



**QUEEN'S
UNIVERSITY
BELFAST**

“I just take them because I know the people that give them to me”: A theory-informed interview study of community-dwelling people with dementia and carers’ perspectives of medicines management

Barry, H. E., McGrattan, M., Ryan, C., Passmore, A. P., Robinson, A. L., Molloy, G. J., Darcy, C. M., Buchanan, H., & Hughes, C. M. (2021). “I just take them because I know the people that give them to me”: A theory-informed interview study of community-dwelling people with dementia and carers’ perspectives of medicines management. *International Journal of Geriatric Psychiatry*, 36(6), 883-891. <https://doi.org/10.1002/gps.5488>

Published in:

International Journal of Geriatric Psychiatry

Document Version:

Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

Copyright 2021 the authors.

This is an open access article published under a Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution and reproduction in any medium, provided the author and source are cited.


General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

'I just take them because I know the people that give them to me': A theory-informed interview study of community-dwelling people with dementia and carers' perspectives of medicines management

Heather E. Barry¹  | Máiréad McGrattan¹ | Cristín Ryan² | A. Peter Passmore^{3,4} | A. Louise Robinson⁵ | Gerard J. Molloy⁶ | Carmel M. Darcy⁷ | Hilary Buchanan⁸ | Carmel M. Hughes¹

¹School of Pharmacy, Queen's University Belfast, Belfast, UK

²The School of Pharmacy and Pharmaceutical Sciences, Trinity College Dublin, Dublin, Ireland

³Centre for Public Health, Queen's University Belfast, Belfast, UK

⁴Belfast Health & Social Care Trust, Belfast, UK

⁵Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK

⁶School of Psychology, National University of Ireland, Galway, Ireland

⁷Western Health & Social Care Trust, Londonderry, UK

⁸Belfast, UK

Correspondence

Carmel M. Hughes, Primary Care Research Group, School of Pharmacy, Queen's University Belfast, Medical Biology Centre, 97 Lisburn Road, Belfast, BT9 7BL, Northern Ireland, UK.

Email: c.hughes@qub.ac.uk

Funding information

HSC Research & Development Division of the Public Health Agency in Northern Ireland and The Atlantic Philanthropies, Grant/Award Number: COM/5020/14

Abstract

Objective: Identify facilitators and barriers to successful medicines management for people with dementia (PwD) in primary care from the perspectives of community-dwelling PwD and carers.

Methods: Semi-structured interviews conducted with PwD and carers in Northern Ireland. The 14-domain Theoretical Domains Framework guided data collection and analysis. Interviews explored participants' experiences and perceptions of medicines management. PwD also completed the Beliefs about Medicines Questionnaire indicating their level of agreement with statements about medicines. Qualitative data were analysed using the framework method and content analysis. Quantitative data were analysed descriptively.

Results: Eighteen PwD and 15 carers were interviewed. PwD believed they were competent with medicines management ('beliefs about capabilities'). Most PwD reported having strategies to prompt them to take their medicines ('memory, attention and decision processes'). Carers played an important role in supporting PwD with medicines management ('social influences') and monitoring adherence ('behavioural regulation') and anticipated having to take on a greater role as patients' cognitive impairment worsened ('beliefs about consequences'). Participants highlighted assistance provided by community pharmacies with medicines acquisition and delivery ('environmental context and resources') and placed great trust in primary healthcare professionals ('social influences'). PwD had positive attitudes towards medication and believed strongly in the necessity of their medicines.

Conclusions: This is the first study to use a theoretical approach to explore medicines management for community-dwelling PwD. The findings provide new insights into the critical role of carers in facilitating optimal medicines management and will

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. International Journal of Geriatric Psychiatry published by John Wiley & Sons Ltd.

inform future intervention development, in which carers' needs assessment and involvement will be key.

KEYWORDS

beliefs about medicines, carers, dementia, medicines management, primary health care, qualitative research, theoretical domains framework

Key Points

- This study used qualitative methods to explore the experiences of community-dwelling people with dementia (PwD) and their carers about medicines management. The beliefs of PwD about medicines were also determined using a validated questionnaire
- PwD generally did not perceive medicines management to be an issue for them at the time of interview and they displayed positive beliefs about medicines. All of the PwD interviewed had carer assistance with medicines. Carers were concerned about the future and how medicines management may become more problematic as the PwD's cognitive and functional abilities declined
- These findings are in contrast with the views of primary healthcare professionals and other findings previously reported in the literature, where issues and concerns about adherence to medication in particular are highlighted
- Carers will be a fundamental part of any future intervention that is developed to improve medicines management for PwD. Understanding how PwD, and especially those living alone, manage their medicines at different stages of the disease trajectory is needed to inform future interventions

1 | INTRODUCTION

Medicines are important for people with dementia (PwD), for management of the condition and co-morbidities.^{1,2} Medicines management, comprising 'the entire way medicines are selected, procured, delivered, prescribed, administered and reviewed to optimise the contribution they make to producing informed and desired outcomes of patient care',³ raises unique challenges for PwD. Due to multi-morbidity, PwD are likely to be prescribed multiple medications (polypharmacy),⁴ resulting in complex medication regimens. Polypharmacy is a risk factor for potentially inappropriate prescribing,^{5,6} associated with increased risk of adverse drug events, hospitalisation, mortality, increased healthcare costs, and reduced quality of life.^{7,8} PwD's beliefs about medicines and treatment expectations may also influence prescribing.⁹ Management of non-cognitive symptoms may challenge prescribers and those assisting with medication administration.¹⁰⁻¹² Impairment of cognitive and communication abilities in PwD, together with their beliefs about medicines, may result in non-adherence and medication-related hospital admissions.¹³⁻¹⁵ Prudent medicines management is therefore vital for improving outcomes for PwD and reducing medicines-related harm.

With cognitive and functional decline, increased assistance with medicines from carers (formal/informal) is needed.¹⁶⁻¹⁸ Studies report informal carers may have difficulty managing complicated medication regimens typical in PwD,^{17,18} adding to their considerable burden.¹⁷⁻²⁰ If carers become unable to cope, alternative options,

such as care home placement, may be required.¹⁷ There is limited research on medicines management in community-dwelling PwD; carers' perspectives often dominate, with fewer PwD participating in previously published interview studies.^{15,17-21} Additionally, experiences of PwD living alone have not been established; such individuals are at greater risk of medication self-administration errors and non-adherence than PwD with support.^{22,23}

Interventions to improve medicines management for PwD are needed.^{13,24} This study was part of a larger project, the overall aim of which was to develop an intervention to improve medicines management for PwD in primary care. The focus was those living in the community, who constitute the majority of PwD,²⁵ many of whom live alone.²⁶ In line with Medical Research Council guidance,²⁷ a theory-base was incorporated during intervention development. The Theoretical Domains Framework²⁸ (TDF) was used to understand behaviours and processes associated with medicines management amongst key stakeholders (i.e., PwD, carers, general practitioners (GPs) and community pharmacists). The 14 theoretical domains may act as barriers or facilitators to an individual's behaviour (Table S1).²⁹

Therefore, the aim of this study was to explore perspectives of community-dwelling PwD and their carers about medicines management (prescribing, dispensing, administration, adherence and review) using a theory-informed approach, to identify facilitators and barriers to successful medicines management. Findings from healthcare professional interviews are reported elsewhere.³⁰

2 | METHODS

Face-to-face, semi-structured interviews were conducted with community-dwelling PwD and their carers in Northern Ireland (NI). Ethical approval was provided by East of England—Cambridgeshire and Hertfordshire Research Ethics Committee (15/EE/0103). The study is reported according to the Consolidated criteria for reporting qualitative research (COREQ) checklist (Table S2).³¹

2.1 | Participant sampling and recruitment

Based on previous experience,^{32–34} a number of sampling approaches were used, with assistance provided by research nurses from NI Clinical Research Network (NICRN).

2.1.1 | Memory clinics

PwD/carer dyads were recruited through two memory clinics in Belfast Health and Social Care Trust. Research nurses screened PwD and carers against inclusion criteria and clinicians confirmed potential participants' eligibility. PwD were eligible if they had a dementia diagnosis (any type), living in their own home, prescribed ≥ 4 regular medications (this numerical cut-off was used in preceding pharmacoepidemiological research⁵), and capable of undertaking an interview. Carers were eligible if they had contact with the PwD at least three times a week and assisted with medicines. Potential participants were approached by a clinician or research nurse, provided with study information, and followed up by telephone after one week by a researcher.

2.1.2 | Primary care

Ten GP surgeries across NI were recruited as part of the larger project.³⁰ We anticipated this recruitment method would identify PwD living on their own who may not receive assistance with medicines. Inclusion criteria were the same as those described above, however, PwD had to be living alone in their own home. Research nurses screened practice records against inclusion criteria, and GPs reviewed the resultant list to confirm eligibility. Study information was mailed to potential participants, who were followed up by telephone after one week by a research nurse.

2.1.3 | Join dementia research

Following slow recruitment of PwD through primary care, the Join Dementia Research (JDR; www.joindementiaresearch.nihr.ac.uk) database was used. This United Kingdom-based service allows people to volunteer to participate in dementia research.³⁵ The online portal matched potentially eligible PwD, using the same inclusion criteria for those recruited through primary care. A researcher telephoned individuals to confirm eligibility. Written information was sent to

those who expressed interest in participating, and the researcher followed-up by telephone after one week.

2.2 | Procedure

Interviews were conducted by two researchers (Heather E. Barry, Máiréad McGrattan; both pharmacists) in patients' homes between October 2015 and November 2016. All participants provided informed consent and were offered £50 for participation. Interviews with PwD/carer dyads were designed to be conducted separately. However, if PwD preferred to be interviewed with their carer present, this was respected.

Interview topic guides, based on the TDF,²⁸ were designed iteratively through discussions within the research team. Separate topic guides were developed for PwD and carers, following a similar format (Data S3 and S4). To ensure a shared understanding of medicines management, participants were provided with an explanation of the term, and asked to reflect upon their experiences, roles and responsibilities. Questions framed according to the 14 TDF domains, explored participants' perceptions of barriers and facilitators to achieving successful medicines management (using prompts where appropriate). All interviews were recorded, transcribed verbatim, checked for accuracy and anonymised. Codes were assigned to differentiate between PwD and carer (CA) participants, together with a two-digit identification number.

PwD's beliefs about prescribed medication and medicines in general were assessed using the Beliefs about Medicines Questionnaire (BMQ).³⁶ To minimise participant fatigue and burden, this was administered either after the interview or left with the PwD to complete in their own time. The BMQ contains 18 items and comprises two subscales. The BMQ-Specific subscale measures beliefs about the necessity of prescribed medication (five items) and assesses concerns about potential negative consequences of taking prescribed medicines (five items). The BMQ-General subscale measures views about overuse of medicines (four items) and perceptions of possible harm (four items) from taking medicines in general. Responses are recorded on a five-point Likert scale, from 1 (strongly disagree) to 5 (strongly agree). A total score for each subscale (necessity, concerns, overuse, harm) is calculated from the sum of individual items within each scale; higher scores indicate stronger beliefs in the concepts represented by the scale.³⁶

2.3 | Analysis

PwD and carer interviews were analysed separately using NVivo 11.³⁷ Two researchers (Heather E. Barry, Máiréad McGrattan) independently analysed each transcript, based upon the approach used in the larger study.³⁰ The framework method³⁸ was used initially to deductively analyse data using TDF domains as coding categories. A framework matrix was generated for each participant group (PwD, carers) to summarise data. Content analysis³⁹ of each framework matrix was performed inductively to identify barriers and facilitators within each TDF domain. The researchers met frequently

to discuss coding; any disagreements were resolved through discussion with another researcher (Carmel M. Hughes).

Quantitative data were coded, entered into SPSS Statistics v22,⁴⁰ and descriptive analyses (frequencies, proportions, means and standard deviations [SD]) conducted. A mean and median score was calculated for each BMQ subscale (necessity, concerns, overuse and harm). Missing data were excluded from analyses.

3 | RESULTS

3.1 | Participant characteristics

Eighteen PwD and 15 carers participated in the study (Table 1). Twenty-four PwD/carer dyads were invited to participate in the study via the memory clinics; 15 dyads agreed to participate, although one patient refused to be interviewed. Seven PwD chose to be interviewed with their carer present and six were interviewed separately. Despite 60 PwD living alone being invited to participate through primary care, only three were recruited. Individuals were either unable to be contacted, lacked capacity to undertake an interview or did not wish to participate. Whilst 23 PwD matched with the study on JDR, 17 did not meet eligibility criteria, and the researcher was unable to make contact with five. The remaining patient agreed to participate. Interviews lasted 27.1 (\pm SD 15.9) minutes on average (range: 10–62 min).

3.2 | Summary of findings from TDF analysis

PwD felt their responsibility was to take their medicines as prescribed and adhere to their medication regimen, whilst carers emphasised their supportive role to ensure that the PwD had taken their medications ('social/professional role and identity'). Carers identified a number of medicines management activities they undertook, including prescription ordering and acquisition, collection of medicines from the pharmacy, dispensing medicines into an adherence aid, administration of medicines and monitoring patient adherence. However, carers' roles varied depending upon the extent of community pharmacy involvement and the severity of the PwD's condition:

Well I'm one hundred percent responsible, that's how I feel now. And I just wonder if there have been mistakes made in the past...? [CA_02]

If she forgets, I have to say 'Did you take that one?' and I have to be there because she might say she did and she didn't. [CA_07]

PwD described feeling competent and confident about medicine-taking, and did not report having any issues with medicines management ('beliefs about capabilities'). PwD identified that having input from a carer ('social influences') was a facilitator:

I can take my medicines without any bother, I feel very confident. I just take them because I know the people that give me them ...so I don't worry. [PwD_02]

I can no longer deal with it by myself...I'm confident that my wife will do the right thing. [PwD_04]

PwD described a range of emotions associated with medicine-taking. While most felt content about taking their medicines ('emotion'), one described feeling frustrated about their dependence on others, and another described feeling fear and anger if they forgot to take their medicines:

I can't hold onto [medicines] information so I'm left in a position where I'm in a dependency. That's a frustration. [PwD_04]

I'd be afraid without them...It would annoy me if I forgot. [PwD_13]

PwD and carers talked about the importance of medicine-taking as part of a routine, linked to other tasks such as mealtimes or bedtime. Many participants displayed high motivation to ensure medication adherence and prioritised medicine-taking ('goals') to ensure well-being and prevent adverse effects ('beliefs about consequences'):

	PwD (n = 18)	Carers (n = 15)
Gender		
Male	9	2
Female	9	13
Recruitment method		
Memory clinics	14 ^a	15
Primary care	3	0
Join Dementia Research (JDR) database	1	0

TABLE 1 People with dementia (PwD) and carer participant characteristics

^aFifteen patient/carer dyads were recruited through memory clinics but one patient refused to be interviewed.

It's top priority. If you don't take them [tablets] you die, it's as simple as that. [PwD_12]

The priority is that she takes her medicines, no more than prescribed, she gets the benefit from them, and there are no safety issues through taking too many of them. [CA_06]

Most PwD reported having strategies to remind them to take their medicines ('memory, attention and decision processes') such as a weekly adherence aid or checklist ('environmental context and resources'), and all received assistance from an informal (e.g., family member) or formal carer (linked to 'social influences'):

They're all separate, in wee slots [compliance aid], you just spilt the slot open and get what you want for that morning, and there's a different one for the night. [PwD_01]

It's just a routine I do first thing in the morning. He [husband] makes me my breakfast and I take my medications then. [PwD_05]

It was apparent that carers played an important role in prompting PwD to take their medicines ('social influences'), checking to ensure medication adherence ('behavioural regulation') and (in one case) rewarding the PwD for taking their medicines ('reinforcement'):

When he's taken these [tablets] I give him two squares of chocolate. It's just a wee thing. I say 'Once you have these down you can have this.' [CA_05]

When I put them [tablets] in the little egg cup in the morning I know if they've disappeared. I don't stand over him and say "Did you swallow those?" Maybe I should do that, I don't know. [CA_14]

In addition, many PwD made use of community pharmacy services such as prescription ordering and delivery ('environmental context and resources'). PwD and carers placed great trust in healthcare professionals such as their GP and community pharmacist ('social influences'):

They're [GP and pharmacist] the experts, there's nothing to suggest that what I'm getting is doing me harm rather than helping me. I would place a lot of trust in their knowledge and judgement. [PwD_07]

PwD appeared to have limited understanding about their medicines ('knowledge'), and their cognitive deficits were a barrier to retaining knowledge about medicines. However, PwD appeared to be content with this because of carer and healthcare professional

support. Carers, on the other hand, were much more knowledgeable about PwD's medications although this varied. Carers' knowledge was facilitated by accessing other sources of information, including patient information leaflets and the internet. However, some indicated that they wanted further information, particularly about medication indications:

Don't ask me what kinds of medicines. All I know is they are all tablets... I don't know what they're for. [PwD_02]

...So for someone to sit down and say 'This is what they're for, there may be side effects' and name a few... I think that is a good idea. [CA_13]

While carers were optimistic about overcoming problems or issues with medicines management ('optimism'), they were fearful about cognitive decline, and how this may impact upon the PwD's medicine-taking abilities in the future ('beliefs about consequences'). This was linked to a perceived lack of confidence ('beliefs about capabilities') about how to ensure the PwD adhered to their medication regimen despite their best intentions ('intentions'). Carers were apprehensive about this ('emotion'):

What happens in the future...I start to worry about that. [CA_05]

Well I would get anxious if he got to the stage where he didn't want to take them [tablets]. [CA_11]

While carers talked about positive relationships they had with healthcare professionals ('social influences'), they also discussed barriers including GP accessibility, lack of continuity in GPs, and limited time to discuss medication issues during a ten-minute appointment. In contrast, accessibility of community pharmacists was acknowledged as a facilitator:

I mean, all you have to do is stand there for five minutes, and in between dispensing they [pharmacist] will come out and have a chat. [CA_06]

3.3 | Beliefs about medicines

Completed BMQs were received from 15 PwD. Table 2 shows participants' responses to individual statements from the BMQ Specific and General subscales. The mean score for the necessity subscale of the BMQ was 21.7 (\pm SD 2.9), indicating that participants had strong beliefs, relative to the mid-point of the scale, in necessity of their medicines for maintaining health (Table 3). Mean scores for the concerns, overuse and harm subscales were 11.3 (\pm SD 3.8), 7.9 (\pm SD 1.9) and 10.4 (\pm SD 1.6) respectively, indicating lower levels of specific concerns about their medications and less general concerns about medication

TABLE 2 Responses to statements from the Beliefs about Medicines Questionnaire (BMQ) from people with dementia (PwD)

	N (%)			
	Strongly agree/ agree	Neither agree nor disagree	Disagree/strongly disagree	Missing
BMQ specific				
My health, at present, depends on my medicines (N)	15 (83.3)	-	-	3 (16.7)
Having to take medicines worries me (C)	2 (11.1)	-	13 (72.2)	3 (16.7)
My life would be impossible without my medicines (N)	9 (50.0)	4 (22.2)	2 (11.2)	3 (16.7)
Without my medicines I would be very ill (N)	11 (61.1)	3 (16.7)	1 (5.6)	3 (16.7)
I sometimes worry about the long-term effect of my medicines (C)	2 (11.2)	4 (22.2)	9 (50.0)	3 (16.7)
My medicines are a mystery to me (C)	5 (27.8)	3 (16.7)	7 (38.9)	3 (16.7)
My health in the future will depend on my medicines (N)	14 (77.8)	1 (5.6)	-	3 (16.7)
My medicines disrupt my life (C)	2 (11.1)	-	13 (72.2)	3 (16.7)
I sometimes worry about becoming too dependent on my medicines (C)	3 (16.7)	2 (11.1)	10 (66.7)	3 (16.7)
My medicines protect me from becoming worse (N)	14 (77.8)	-	1 (5.6)	3 (16.7)
BMQ general				
Doctors use too many medicines (O)	2 (11.1)	6 (33.3)	7 (38.9)	3 (16.7)
People who take medicines should stop their treatment for a while every now and again (H)	-	4 (22.2)	11 (61.1)	3 (16.7)
Most medicines are addictive (H)	2 (11.1)	7 (38.9)	6 (33.4)	3 (16.7)
Natural remedies are safer than medicines (O)	2 (11.1)	6 (33.4)	7 (38.9)	3 (16.7)
Medicines do more harm than good (H)	-	1 (5.6)	14 (77.7)	3 (16.7)
All medicines are poisons (H)	1 (5.6)	2 (11.1)	12 (66.6)	3 (16.7)
Doctors place too much trust on medicines (O)	-	5 (27.8)	10 (55.6)	3 (16.7)
If doctors had more time with patients they would prescribe fewer medicines (O)	2 (11.1)	9 (50.0)	4 (22.2)	3 (16.7)

Abbreviations: C, concerns sub-scale item; H, Harm sub-scale item; N, necessity sub-scale item; O, overuse sub-scale item.

Beliefs about Medicines Questionnaire subscale	Mean score (SD)	Median (range)
Necessity ^a	21.7 (2.9)	22.0 (16.0–25.0)
Concerns ^a	11.3 (3.8)	11.0 (7.0–21.0)
General overuse ^b	7.9 (1.9)	7.0 (5.0–11.0)
General harm ^b	10.4 (1.6)	10.0 (7.0–14.0)

^aScale from 5 to 25, where high scores indicate strong belief.

^bScale from 4 to 20, where high scores indicate negative attitudes towards medicines.

TABLE 3 Beliefs of people with dementia (PwD) about medicines

overuse and harms, relative to the mid-points of these three scales. Standard deviations calculated for each of these four sub-scales for the BMQ also provide evidence for variability, and hence diversity, in beliefs about medicines across the PwD participants.

4 | DISCUSSION

This is one of only two studies, to our knowledge, to use a theory-based approach to explore experiences of community-dwelling

PwD and their carers about medicines management, and determine beliefs of PwD about medicines.⁴¹ It extends a limited evidence base to provide valuable findings for future intervention development to improve medicines management for PwD. This study emphasises that carers provide critical assistance with medicines for many PwD and their input will be integral to future interventions.^{27,41} In addition, intervention components may need to be tailored according to disease trajectory, cognitive function, and personal circumstances of PwD (if they have carer support or are living alone).

This study included a greater number of PwD ($n = 18$) than reported previously; other studies were dominated by carer participation.^{5,17-20,21} This is a key strength; the 'patient voice' is missing from the literature,⁴² and it is important to portray and consider views of PwD to inform intervention development. Participants revealed they did not experience any major issues with medicines management at the time of interview and were happy with the status quo, contrasting with other studies,^{16,17,18} and concerns expressed by healthcare professionals, particularly about adherence.^{16,17,30} Whilst cognitive status was not assessed, PwD appeared to have mild-moderate cognitive impairment, received appropriate support from their GP surgery and community pharmacy, and all had a formal/informal carer to assist with medicines. In addition, PwD displayed positive beliefs about medicines, particularly medication necessity, which likely explains the observed intrinsic motivation towards medicine-taking and adherence.^{9,43} Beliefs about medication are shown to be potentially important determinants of adherence in cognitively intact older adults.⁴⁴⁻⁴⁷ Our findings suggest that such beliefs may also exert influence on PwD, although this would need to be confirmed with larger sample sizes. Conversely, carers anticipated future difficulties with medicine administration and adherence, when refusal of medicines and difficulties with swallowing may be apparent.^{16,43} Disparity between PwD and carer views may also be due to the nature of the condition and impact that dementia may have on PwD's problem-solving, judgement and decision-making abilities. However, it has been reported that self-ratings by those with early-stage dementia about their medication management abilities were more accurate than those provided by carers.⁴⁸ Future work should focus on determining medicines management experiences and beliefs about medicines of community-dwelling PwD at moderate to severe stages of the condition (the needs of those living in care homes are already established) and their carers.

This study identified some similar barriers and facilitators to successful medicines management for PwD to those already identified in the literature, such as the importance of carers, having supportive and trusting relationships with healthcare professionals, carers' desire for further information about medicines, and use of cues and reminder strategies.^{15,16,18,20,21,41,48} However, we also report some contrasting findings. For example, difficulties in obtaining prescriptions and medicine supplies have been reported previously^{11,17,18}; this was not an issue for participants in our study because much of the burden associated with these tasks was removed by community pharmacists. This study also identified aspects of medicines management not previously reported. A more detailed explanation of carers' roles in ensuring adherence and the reassurance that a carer provides to PwD were noted, likely related to the structured analytical approach offered by the TDF. In contrast to other studies which focused more specifically on distinct parts of the medicines management process, particularly adherence, we took a broader approach to ensure that issues of significance to PwD and carers were not overlooked. Relevance of individual TDF domains was not assessed as the remainder of the analysis in relation to

intervention development focused predominantly on healthcare professional data.³⁰ However domains such as skills and optimism, were seldom discussed by participants.

Insights from this study should also inform future clinical practice. Primary healthcare professionals should seek to engage with carers of PwD soon after diagnosis, so that they can work collaboratively and form good working relationships. GPs and community pharmacists should hold contact details for carers so that medicines information can be relayed, and issues resolved in a timely manner. Our previous work indicated that healthcare professionals value carer input with medicines,³⁰ however they should be mindful of carers' knowledge and educational needs. While carer support is important throughout the disease course, this will become more critical with disease progression to avoid additional burden and stress placed upon them by medicines management.

4.1 | Strengths and limitations

A major strength of this study was that most accounts from PwD were triangulated with those of their carer, which allowed needs and experiences of both key stakeholders to be considered. It should be noted, however, that findings represent the views and perspectives of PwD and carers who were interviewed, and are therefore subject to any reporting biases pertinent to PwD and carers in this context and at that time. Interviewer bias was minimised by adopting a reflexive interviewing style, conducting regular debriefing sessions during data collection, and having regular meetings with the wider research team to discuss and agree upon analysis. We acknowledge the self-reported dementia diagnosis provided by the participant recruited through JDR is a limitation. In addition, participants' level of cognitive impairment was not measured in this study; further work is needed to fully ascertain medicines management issues experienced by community-dwelling PwD and their carers at moderate to advanced stages of the condition, enabling any future intervention to be adapted and refined accordingly. One limitation was the difficulty in trying to recruit PwD living alone, despite taking a number of approaches to sampling.³¹ Such patients are at risk of social isolation, receiving inadequate medical supervision and having unmet medical needs.^{26,49} It is still unknown as to how they cope with medicines management; future work must identify their needs so that appropriate support can be provided.

5 | CONCLUSION

This study provides a rich insight into the experiences and views of PwD and their carers about medicines management. The findings from this study have extended the evidence-base for complex intervention development in this area and have emphasised the importance of integrating carers of PwD and their needs into the design of future interventions to support medicines management.

ACKNOWLEDGEMENTS

The authors wish to thank all of the study participants. We would also like to thank Dr. Janine Cooper and Mr. John Barry for their feedback on the interview topic guides. We are grateful to Mrs. Claire Leatham, Ms. Aine Wallace and colleagues in the Northern Ireland Clinical Research Network, Dr. Bernadette McGuinness and memory clinic staff in Belfast HSC Trust, and Mr. Adam Smith from the Office of the NIHR National Director for Dementia Research for their assistance with recruitment. This work was funded by the HSC Research & Development Division of the Public Health Agency in Northern Ireland and The Atlantic Philanthropies (COM/5020/14). The funders had no role in the design or conduct of the study; in the analysis and interpretation of the data; or in the preparation or approval of the manuscript.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to the content of information that could compromise research participant privacy/consent.

ORCID

Heather E. Barry  <https://orcid.org/0000-0002-9684-8182>

REFERENCES

- Poblador-Plou B, Calderón-Larrañaga A, Marta-Moreno J, et al. Comorbidity of dementia: a cross-sectional study of primary care patients. *BMC Psychiatr*. 2014;14:84.
- Browne J, Edwards DA, Rhodes KM, et al. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. *BMJ Open*. 2017;7(3):e012546.
- Audit Commission. *A spoonful of sugar: medicines management in NHS hospitals*; 2001. Available from <http://www.eprescribingtoolkit.com/wp-content/uploads/2013/11/nrspoonfulsugar1.pdf>. Accessed 20 May 2020.
- Clague F, Mercer SW, McLean G, et al. Comorbidity and polypharmacy in people with dementia: insights from a large population-based cross-sectional analysis of primary care data. *Age Ageing*. 2017;46(1):33-39.
- Barry HE, Cooper JA, Ryan C, et al. Potentially inappropriate prescribing among people with dementia in primary care: a retrospective cross-sectional study using the Enhanced Prescribing Database. *J Alzheimers Dis*. 2016;52(4):1503-1513.
- Delgado J, Bowman K, Clare L. Potentially inappropriate prescribing in dementia: a state of the art review since 2007. *BMJ Open*. 2020;10(1):e029172.
- Dedhiya SD, Hancock E, Craig BA, et al. Incident use and outcomes associated with potentially inappropriate medication use in older adults. *Am J Geriatr Pharmacother*. 2010;8(6):562-570.
- Stockl KM, Le L, Zhang S, Harada AS. Clinical and economic outcomes associated with potentially inappropriate prescribing in the elderly. *Am J Manag Care*. 2010;16(1):e1-e10.
- Clyne B, Cooper JA, Boland F, Hughes CM, Fahey T, Smith SM, OPTI-SCRIPT study team. Beliefs about prescribed medication among older patients with polypharmacy: a mixed methods study in primary care. *Br J Gen Pract*. 2017;67(660):e507-e518.
- Wood-Mitchell A, James IA, Waterworth A, et al. Factors influencing the prescribing of medications by old age psychiatrists for behavioural and psychological symptoms of dementia: a qualitative study. *Age Ageing*. 2008;37(5):547-552.
- Alaseed D, Jamieson E, Gul MO, Smith FJ. Challenges to optimal medicines use in people living with dementia and their caregivers: a literature review. *Int J Pharm*. 2016;512(2):396-404.
- Jennings AA, Foley T, McHugh S, et al. 'Working away in that grey area...' A qualitative exploration of the challenges general practitioners experience when managing behavioural and psychological symptoms of dementia. *Age Ageing*. 2018;47(2):295-303.
- El-Saifi N, Moyle W, Jones C, Tuffaha H. Medication adherence in older patients with dementia: a systematic literature review. *J Pharm Pract*. 2018;31(3):322-334.
- Hudani ZK, Rojas-Fernandez C. A scoping review on medication adherence in older patients with cognitive impairment or dementia. *Res Soc Adm Pharm*. 2016;12(6):815-829.
- While C, Duane F, Beanland C, Koch S. Medication management: the perspectives of people with dementia and family carers. *Dementia*. 2012;12(6):734-750.
- Kaasalainen S, Dolovich L, Papaioannou A, et al. The process of medication management for older adults with dementia. *J Nurs Healthc Chronic Illn*. 2011;3(4):407-418.
- Maidment ID, Aston L, Moutela T, et al. A qualitative study exploring medication management in people with dementia living in the community and the potential role of the community pharmacist. *Health Expect*. 2017;20(5):929-942.
- Smith F, Grijseels MS, Ryan P, Tobiansky R. Assisting people with dementia with their medicines: experiences of family carers. *Int J Pharm Pract*. 2015;23(1):44-51.
- Erlen JA, Lingler J, Sereika SM, et al. Characterizing caregiver-mediated medication management in patients with memory loss. *J Gerontol Nurs*. 2013;39(4):30-39.
- Gillespie RJ, Harrison L, Mullan J. Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia*. 2015;14(1):47-62.
- Poland F, Mapes S, Pinnock H, et al. Perspectives of carers on medication management in dementia: lessons from collaboratively developing a research proposal. *BMC Res Notes*. 2014;7:463.
- Bourgeois J, Couturier P, Tyrrell J. Safety at home for people with dementia: preliminary evaluation of situations-at-risk in a French geriatric memory clinic. *Psychol Neuropsychiatr Vieil*. 2009;7(3):213-214.
- Douglas A, Letts L, Richardson J. A systematic review of accidental injury from fire, wandering and medication self-administration errors for older adults with and without dementia. *Arch Gerontol Geriatr*. 2011;52(1):e1-e10.
- McGrattan M, Ryan C, Barry HE, Hughes CM. Interventions to improve medicines management for people with dementia: a systematic review. *Drugs Aging*. 2017;34(12):907-916.
- Prince M, Knapp M, Guerchet M, et al. *Dementia UK: update*; 2014. Available from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf. Accessed 24 Apr 2020.
- Miranda-Costillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr*. 2010;22(4):607-617.
- O'Cathain A, Croot L, Duncan E, et al. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*. 2019;9(8):e029954.
- Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci*. 2012;7:37.

29. Francis JJ, O'Connor D, Curran J. Theories of behaviour change synthesised into a set of theoretical groupings: introducing a thematic series on the theoretical domains framework. *Implement Sci.* 2012;7:35.
30. Barry HE, Bedford LE, McGrattan M, et al. Improving medicines management for people with dementia in primary care: a qualitative study of healthcare professionals to develop a theory-informed intervention. *BMC Health Serv Res.* 2020;120:20.
31. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
32. Iliffe S, Waugh A, Poole M, et al. The effectiveness of collaborative care for people with memory problems in primary care: results of the CARDEM case management modelling and feasibility study. *Health Technol Assess.* 2014;18(52):1-148.
33. Barry HE, Parsons C, Passmore AP, Hughes CM. Pain in care home residents with dementia: an exploration of frequency, prescribing and relatives' perspectives. *Int J Geriatr Psychiatry.* 2015;30(1):55-63.
34. Barry HE, Parsons C, Passmore AP, Hughes CM. Exploring the prevalence of and factors associated with pain: a cross-sectional study of community-dwelling people with dementia. *Health Soc Care Community.* 2016;24(3):270-282.
35. Smith AM, Rosser MN, Kotting PM. Developing standards for research registers: applying learning from the UK's national 'Join Dementia Research' service. *Alzheimers Dement.* 2017;13(7):S524.
36. Horne R, Weinman J, Hankins M. The beliefs about medicines questionnaire. The development and evaluation of a new method for assessing the cognitive representation of medication. *Psychol Health.* 1999;14(1):1-24.
37. QSR International Pty Ltd. *NVivo qualitative data analysis software Version 11*; 2015.
38. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol.* 2013;13:117.
39. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: *Analyzing Qualitative Data*. London, UK: Routledge; 1994.
40. IBM Corp. *IBM SPSS Statistics for Windows, Version 22.0*. Armonk, NY: IBM Corp; 2013.
41. Maidment I, Lawson S, Wong G, et al. Towards an understanding of the burdens of medication management affecting older people: the MEMORABLE realist synthesis. *BMC Geriatr.* 2020;20:183.
42. Lim RH, Sharmeen T. Medicines management issues in dementia and coping strategies used by people living with dementia and family carers: a systematic review. *Int J Geriatr Psychiatry.* 2018;33(12):1562-1581.
43. Reeve E, Bell JS, Hilmer SN. Barriers to optimising prescribing and deprescribing in older adults with dementia: a narrative review. *Curr Clin Pharmacol.* 2015;10(3):168-177.
44. Arlt S, Lindner R, Rösler A, von Renteln-Kruse W. Adherence to medication in patients with dementia: predictors and strategies for improvement. *Drugs Aging.* 2008;25:1033-1047.
45. Schüz B, Marx C, Wurm S, et al. Medication beliefs predict medication adherence in older adults with multiple illnesses. *J Psychosom Res.* 2011;70(2):179-187.
46. Park HY, Seo SA, Yoo H, Lee K. Medication adherence and beliefs about medication in elderly patients living alone with chronic diseases. *Patient Prefer Adherence.* 2018;12:175-181.
47. Aston L, Hilton A, Moutela T, Shaw R, Maidment I. Exploring the evidence base for how people with dementia and their informal carers manage their medication in the community: a mixed studies review. *BMC Geriatr.* 2017;17:242.
48. Martyr A, Clare L. Awareness of functional ability in people with early-stage dementia. *Int J Geriatr Psychiatry.* 2018;33(1):31-38.
49. Gilmour H, Gibson F, Campbell J. Living alone with dementia: a case study approach to understanding risk. *Dementia.* 2003;2:403-420.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Barry HE, McGrattan M, Ryan C, et al. 'I just take them because I know the people that give them to me': A theory-informed interview study of community-dwelling people with dementia and carers' perspectives of medicines management. *Int J Geriatr Psychiatry.* 2021;1-9. <https://doi.org/10.1002/gps.5488>