fit with their lives.

Second, using a realist approach[17–21], MEMORABLE synthesised data from the literature and narrative accounts, generating theory-informed evidence to explain how and why this medication management process worked for those involved, or not. Burden[22–25] emerged as a key concept with robust explanatory value. The researchers identified five burdens on which practice improvements were proposed. The realist approach, medication management process and burdens have been applied here.

Within MEMORABLE, a realist evaluation[26] generated rich data for three participant groups: older people, family carers and practitioners. Beyond the scope of the original study, the subset of family carer data pointed to unique experiences and complex dynamics that warranted further analysis. This paper reports findings from a supplementary evaluation of family carer data.

2. Background

There are approximately 6.5 million family carers providing unpaid support to relatives living with deteriorating physical or mental health, or with care needs arising from ageing or frailty.[27–31] Family carer numbers are increasing, along with their 'informal' responsibilities for older relatives.[28,30,32,33] Most family carers are women (58%), from White ethnic groups (94%), and aged between 50 and 64 years (20%).[30] However, the proportion of family carers aged 65 plus has grown rapidly (currently 20%).[30]

The value of UK family carers' contribution is estimated between £57-100 billion annually, greater than the costs of formal care provided by local government and the National Health Service (NHS).[27,34] Most family carers provide between 1 and 19 hours of care each week, with the greatest growth in those providing more than 50 hours; currently, 25% of all carers.[27,18] This exceeds the 48 hour Working Time Directive limit for paid staff.[35] However, lacking visibility,[36] the numbers, hours and contribution of family carers may be underestimated, along with the way 'caring' impacts on them.[33,37]

Family carers often fulfil a key role in managing their relatives' medicines[27,38–41], such as setting them up or giving them, adding to their workload inside the home. Outside the home, they may be ordering and collecting medicines and attending appointments with practitioners. Workload fluctuates but generally increases over time with their relative's advancing age and deteriorating health, independence or safety.

Local authorities in the UK have a statutory duty to identify family carers, who have a right to have their support needs assessed.[42,43] However in 2015-16, a third of carers in contact with their local authority did not receive any such assessment.[27,44] The majority of family carers (66%) believe that they lack access to information and support from healthcare practitioners, often relying on third sector organisations to offset this deficit.[28]

Some carers benefit from a sense of psychological well-being in their caring role, while others experience adverse impacts on employment, finances, health and relationships.[45] They may also experience 'burden' when there is an imbalance between their workload and capacity.[15,46,47]

The aim of this paper is to extend the understanding of burdens on family carers experience as key contributors to the care of the growing number of older people living with co-morbidities, when managing complex medication regimens across any or all stages of the process, and from this, to propose practice/policy and health outcome improvements.

3. Methods

This subset analysis uses the same realist approaches[17–21] as MEMORABLE. The analysis draws on the original realist review[18,20,48] of secondary data combined with a further realist evaluation[19,20,26] of family carer interviews to explain their experiences in greater depth. This study falls within the MEMORABLE ethics approval given by Aston University (sponsor) and following proportionate review by the regional Research Ethics Committee and the Health Research Authority (REC reference 17/EE/3057, 26th September 2017).

The family carer subset (n=16) was recruited in MEMORABLE through research recruitment sites, by identifying individuals known to the Research Team because of work or professional activities and by publicising the study on national television. Family carers who were considering getting involved were sent a Participant Information Sheet and Consent Form and offered a phone call with the Research Associate to discuss the study or any concerns before being recruited.

Family carers were interviewed face-to-face by the Research Associate, lasting about an hour and audio-taped. Recordings were then anonymised and transcribed for analysis. The realist-informed interview schedule had two parts. First, there were process questions to elicit a description of family carer involvement in medication management including its scope, evolution and challenges. Second, there were realist-informed questions[49] to generate an explanation of how this process worked for them or not. These enabled the family carer to identify what they intended or did not intend to get from the process or parts of it (outcomes) and how these outcomes came about (context-mechanisms). The Research Associate's prior realist interviewing experience enabled the interviewee to explore in increasing depth what mattered to them and why, based on what they did. Thus, new aspects and ways of explaining the medication management experiences of family carers were derived directly from participants.

Subset analysis was undertaken by the Research Associate who had originally undertaken the MEMORABLE analysis. The Research Associate listened to the recordings and focused on explanatory content, identifying intended and unintended outcomes, particularly burden related, and their associated context-mechanisms. These patterns of explanatory factors were attributed to individual, interpersonal, institutional and /or infrastructural levels. This structuring of complexity enabled consistent or significant patterns to be highlighted. The results were then compared with those of the broader MEMORABLE analysis in order to confirm or refine the MEMORABLE burdens, as well as identify any new burdens specific to the subset. Members of the Research Team reviewed the results. Finally, new burdens were drafted in the same format as MEMORABLE.

4. Results

Five males and 11 females were interviewed (n=16). Four interviewees identified with Minority Ethnic communities, two male and two female. The majority of carers were living permanently with the older person they supported, while some were staying temporarily following a 'crisis'. Six cared for a spouse, while the others cared for older relatives who were not spouses**.** Seven cared for a family member living with memory problems or diagnosed with dementia. Two cared for more than one person living with dementia. Quotations are in italics, identified by ‘C’ and their MEMORABLE participant number.

4.1 Describing family carers’ involvement in managing medications: actions and issues

4.1.1 What family carers said they were doing across medication management stages: see Figure 1. Some family carers organised prescriptions, mainly on-line, and collected or arranged for medications to be delivered (Stage 2): *“…system came in and (she) doesn’t do computers...I can order…online and so I will…”* (C43). Older people were then able to follow their own medication routines independently. Some attended appointments and reviews with informal or formal consent from their relative, irrespective of formal ‘capacity’ issues (Stages 2 and 5).[50]

However, many family carers did more than this. Some put out every dose and checked they had been taken (Stage 4): *“I’ve got little ramekin pots and I just put all the tablets in there”* (C32). Others took on specialised, high risk tasks: one providing liquid-form medicines via Per Enteric Gastrostomy (PEG) (Stage 3 and 4): *“PEG feeding…(supplier) came down and went through the training”* (C35); another injecting high dose antibiotics into a central line (Stages 3 and 4): *“We’d been to the hospital that afternoon. He had got a line in…I’d suggested was there any way I can help…they said 'Oh yes.”* (C32).

4.1.2 Underlying medication management issues and concerns for family carers:

- **transitioning into a medication management role:** some family carers took this on gradually: *“Tablets lying around loose in the kitchen…in the last four years I've had to really struggle with him to get to where, basically, I'm in charge”* (C9). However, transition for others was sudden: *“The third (heart attack) he had two days after his second…because he didn’t take his medication. And that’s when I intervened*” (C15). The role change from family member to family carer was not always welcomed: *"He's not happy with that (I control medication)…go to the doctors with him for all his appointments…It's a loss of independence…(but) he can't remember what's been said (dementia)"* (C14);

- **role uncertainty:** role boundaries were described as unclear: "*You can't help but feel responsible…I don't know whether it is my job…People assume that you are going to do things*" (C20). But the perceived 'informality' of the family carer role created barriers to engagement with practitioners: "*The GP knows that they can give me information about my dad…only recently…make it clear…I would need to get a letter from my dad*" (C15);
- **learning by experience:** many family carers described learning day by day, often with limited information and lacking training or support, causing stress: *"Frustration of (family) carer that has learnt an awful lot…and had to do a lot"* (C32);
- **information seeking:** some family carers searched for information: *"I go to different websites…(not)…just…one"* (C15);
- **physical and cognitive workload:** managing complex regimens involved significant effort: *"The (blister packs) are just automatic, they're done every week for us…inhalers and different things that don't fit in the (packs), I have to order and then collect...wash emollient...cream, eye drops...Gaviscon…continence stuff"* (C32), including additional work for certain types of medicines: *"A specialist drug I can only get in one place (hospital some distance away)"* (C14);
- **coping through routines:** family carers described the ways they reinforced their relative's day-to-day routine: *"Easier for me to just take what he needed out of the box, put it in a little dish…by his cereal bowl" (C12).* Some also kept records and shared information about practitioner contacts: *"I'll take my dad to his appointment…I'll make the notes…I've got a WhatsApp group with my (three) sisters if I need to tell them anything…if we needed to tell anybody, that would be the most up to date list (of medication)*" (C15);

- **stress from responsibility:** family carer stress was compounded by the lag in gaining experience and expertise, and potential risks they envisaged: *"It frightens me...these side effects...I don't want to misunderstand the information…I wouldn't want to put my dad in a dangerous position"* (C15). Some carers felt the responsibility of co-ordinating practitioners and systems, following up unresolved issues: *"I have to chase up an awful lot of stuff…there's nobody over-seeing it and drawing it together apart from me"* (C32);
- **what they give up or lose**: family carers relinquished aspects of their own lives: *"I was staying at mum and dad's for about three (or four) nights a week…then going back (home 50 miles away) "* (C9). They also endured losses, such as their identity as spouse, or physical and emotional space for themselves *"Not being able to go out and see your friends…I can't make phone calls to my friends because he listens in…I'm caring so much and I'm losing my temper and we're arguing…but he's slipping away (dementia)"* (C14);
- **support and recognition:** many family carers said they would value more support for themselves: *"I want to feel that other people are on board with me…That's very important to me...absolutely key that I'm not on my own."* (C11). They also wanted their role to be recognised: *"any carer…should get that (respect from health and care practitioners)…you learn so much. You take so much on…there is a massive responsibility managing other people's medications"* (C11);
- **contrast with formal carers' training and support:** family carers rely on limited information for managing complex regimens: *"I had to try and understand what he was taking and when to take it…Because you've got a box (and Patient Information Sheet). It's frustrating having to go through each one"* (C15). However, formal carers work within service and employment contracts that restrict medication management tasks, often less complex or risky than family carers do. Encouraging or reminding older people to take their tablets is often perceived as the safest form of practice for front-line staff, a pervasive risk-averse culture within performance-driven systems. They also receive dedicated training and follow-on support to develop and sustain their

competence and confidence: *"Full day's training that is taught…face-to-face (then)…medication observation…all staff get that at least once a year, if not twice…and…go on a 12-month refresher."* (P38 – community service manager).

4.1.3 Process and issues summary: family carers were found to have an increasing and key, trusted role in managing complex regimens, amid assumptions about their coping ability. They were pivotal in individualising health and care delivery for their relative, with significant phyical and cognitive challenges. This included establishing, following and adjusting medication-related routines and tasks (Stages 3 and 4), and particularly recognising and resolving problems at multiple levels (Stage 1), encountering numerous disruption loops and making decisions, often in isolation.

Role-stress appeared to stem from issues such as a lack or lag in knowledge, information, training or support. Whilst experiencing varying levels of uncertainty and ambivalence about their 'informal' role, family carers valued recognition for the responsibility and complexity of what they did, as well as the expertise they developed over time.

4.2 Explaining family carers' involvement in medication management

4.2.1 Confirming transferability of MEMORABLE's five burdens to family carers: see Table 1:

- **ambiguity burden:** uncertainty about formal, interpersonal contacts: *"I can't remember the last time we had a review. I don't know what they do"* (C12);
- **concealment burden**: a lack of or limited information preventing carers understanding, personalising and using what they need or want to know: "*They've said he needs to come off (Lorazepam). And then you're thinking 'well, how do you take somebody off Lorazepam who's been on it for so many years?' And there was no guidelines*" (C14);
- **unfamiliarity burden**: a lack of continuity from not seeing the same practitioner: "*There was one GP a couple of years ago who was consistently seeing my dad…it was handy having one person so that they understood your situation…they understood my dad's personality*" (C15);

- **fragmentation burden:** structural divisions in the organisation and delivery of health and care limiting the way that older people and their family carers are understood and their needs addressed comprehensively: *"It just feels like they don't talk to each other…they probably do. But from an outsider's perspective it doesn't feel like that"* (C15); and
- **exclusion burden:** when family carers are neither recognised for their experience and expertise, nor effectively and fully engaged in decisions that affect the care of their relative: "*Unless I tell them, they don't see the whole picture. They just see snapshots here, there and everywhere. And that is so frustrating"* (C32).

4.2.2 Identifying additional burdens specific to family carers: see Table 1

- **conflicted interests burden:** the complex and powerful interpersonal dynamic experienced by family carers about whose interests prevail, day-to-day and across stages, including how interests are negotiated, enacted and flexed: *"(My parents) tend to be a bit complacent and just accept whatever the doctor or the nurse or whoever tells them. Whereas I don't accept that. I want an explanation"* (C35).

  Embedded and often unspoken differences in expectations of family carers can be pivotal for relationships and interactions. Examples include older people and issues of independence/ dependence on relatives; practitioners and generic guidelines/individuality and family carers' informal role/formal responsibilities; and service drivers for performance/effectiveness.
- **expectation of coping burden**: a presumption that family carers can and should manage complex medication regimens and reciprocal feelings that they have to 'soldier on' regardless: *"They assume that you can do it. They don't realise that perhaps sometimes you can't cope"* (C20).

As with conflicted interests there are underpinning dynamics to family carer expectations, such as older people's presumptions about what they can ask family members to do; practitioners' decisions and actions that may not address the workload-capacity impact on family carers, including their knowledge, skills and energy to adjust to change; and family carers' experiences of practical, cognitive and emotional challenges and conflicts as they move from a family to a care role, managing complex regimens.

4.2.3 Burden summary: see Figure 2. Managing complex medications for and with an older relative can be understood through the mechanism of burdens, along with the contextual factors that effect these mechanisms and the outcomes they generate. Family carers' explanatory accounts highlighted significant combinations of potentially inhibitory factors that drove the medication management process and the dynamic between them, their relatives and practitioners. Subset analysis confirmed the transferability of the five MEMORABLE burdens to them, highlighting mainly interpersonal issues and the way practitioners' decisions and actions in particular impacted on the experience, workload and capacity of family carers through ambiguity, concealment, unfamiliarity and exclusion. Fragmentation appeared to be institutionally generated and structural. Two additional burdens from this analysis exposed the pervasiveness of dissonance between those involved. The impact of reinforcing burdens at different levels was also significant, such as the disruptive effects of fragmentation and unfamiliarity, often buffered by practitioners.

5. Discussion and Conclusion

5.1 Discussion

Increasing numbers of family carers make a vital but potentially burdensome contribution to the support of relatives living at home with multi-morbidity and complex medication regimens, across all stages of the medication management process. Family carers are often untrained, unsupported and under-informed regarding medicines management. Many fill the gaps in formal services, experiencing multiple burdens associated with poorer outcomes for them and increased risk of medication mismanagement for their relative. Mitigation steps at interpersonal and organisational levels have potential to improve outcomes.

Much of the developing literature on this subject addresses burden issues directly associated with the caring role[51,52]. Over the past few years, there has been an increased appreciation for the essential role that family carers play role in managing medicines, especially for people living with dementia.[38,53,54] This study explains the way services and practitioners can work to reduce the medication management burdens that family carers endure. The researchers have generated evidence-based recommendations to strengthen and align systems and relationships through which medication management burdens could be more effectively mitigated and outcomes improved.

First, the provision and sharing of meaningful information would address ambiguity and concealment burdens through the clarification of the purpose, content and timing of contact between practitioners and family carers. This information would meet the need of family carers to understand why and how they could engage in formal medication management processes, such as reviews, so that decisions and actions could be sustained at home. It would also increase personal efficacy, agency and control, likely to improve family carers' management of their relative's medication, health and wellbeing, and avoid wasting time and other resources. Second, relationship continuity would mitigate the unfamiliarity burden. Mutual confidence and trust would be established through continuity along with the accumulation of knowledge about individuals and working relationships that underpin effective collaboration and decision sharing. Consistency would also be enhanced in the management of individuals, complexity and risk. Third, inter and intra-agency collaboration driven by user needs in simplified and integrated strategic and operational networks would reduce the fragmentation burden. This would co-ordinate interventions to address complex needs as a whole, potentially enhancing the way people are understood and reducing complexity and risk. Fourth, sharing information and decision making that value experience and expertise would address the exclusion burden. Inclusion is key to the development of mutual trust, relationship building and purposeful and effective collaboration. Finally, the protection of time and space where family carers could disclose experiences, and have them validated and acted on would mitigate the conflicted interests and expectation of coping burdens. This would provide the opportunity for questioning, listening and negotiating problem identification and burden resolution whilst building on mutually trusting, stable, enduring, collaborative relationships.

Of these burdens, exclusion, conflicted interests and expectation of coping appear significant in the way they marginalise family carer needs and concerns. Lack of recognition undermines family carers' contribution, prevents engagement with their growing experience and expertise and avoids addressing their needs, individually and collectively. Greater inclusion of family members within teams would engage them as a valid contributor to the health and care of their relative in the same way health or care staff with similar responsibilities need and expect to be involved. Inclusion work would improve access to practitioners alert to the unique experiences of family carers, promote individualised information sharing, ensure decisions are practicable, and provide individualised support and learning opportunities. Practitioners need to address all burdens proactively and collaboratively in contact with family carers, sensitive to combinations and fluctuations over time. Burdens on family carers mirror the long-term conditions with which many older people live and should be taken as seriously in all contacts with individuals and systems.

5.2 Conclusion

More family carers are taking on the burdens of their relatives' complex medication management. The 'informality' of their contribution is neither a reasonable expectation nor sustainable. This study highlights that family carers want validation and need better information and support. This requires strategic recognition in policy and funding, collaboration enabled by health and care practitioners who tacitly rely on them, and researched opportunities to identify how to further support their contribution to medication management and improved health outcomes.

5.3 Practice Implications

Health or social care practitioners should formally identify family carers who are struggling to cope, see them consistently and regularly, and enable more meaningful conversations as part of shared decision making, including within teams. Information provision needs to be individualised. In addition, family carers who might wish to take part could be offered places on relevant training courses alongside formal carers; provided with appropriate learning resources to use at home; or signposted to safe web-based information, as well as accessible advice and direct support through known, trusted and consistent contacts such as a GP surgery or local pharmacist.

Declarations

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Figure 1: Five stages of medication management applied to family carers (developed from MEMORABLE)

Stage	**Stage 1** **Identifying problem**	**Stage 2** **Getting a diagnosis and/or medications**	**Stage 3** **Starting, changing or stopping medications**	**Stage 4** **Continuing to take medications**	**Stage 5** **Reviewing / reconciling medications**
Who	Family carer and older person	Family carer, older person and practitioner	Family carer and older person	Family carer and older person	Family carer, older person and practitioner
	The older person's capacity will determine their involvement in each stage, subject to changes over time				
Doing what	Identifying something is wrong.	Agreeing what is wrong, how to treat it. Issuing a prescription (practitioner). Filling a prescription.	Starting new medication and adjusting daily medication routine to include new medication, or adjusting or omitting current medication.	Fitting new routine into day-to-day life.	Confirming medication safety and efficacy (practitioner). Agreeing appropriateness, and checking adherence and fit with day-to-day life.

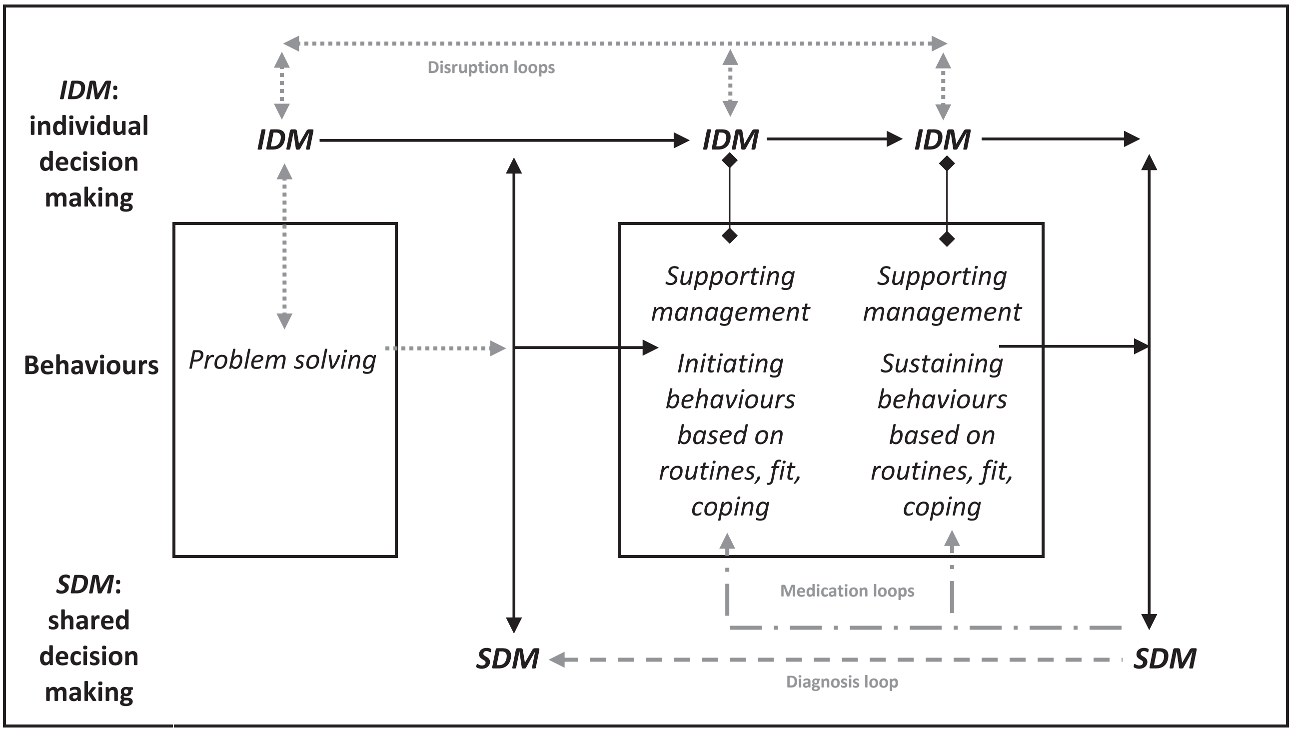
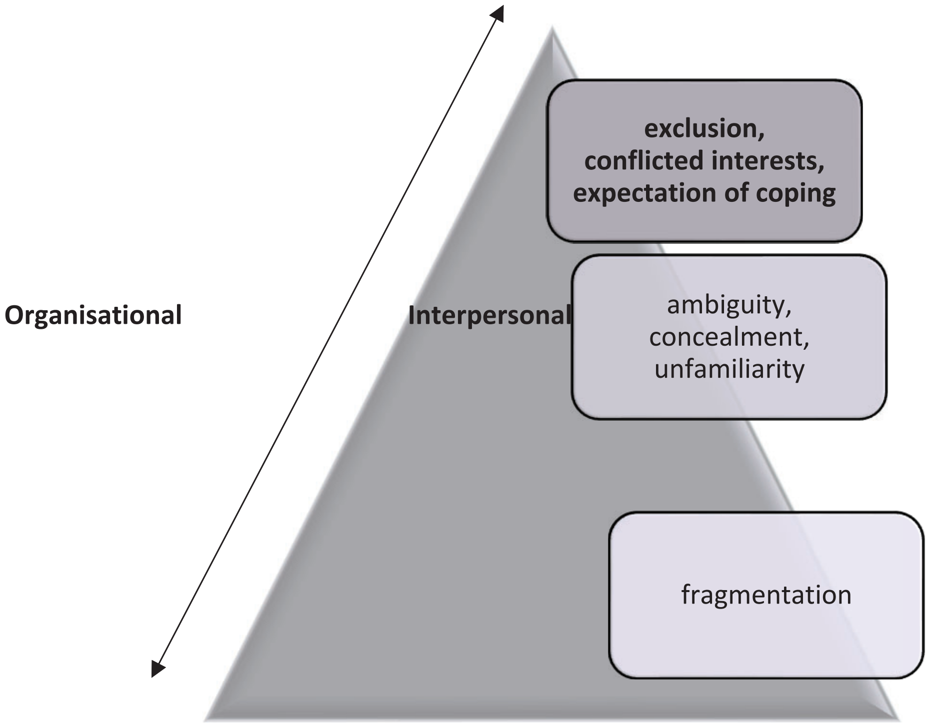


Figure 2: Burdens experienced across organisational and interpersonal levels: mitigation steps



Building trusted, enduring and stable relationships for purposeful collaboration in which information and decisions are shared and the experience of burdens, their needs and the growing expertise of family carers are validated and supported as they change over time

…underpinned by…

Inter/intra agency collaboration, integrating strategic and operational networks for needs-driven, co-ordinated interventions

Table 1: Burdens: generated from causal analysis

Confirmed from MEMORABLE research analysis		
Burden	**Description**	**Context, mechanism, outcome**
Ambiguity	Uncertainty about formal, interpersonal contacts	When family carers are uncertain about the purpose, content and/or timing of contact between practitioners and the older person they care for (context), they are not able to engage effectively in formal medicines management activities (outcome), because of **ambiguity** (mechanism)
Concealment	Lack of information that prevents family carers understanding, personalising and using what they want or need to know	When family carers do not get information they want and need in ways that are personalised, meaningful and consistent (context), they do not engage effectively in this key intervention that supports them to manage their relatives' medications, health and wellbeing (outcome), and waste time and other resources (outcome), because of **concealment** (mechanism)
Unfamiliarity	Not seeing the same practitioner consistently and the absence of continuity	When there is change and discontinuity in services and practitioners (context), family carers and practitioners do not establish and sustain mutual confidence and trust that come from enduring relationships that are key factors in shared decision making (outcome), or benefit from the co-ordinated management of complexity and risk (outcome), because of **unfamiliarity** (mechanism)
Fragmentation	Structural divisions in the organisation and delivery of health and care that limit the way older people and family carers are understood and their complex needs addressed as a whole	Increasing specialisation and centralisation, and extending responsibility for prescribing and reviewing medications to multiple practitioner groups in a variety of settings (contexts), results in family carers having multiple, discrete contacts with services (outcome), because of **fragmentation** (mechanism)
Exclusion	Family carers are neither recognised for their experience and expertise, nor fully or effectively engaged in decisions that affect the health and care of their relative	When the lived experience and expertise of family carers are not recognised, engaged with and used by practitioners during their contacts (context), the individualised basis for decisions is limited, family carers are less likely to apply what has been agreed, and their relationship with practitioners is undermined (outcomes), because of **exclusion** (mechanism)
Added from re-analysis of family carer subset		

Conflicted interests	Complex and powerful stressor about whose interests prevail, day-to-day, over time and across stages, including how interests are negotiated, enacted and flexed	When there are differences in the expressed or perceived expectations between family carers, older people and practitioners (context), family carers experience uncertainty and stress about their evolving role, priorities and preferences and how to resolve them (outcomes), because of these **conflicted interests** (mechanism)
Expectation of coping	Unstated presumption **by others** that family carers can and should manage medication regimens, however complex, and reciprocal feelings that they have to 'soldier on' regardless	When family carers have been implicitly or explicitly pressurised into caring for an older person, and lack support (contexts), they experience isolation and can lose confidence (outcomes), because of the **expectation of coping** (mechanism)