

# BMJ Open Development of a tool to evaluate medication management guidance provided to carers of people living with dementia at hospital discharge: a mixed methods study

Mouna J Sawan <sup>1</sup>, Melissa Gench,<sup>1</sup> Christine Bond,<sup>2</sup> Yun-Hee Jeon,<sup>3</sup> Sarah N Hilmer,<sup>4</sup> Timothy F Chen,<sup>1</sup> Danijela Gnjjidic<sup>1,5</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Mouna J Sawan;  
mouna.sawan@sydney.edu.au

## ABSTRACT

**Objective** Medication management guidance for carers of people with dementia at hospital discharge is important to prevent medication-related harm during transitions of care. This study aimed to develop a tool to evaluate medication management guidance provided to carers of people with dementia at hospital discharge.

**Design** The tool was developed using mixed methods involving two stages. Stage 1 involved item generation and content validation. Items were based on a previous qualitative study and systematic review. Content validation involved experts and consumers with knowledge or experience of medication management guidance in the acute care setting, and rating each item on importance and relevance. Stage 2 involved conducting cognitive interviews with carers of people with dementia to pretest the tool.

**Setting** For stage 1, experts and consumers from Australia, USA and New Zealand were included. For stage 2, carers of people with dementia were recruited across Australia.

**Participants** 18 experts and consumers participated in round 1 of content validation, and 13 experts and consumers completed round 2. Five carers of people with dementia participated in cognitive interviews.

**Results** The final tool contained 30 items capturing information across five domains: (1) provision of medication management guidance at hospital discharge; (2) carer understanding of medication management guidance provided at discharge; (3) carer engagement in discussing the safe use of medications at discharge; (4) carer preparedness to conduct medication management activities after discharge; and (5) co-ordination of medication management guidance after discharge.

**Conclusions** We developed the first tool to assess medication management guidance provided for carers of people with dementia at hospital discharge. The tool may be useful to inform future research strategies to improve the delivery of medication management guidance at discharge.

## INTRODUCTION

Approximately 41% of older adults with dementia have a medication-related adverse event immediately after hospital discharge,<sup>1</sup>

## Strengths and limitations of this study

- The tool content was informed by people with lived experience who were involved throughout the research study.
- The tool comprises five domains, which comprehensively evaluated carers' experience of medication management guidance for people living with dementia provided at discharge.
- The adoption of cognitive interviews and feedback from people with lived experience ensured that the tool instructions and items were easy to understand by the end user.
- Further studies are required to explore the opportunities to implement the tool in clinical practice.

including cognitive decline, hospital readmission and mortality, of which 35% are deemed to be preventable.<sup>2 3</sup> Carers play an important role in overseeing medications for the person with dementia.<sup>4-6</sup> Over 54% of carers are involved in medication management, and this increases to 95% of carers in people with moderate to severe dementia.<sup>7 8</sup> Compared with other populations, medication management for people with dementia is often complex and a major contributing factor to adverse events after discharge from the hospital.<sup>6</sup> Between 53% and 90% of inpatients with dementia are exposed to potentially inappropriate polypharmacy,<sup>9</sup> which increases the risk of non-adherence and creates difficulty in managing side effects after discharge.<sup>5 8</sup> Furthermore, complexity in medication management may increase for carers after hospital discharge due to complex dosage regimens, increased medication burden and managing medications without formal training.<sup>9 10</sup> This may



contribute to adverse outcomes in people living with dementia.<sup>11</sup>

To support carers in their unique responsibilities in managing medications and to ensure co-ordination and continuity of transitions of care for a person living with dementia, it is important to provide carers with tailored medication management guidance at discharge.<sup>12</sup> However, studies have reported that at discharge, carers are provided with little or no medication management advice.<sup>6 13 14</sup> In addition, there is limited carer engagement in medication management decisions and challenges in ensuring continuity of medication supply after discharge, which may lead to errors in medication management.<sup>6 13 14</sup> Our recent systematic review highlighted the need for well-designed interventions to guide carers in all aspects of medication management for people living with dementia to prevent postdischarge adverse drug events.<sup>15</sup>

Currently, there are gaps in tools that assess medication management guidance for carers of people living with dementia at hospital discharge. Existing tools evaluate carer management of medications for people with dementia in community and long-term care settings.<sup>16 17</sup> These tools focus only on how well carers can manage medication supply, administration and monitoring in their daily responsibilities.<sup>5 7 18 19</sup> For instance, the Family Caregiver Activation in Transitions (FCAT) tool is the only measure of carer-perceived self-efficacy with respect to discharge or transition-specific tasks.<sup>20</sup> However, the FCAT tool does not provide insights into the type of medication guidance and the specific advice on medications provided to carers at discharge. This is important as carers often report that they feel unprepared to manage medications for the person with dementia after hospitalisation.<sup>13</sup> Therefore, an understanding of the overall medication management guidance which carers are given at discharge is needed to identify areas of improvement to ensure safe use of medications. At present, there are no published validated tools that describe or quantify these aspects of medication management.<sup>5</sup> Therefore, the aim of this study was to develop a tool to evaluate medication management guidance provided to carers of people with dementia at hospital discharge.

## METHODS

The development of the tool was guided by Boateng *et al* and included a mixed methods study involving two stages: item development and pretesting.<sup>21</sup> This method was chosen as it is considered best practice for developing survey scales. The tool targets carers who have a major role in managing medications for people living with dementia. It is designed for both research and clinical purposes to evaluate the guidance on medication management at hospital discharge. Medication management guidance is defined as the provision of information and instructions in written or verbal format to ensure that all aspects of medication management (including the selection, supply, preparation, administration, recording

and monitoring) are managed safely.<sup>22</sup> The tool could also be used to evaluate the experiences of carers at transitions of care to identify areas for further guidance in medication management for people living with dementia.

For this study, a carer was defined as a person who assists and supports a person living with dementia. The type of care may be routine, regular or occasional. The person may have carer responsibilities that are either informal in nature (unpaid) or formal (paid). The informal carer provides care to those who need it within the context of an existing relationship (eg, family member or friend).<sup>23</sup> The formal carer directly provides or manages care in the community or in a long-term care facility (also known as a residential care facility).<sup>23</sup>

### Stage 1: item development

Stage 1 comprised domain and item generation and content validation by experts and consumers.

#### Domain and item generation

The content of the tool was informed by the findings of the two previous studies conducted by the research team, qualitative research<sup>13</sup> and a systematic review,<sup>7</sup> and two resources, the Australian Commission National Safety and Quality Health Service Standards<sup>24</sup> and the WHO Medication Safety in Transitions of Care.<sup>25</sup>

The qualitative study explored the experiences of 31 informal carers about the medication management advice they received at hospital discharge for people with dementia.<sup>13</sup> The study identified that carers experienced: (1) insufficient medication management information at discharge, (2) limited carer involvement in decisions about medication management and (3) challenges in obtaining medication supply after discharge. The systematic review identified tools evaluating medication management for informal carers of people with dementia and summarised carer involvement in aspects of medication management.<sup>7</sup>

The qualitative study, literature review and two resources were content analysed by the researcher (MS) to derive the domains of the tool.<sup>26</sup> The process involved familiarisation with the content of these sources, conducting line-by-line coding of the content of the sources, grouping codes into broader categories to evaluate medication management guidance provided to carers of people living with dementia at hospital discharge. The tool domains were reviewed by the coauthors, and consensus was reached about which domains to include in the tool.

The identified domains were used as a guide for the development of tool items. The items were derived from the findings of the qualitative research.<sup>24</sup> The author (MS) generated the items from the description of participants' experiences of medication management guidance provided at discharge that were linked to the domains. For this step, items were worded simply, and participant quotes were used to inform the wording. Items requiring responses from participants were also generated by MS and reviewed by the research team. The initial pool of

items was reviewed and refined by coauthors and until consensus was reached on which items to include in the first version of the tool.

### Content validation

Content validation is an established method to assess the degree to which elements of an instrument are relevant and measure the domain of the targeted construct. The targeted construct examined was medication management provided to carers of people living with dementia at hospital discharge.<sup>27</sup> The Content Validity Index (CVI) was selected as the method to guide the content validation of the tool.<sup>27</sup> The process involved rating each item for relevance and importance by an expert and consumer panel with relevant knowledge and experience.<sup>27 28</sup>

Purposive sampling was undertaken to recruit health-care professionals and consumers with the relevant knowledge and experience of medication management across Australia. Experts from the USA and New Zealand were also recruited to obtain international perspectives regarding the content of the tool. Invited expert panel participants were geriatricians, registered nurses, pharmacists, clinicians from the Australian Aged Care Quality and Safety Commission<sup>29</sup> and academics and researchers in the field of geriatrics and dementia. A sample of carers of people living with dementia were also invited to participate. Twenty-two participants were invited by email to participate in the survey to ensure at least five responses. This followed the guidance on the content validity process, which recommends a minimum of three panel members to review the content of the tool and control for chance agreement.<sup>27 30 31</sup> Participants were given 2 weeks to complete the survey. Reminders were sent to participants 1 week after the initial invitation.

The content validity assessment form included conceptual definitions of the target construct and domains. Participants were requested to rate each item's importance and relevance using 5-point Likert scales (strongly disagree=1, disagree=2, neither agree nor disagree=3, agree=4 and strongly agree=5).<sup>27</sup> The end of each domain of the survey included an open-ended text box for participants to provide comments on the wording of each item and suggest additional items. The invitation email included a cover letter and an online link to the content validity assessment form hosted by Research Electronic Data Capture.

The data were managed in Excel files and descriptive statistics was conducted. For the first round, the Item-Level Content Validity Index (I-CVI) for each item and comments from the panel were used to determine if items were included, reworded or deleted.<sup>27</sup> The I-CVI represents the proportion of agreement about the content validity of an item. It is calculated by the number of experts and consumers who have rated an item as 'agree' or 'strongly agree' for its relevance and importance and dividing that number by the total number of respondents.<sup>28</sup> Items with an I-CVI of 0.78 or greater for importance and/or relevance were the threshold taken

as this is the consensus standard for CVI practice.<sup>27</sup> Open-ended text suggesting rewording of items and analysis of items was considered. Items with an I-CVI of 0.78 or greater for importance and/or relevance and received no suggestions for rewording were accepted verbatim. Items with an I-CVI of 0.78 for relevance or importance but identified by participants to require modification to improve clarity were reworded. Items with an I-CVI below 0.78 for both importance and relevance were deleted or reworded. Participant feedback was also used to identify if changes to item response options were required and to determine the need for additional items for inclusion in the tool.

To achieve content validity of the reviewed and added items, a second round of content validation was conducted with participants who had responded in the first round.

### Stage 2: pretesting–cognitive interviews

Pretesting was conducted using cognitive interviews to evaluate the extent that the items reflected the domains and to ensure the tool instructions and items were clear and easy to understand for end users.<sup>21</sup> We followed standards for reporting qualitative research reporting guidance (online supplemental file A)<sup>32</sup> to guide the reporting of the qualitative components of the study. For pretesting, a minimum of five cognitive interviews are recommended until saturation is achieved.<sup>21</sup> For this reason, 13 informal carers from across Australia who participated in the earlier qualitative study and consented to participate in further research<sup>13</sup> (see the Domain and item generation section) were invited to participate in cognitive interviews via email. Additional consent was obtained from carer participants for participation in cognitive interviews. Participants were sent the participant information statement and consent forms via email. On obtaining written consent, appointments were arranged with the carer participant for a phone interview.

The online version of the tool was administered via email before the scheduled phone interview and participants were requested to briefly read over the tool and think over what the items meant. Throughout the interview, two methods were adopted: think-aloud technique and verbal probing.<sup>33</sup> For the think-aloud technique, respondents were instructed to talk through their answer to an item to describe their thought processes that underpinned their response.<sup>33</sup> For verbal probing, participants were asked to provide feedback on the items, item response options and the need for additional items for inclusion in the tool. The interviews were transcribed, imported into a qualitative software program (NVivo V.12) and content analysed by MS. The items were modified based on participants' suggestions for rewording of the items to improve clarity.

### Patient and public involvement

Public contributors were actively involved in the design, conduct, reporting and dissemination of our research. Our research advisory group comprised five members

with lived experience: carers of a person living with dementia, health professionals and experts in dementia research. The advisory group ensured consumer needs were considered and provided extensive consumer input into the research proposal, the design of the project and the project information statement to be sent to the participants.

The research question and the first draft of the tool were informed by the experiences and preferences of carers on medication management advice they received at hospital discharge for people with dementia.<sup>13</sup> The draft and final version of the tool were reviewed by the research advisory group and the Sydney Dementia Network Lived Experience Expert Advisory Panel (members are people with lived experience in dementia). In addition, carer

participants were recruited via consumer groups and networks.

## RESULTS

### Stage 1: item development

#### Domain and item generation

Five domains of the tool were derived from content analysis of the previous qualitative study and systematic review and resources (table 1).<sup>13</sup> These were (1) provision of medication management guidance at hospital discharge, (2) carer understanding of medication management guidance provided at discharge, (3) carer engagement in discussing the safe use of medications at discharge, (4) carer preparedness to conduct medication management

**Table 1** Tool domains identified from thematic analysis

Section	Domain	Categories	Source	Items (n)
1	Provision of medication management guidance at discharge	Carer was provided guidance in written and/or verbal form on some or all medications at discharge	Qualitative study Australian Commission National Safety and Quality Health Service Standards WHO	3
		When carer was provided medication guidance	Qualitative study	1
		Carer asked about being able to obtain a supply of medications after discharge	Qualitative study Systematic review	1
2	Carer understanding of medication management guidance provided at discharge	Carer understood medication management guidance provided at the time of discharge	Qualitative study	3
		Healthcare professional spent adequate time to explain the medication guidance for the person with dementia	Qualitative study	1
3	Carer engagement in discussing the safe use of medications at discharge	Carer was provided guidance on all aspects of medication management: selection, administration, monitoring, indications, adverse effects and changes to medications	Qualitative study Systematic review Australian Commission National Safety and Quality Health Service Standards WHO	9
		Carer was involved in decision-making for medications	Qualitative study	4
4	Carer preparedness to conduct medication management activities after discharge	Carer was satisfied with the medication guidance provided at discharge	Qualitative study	2
		Carer was confident to manage medications after discharge	Qualitative study	1
		Carer was provided recommendations to increase medication adherence and address concerns	Qualitative study	1
5	Co-ordination of medication management guidance after discharge	Carers obtained a medication supply from the local pharmacists	Qualitative study Systematic review	1
		Hospital communication with the primary care physician, local pharmacists and/or the long-term care facility about medications changed at discharge	Qualitative study Systematic review Australian Commission National Safety and Quality Health Service Standards WHO	3



**Table 2** Content validation and cognitive interview participant characteristics

Content validation						
	Geriatrician	Pharmacist	Nurse	Research/academic	Professional body*	Informal carer
Round 1						
Number	3	3	5	3	1	3
Years in practice, median (IQR)	6 (0.6)	38 (6)	34.5 (6.5)	6 (0.9)	29	5 (0.2)
Location						
Australia	2	4	3	2	1	3
USA				1		
New Zealand	1					
Round 2						
Number	2	2	2	3	1	3
Cognitive interviews						
Number						5†
Location						
Australia						5

\*Australian Aged Care Quality and Safety Commission.

†3 married/partner, 2 adult/child.

activities after discharge and (5) co-ordination of medication management guidance after discharge. [Table 1](#) outlines the categories and the number of items for each domain.

Items were reviewed iteratively until the coauthors reached consensus on 36 items (from an initial 49 items) for the first round of content validation.

### Content validation

#### Round 1

Out of 22 experts and consumers invited to participate in the content validation, 18 participated (82%) ([table 2](#)). [Table 3](#) provides examples of the I-CVI results and [figure 1](#) outlines the items that were excluded, included, and modified or reworded during content validation stages. In the first round, 30 out of 36 items (83%) met the I-CVI threshold score of 0.78 or greater for relevance and/or importance. Out of these 30 items, 9 were reworded for the next round to improve clarity, and 6 items were deleted due to duplication with other items. The remaining six items that did not meet the I-CVI threshold score for relevance and/or importance were reviewed by the research team. One item was reworded for the second round to improve clarity, and five were deleted because they did not meet the threshold.

Five items were added for the second round. For example, domain five contained items relating to whether healthcare professionals involved in the care for the person with dementia were aware of postdischarge medication changes. One free-text comment noted that people with dementia are sometimes transferred into long-term care facilities at discharge, and therefore long-term care staff should also be included. Consequently,

a new item was added for the second round: 'The residential aged care facility (or long-term care facility) staff knew about the changes to medications for the person with dementia'. Overall, 15 modified or new items were added for testing in round 2 ([figure 1](#)).

#### Round 2

Thirteen out of the original 22 respondents completed the second round (15 items), resulting in a response rate of 59% ([table 2](#)). Thirteen out of the 15 items (87%) were rated as relevant and important. Three items were reworded based on feedback from respondents. For example, several respondents reported it was important for carers to receive information on all of the medications that were discontinued during the hospital stay. Therefore, the item 'I was given information about any medications that were ceased in hospital' was changed to 'I was given information about all medications that were ceased in hospital'.

#### Final tool

Across the two CVI rounds, the tool included 30 items that evaluated medication management guidance provided at discharge. Twenty-eight items out of 30 (93%) met the predefined cut-off for the I-CVI.

### STAGE 2: PRETESTING–COGNITIVE INTERVIEWS

Five carers consented to participate, resulting in a response rate of 38% of the 13 participants who had agreed to be contacted ([table 2](#)). Results from the interviews with carers are presented in [table 4](#). In summary, after the cognitive interviews, the final survey included 30

**Table 3** Examples of I-CVI calculations for the relevance of the tool items over two rounds

Items	Relevance	Importance	Decision	Revised item for second-round CVI	Relevance	Importance	Decision
	I-CVI relevance score	I-CVI importance score			I-CVI relevance score	I-CVI importance score	
I was given information about the purpose of the medications.	1.00	1.00	Keep item				
I was given information about how long the person with dementia should be using their medications.	0.89	0.89	Keep item				
I was given information about any medication changes made in the hospital.	0.94	0.94	Keep item				
I was given information about the possible benefits and harms of medications.	0.89	0.89	Revise item	I was given information about the possible benefits of medications. I was given information about the possible harms of medications.	1 1	0.92 0.92	Accept Accept
I was asked if the person with dementia had problems taking their medications.	0.94	0.94	Keep item				
I was included in decisions about medications for the person with dementia.	0.94	0.94	Keep item				
I found the medication management guidance provided by the hospital healthcare professionals easy to understand.	0.89	0.89	Keep item				
I felt overwhelmed when receiving medication management guidance at discharge.	0.89	0.89	Keep item				
I felt confident to manage the medications for the person with dementia after discharge.	1.00	1.00	Keep item				
I was offered the choice of a dose administration aid prefilled with the medications for the person with dementia.	0.72	0.76	Revise item	I felt satisfied that I was offered the choice of a dose administration aid (eg, blister pack and dosette box) for the person with dementia.	0.92	0.92	Accept
The general practitioner (or primary care provider) knew about the hospital admission.	0.78	0.78	Delete item				

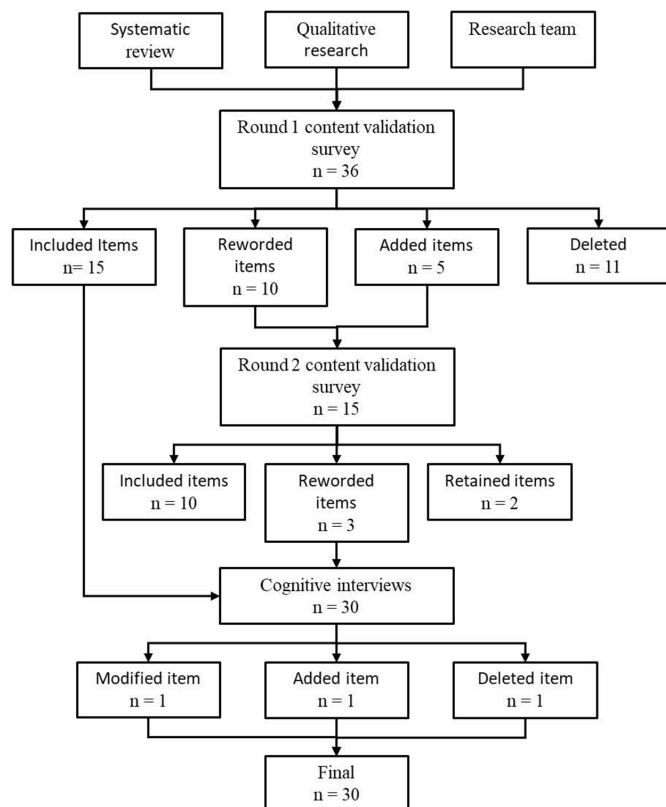
Continued

Table 3 Continued

Items	Relevance	Importance	Decision	Revised item for second-round CVI	Relevance	Importance	Decision
	I-CVI relevance score	I-CVI importance score			I-CVI relevance score	I-CVI importance score	
The general practitioner (or primary care provider) knew about the changes to medications for the person with dementia.	1.00	0.94	Revise item	The general practitioner (or primary care provider) knew if any medications were changed at discharge.	1	1	Accept
The community pharmacist knew about the hospital admission.	0.67	0.67	Delete item				
The community pharmacist knew about the changes to medications for the person with dementia.	0.78	0.78	Revise item	The local or regular pharmacist knew if any medications changed at discharge.	0.77	0.77	Keep

CVI, Content Validity Index; I-CVI, Item-Level Content Validity Index.

items: the item on harms was removed, and an additional item on carer participation in medication discussions was added. The tool is available in online supplemental table B (further validation of the tool is in progress, and this version of the tool should be considered as provisional).



**Figure 1** Items excluded, included and modified or reworded during content validation and cognitive interviews.

## DISCUSSION

This is the first study to develop a tool to evaluate the medication management guidance provided at discharge to carers of people living with dementia. This 30-item tool is unique in that it evaluates guidance provided on all aspects of medication management at hospital discharge.

In our study, the experts and consumers agreed that the items for domain 1 (provision of medication management guidance at discharge) were one of the key questions to capture. The feedback from several respondents highlighted that it was important to ask carers if they were provided guidance after discharge. Interestingly, several studies have shown that interventions provided to carers that extend beyond inpatient care resulted in lower use of high-risk medications, reduction in carer burden<sup>34</sup> and 30-day rehospitalisation rates.<sup>35</sup> Therefore, to capture this aspect, for the item on ‘When were you given medication guidance for the person with dementia?’ we included *after discharge* as an option.

Furthermore, the tool includes items that ask the carer if they have received advice on all aspects of medication management (table 1). Both formal and informal carers are reported to spend significant time after discharge to clarify medication changes with the hospital and often receive insufficient guidance on medication management at discharge particularly on the benefits and harms of medications, which reduces their capacity to provide appropriate medication management for the person with dementia.<sup>36–38</sup> For people living with dementia, this is even more critical as they are at higher risk of inappropriate polypharmacy, which increases risk of adverse events such as falls and hospitalisation.<sup>39 40</sup> Guidance on the benefit and risk of treatment with the carer can facilitate a review of medications, particularly those that have no additional

**Table 4** Results from cognitive interviews

Theme	Findings	Quotes	Action taken
Medication guidance	Most respondents understood the concept of 'medication management guidance' but were unsure if it should be interpreted as information provided in the written format, verbally by hospital staff information or both.	'It could be a little bit clearer that whether that is verbal, a fact sheet, a medication fact sheet, or directed to a website, or something like that' (Participant 1) 'Is guidance when someone talks to you, guiding you through it or is when the hospital gives you a piece of paper'. (Participant 2)	Include a clearer definition of medication guidance at the beginning and at the start of each section of the tool.
Hospital discharge	All respondents understood the concept 'hospital discharge'. However, one respondent reported that hospital discharge could be understood as any time period from admission to the time the person leaves the hospital to go home or to another facility.	'More explanation about hospital discharge. Just defining where is the period of hospital discharge. Is it when they go to the pharmacy to pick up the medications for the person, or is it when the doctor comes around? Just some examples of what it means'. (Participant 1)	Include a definition of discharge prior to the start of the tool to avoid ambiguity.
Side effects	Several respondents questioned the difference between the items 'I was given information about medication side effects' and 'I was given information about the possible harms of medications'. Participants reported 'side effects' to mean the same thing as 'harms', and a number felt that 'possible harms' would not be understood by the end user.	'I was given information about the probable harm. Is it saying side effects?' (Participant 3)	Delete the item 'I was given information and about the possible harms of medications' and keep the item 'I was given information about possible medication side effects'.
Carer involvement in medication management guidance	One participant noted that the item 'My concerns about the discharge medications for the person with dementia were listened to' needed to be modified to the active voice and reflect the carer requesting information about medications at the time of discharge.	'In every other instance (of the tool section) you're the recipient of information. For this item, you are the giver of information. I would change that statement and I would say something along the lines that when I was concerned about things they were answered'. (Participant 4)	Change the item into two items: (1) 'I had the opportunity to ask questions about medications for the person with dementia'; and (2) 'My questions about medications for the person with dementia were answered'.

benefit over the person's remaining life span.<sup>41</sup> Also, both formal and informal carers are reported to request increased support to manage complex medication regimens.<sup>42–44</sup> The tool is designed to encourage questions about the carers' need for support strategies, such as dose administration aides.

Cognitive interviews highlighted that it was important to include items that characterised the carer being actively engaged in medication decisions. Therefore, we included items which asked if they had the opportunity to ask questions and whether they had all their questions addressed. This is consistent with the literature on patient and carer participation as an important factor in improving care transitions after discharge from the hospital.<sup>45</sup> Several qualitative studies have shown that patient and carer engagement in medication guidance is limited at discharge, and some participants reported wanting to be engaged in medication decisions, including medications that can affect the cognition of the person with dementia.<sup>6 13</sup> Likewise, the tool includes items that evaluated how useful and easy to understand the medication guidance was, unlike other tools.<sup>16 20</sup> Difficulties in understanding medication guidance increase risk of medication-related problems and hospitalisation for the person with dementia.<sup>46</sup> Therefore, evaluating carer engagement and understanding of advice at hospital

discharge is important to identify gaps to inform interventions to improve safe medication management by carers.

Carers' limited confidence and preparation to manage medications for a person with dementia after hospital discharge and having poor care co-ordination are significant factors in preventable medication-related harm.<sup>13 47</sup> Existing tools focus on how carers conduct medication management activities for people living with dementia and not on the actual experiences of carers with respect to medication guidance at discharge. Without focusing on the experiences of medication advice provided at discharge, the opportunity to optimise medication use and management for people living with dementia and their carers is missed.

Continuity of care after hospitalisation is paramount to ensure safe medication management, particularly as people with dementia often experience potentially inappropriate polypharmacy.<sup>5 38 48</sup> Domain 5 of the tool evaluated whether primary care physicians, the long-term care facility and community pharmacists were aware of medication changes for the person with dementia, and if further instructions on medication management were obtained by the carer. The item that referred to the local or regular pharmacist for the person with dementia knowing about the medication changes at discharge did not meet the threshold for I-CVI. However, we retained



the item as pharmacists are involved with providing carers tailored medication advice and dose administration aids to manage polypharmacy after discharge.<sup>5</sup> Studies report a reduction of medication-related problems through engaging pharmacists for postdischarge review or reconciliation.<sup>49</sup> Likewise, communication about medication changes between hospital healthcare professionals, the primary care physician and long-term care facility staff is important to enabling continuity of care.<sup>48</sup> The uniqueness of our tool is that it captures whether medication changes are conveyed to all healthcare providers at discharge and identifies the sources of medication management guidance obtained by the carer other than what the hospital staff provides.

Moreover, the tool provides a comprehensive evaluation of medication management guidance for carers of people living with dementia during discharge. Hospitals could use the tool to identify gaps and monitor improvements in optimising medication management guidance for carers of people living with dementia and to promote standardisation of quality care. The tool could also be used by healthcare professionals during consultations at discharge to ensure that medication management guidance is complete. However, further work is required to explore how the tool could be implemented by healthcare professionals in routine clinical practice. The tool may also serve as a conversation guide provided to carers of people living with dementia before discharge to facilitate active engagement during guidance provided by the healthcare professional. Furthermore, it may be used to enhance communication across transitions of care by documenting the aspects of medication management guidance which were initially provided to carers so that guidance could be continued and any gaps could be addressed after discharge. The tool has the potential to be integrated with other patient-reported measures as part of a multifaceted approach to help hospitals monitor practices and ensure value-based care for people living with dementia.<sup>50</sup> In terms of research, the tool may serve to inform the design of interventions to improve the delivery of medication management guidance at discharge. Also, it could ascertain the success of interventions directed at improving carer medication management at discharge.

### Strengths and limitations

The main strengths of this study were the adoption of a mixed methods approach to ensure comprehensiveness of the tool, and that the tool was developed in partnership with carers of people living with dementia throughout all phases of the research process. The tool's inception was based on the research team's earlier work with carers of people living with dementia which was also used to inform the tool domains.<sup>7 15</sup> The tool comprised five domains which comprehensively evaluated medication management guidance at discharge. As such, the tool is unique and fulfils a gap in the literature as current tools only evaluate carer activities with respect to medication management for the person with dementia in other

care settings.<sup>16 17 20</sup> Content validation allowed amendments to be made to the tool over two rounds using expert and consumer feedback. The subsequent adoption of cognitive interviews with carers of people with dementia ensured that the tool instructions and items were easy to understand by the end user. This method encouraged respondents to answer in any manner they choose, free from bias from the interviewer.<sup>33</sup> Furthermore, the tool could also be adapted for use in different populations other than carers of people with dementia. Carers for older adults with chronic conditions (eg, Parkinson's disease and very frail older adults) similarly struggle with medication regimen complexity at hospital discharge and communication about medication plans of care across transitions being poorly organised and disjointed.<sup>6</sup>

There are limitations to this study. For the content validation, it was unknown whether the panel interpreted the items' importance and relevance correctly or not. However, we did provide explanations for rating both the importance and relevance of the items at the beginning of the survey and for content validation studies. At this stage, the tool is designed for carers who have a major role in managing medications for people living with dementia. However, there is a potential for the tool to be used for people living with dementia and who are independent in their medication management. However, this needs to be explored further. Also, while the tool is comprehensive and easy to administer without training, it may take up to 15 min to complete. Furthermore, it may prove useful to develop a simple patient/carer checklist form to empower carer involvement in medication management guidance at discharge. Information on co-ordination of medication management guidance after discharge may not be available at the time of discharge, and as such, these data may not be completed by all respondents. Another study limitation was that cognitive interviews were not conducted with formal carers. Finally, further work to provide insights into whether this tool might be useful in guiding clinical decision needs to be conducted. The next steps are to pilot the tool with healthcare professionals and carers at the time of hospital discharge to test the acceptability and utility of the tool in practice.

### CONCLUSIONS

This tool is the first to evaluate medication management guidance provided at discharge for carers of people with dementia. The tool comprised 30 items addressing five key domains. The next steps are to pilot the tool to establish acceptability across different practice settings (eg, large/small hospitals in urban, regional and rural settings). While the implementation of the tool in practice is yet to be established, the tool may be useful to inform future research strategies to improve medication management guidance at discharge, which may reduce medication-related harm and reduce carer stress.

### Author affiliations

<sup>1</sup>Sydney Pharmacy School, Faculty of Medicine and Health, The University of Sydney, Camperdown, New South Wales, Australia

<sup>2</sup>Institute of Applied Health Sciences, University of Aberdeen, Aberdeen, UK

<sup>3</sup>Sydney Nursing School, Faculty of Medicine and Health, The University of Sydney, Camperdown, New South Wales, Australia

<sup>4</sup>Clinical Pharmacology and Aged Care, Kolling Institute of Medical Research, Royal North Shore Hospital and the University of Sydney, St Leonards, New South Wales, Australia

<sup>5</sup>Charles Perkins Centre, The University of Sydney, Camperdown, New South Wales, Australia

**Twitter** Christine Bond @christinebond20

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**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, reporting or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by the human research ethics committee of the University of Sydney (project number 2019/578). Written informed consent was obtained from all carer participants prior to participation. The participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information.

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### ORCID iD

Mouna J Sawan <http://orcid.org/0000-0002-0565-3524>

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**Supplementary table A. Standards for Reporting Qualitative Research (SRQR)<sup>1</sup> Checklist**

No	Topic	Item	Reported in Section
<b>S1</b>	Title	Concise description of the nature and topic of the study Identify in the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title
<b>S2</b>	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Abstract
<b>S3</b>	Problem Formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Introduction
<b>S4</b>	Purpose or research question	Purpose of the study and specific objectives or questions	Introduction
<b>S5</b>	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	Methods
<b>S6</b>	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Methods
<b>S7</b>	Context	Setting/site and salient contextual factors; rationale	Methods
<b>S8</b>	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	Methods
<b>S9</b>	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Methods
<b>S10</b>	Data collection methods	(as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	Methods



<b>S11</b>	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study; Number and relevant characteristics of participants,	Methods
<b>S12</b>	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Methods
<b>S13</b>	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Methods
<b>S14</b>	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	Methods
<b>S15</b>	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	Methods
<b>S16</b>	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Results
<b>S17</b>	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 4
<b>S18</b>	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Discussion
<b>S19</b>	Limitations	Trustworthiness and limitations of findings	Discussion
<b>S20</b>	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Conflict of interest
<b>S21</b>	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Funding Information

1. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;**89**(9):1245-51.

## An evaluation of medication management guidance provided to carers of people living with dementia at hospital discharge

**Definition of Carer:** A person who assists and supports a person living with dementia and:

- is the primary or secondary carer;
- the type of care may be routine, regular or occasional; or
- has caregiving responsibilities that are either informal in nature (unpaid) or formal (paid)
  - informal carers provide care within the context of an existing relationship e.g. family member, friend or neighbour;
  - formal carers directly provide or manage care in the community or in a residential care facility (also known as a long-term care facility). They are registered nurses, enrolled nurses, assistants in nursing, allied health workers, community care workers and personal care attendants.

**Definition of medication management:** As a carer, you are involved in one or more of the following activities: select, supply, prepare, administer, record and monitor (including review) medications for the person you care for. The person you care for is someone who lives with dementia in the community, a retirement home or a residential aged care facility.

**Definition of medication management guidance:** As a carer, this means a hospital provides you with information in written and/or verbal form to ensure that you safely manage medications for the person living with dementia. Examples of medication management guidance are:

- information in a discharge summary (summarises care provided during hospital stay including an explanation of any changes made to medications and instructions for follow-up care),
- a list of medications (detailed instructions on how to take medications); or
- hospital staff talking with you about medications for the person you care for.

**Hospital Discharge:** this occurs when the person you care for no longer needs care in hospital and can go home or to another facility. On leaving the hospital, the hospital provides you with medication management guidance to help manage medications for the person living with dementia in their home or at another facility. Medication management guidance provided by the hospital can occur at, during or after the time of discharge.

**Please confirm that you are eligible to participate in the survey by confirming that you meet ALL of the following criteria:**

1. I am a carer (as defined above) of a person living with dementia, who is taking medication;
2. I am responsible for managing the medications of the person living with dementia who I care for;
3. The person living with dementia who I care for has had at least one admission to and discharge from a hospital
4. I am aged 18 years and over

**[Survey Starts here](#)**

**Part 1: Provision of medication management guidance at hospital discharge**

The following statements are about the most recent time the person you care for was discharged from hospital. How and when was medication management guidance provided to you in your role as the carer for the person living with dementia? **This can include receiving guidance in written and/or verbal form** on some or all medications.

<p>1. When were you given medication management guidance for the person with dementia? (more than one answer is possible)</p> <p>Answer options:</p> <p><input type="checkbox"/> On the day of discharge</p> <p><input type="checkbox"/> On the day before discharge</p> <p><input type="checkbox"/> On another day during hospital admission</p> <p><input type="checkbox"/> After discharge</p> <p><input type="checkbox"/> I was not given medication management guidance</p> <p><input type="checkbox"/> Other (please specify) .....</p>
<p>2. Which healthcare professional provided medication management guidance on discharge? (More than one answer is possible)</p> <p><input type="checkbox"/> Physician (doctor)</p> <p><input type="checkbox"/> Nurse</p> <p><input type="checkbox"/> Pharmacist (Chemist)</p> <p><input type="checkbox"/> Other (please specify) .....</p> <p><input type="checkbox"/> I do not know</p> <p><input type="checkbox"/> Not applicable</p>
<p>3. How was the medication management guidance provided? (more than one answer is possible)</p> <p>Answer options:</p> <p><input type="checkbox"/> Face to face</p> <p><input type="checkbox"/> Written communication (e.g. list of medications, discharge summary, medication instructions)</p> <p><input type="checkbox"/> Verbal communication (e.g., telephone)</p> <p><input type="checkbox"/> Other (please specify) .....</p> <p><input type="checkbox"/> Not applicable</p>
<p>4. Were you asked about your ability to obtain a supply of medications after discharge?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Not applicable</p>

Please feel free to comment:

**Part 2: Carer understanding of medication management guidance provided at discharge**

The following questions are about your understanding of the medication management guidance the hospital provided for the person you care for. Medication management guidance could have

occurred at, during or after the time of discharge. Examples of medication management guidance are:

- information in a discharge summary (summarises care provided to the person you care for during hospital stay including an explanation of any changes made to medications and instructions for follow-up care),
- a list of medications (detailed instructions on how to take medications); or
- hospital staff talking with you about medications for the person you care for.

**How much do you agree** with the following statements?

If you answered 'I was not given medication management guidance' in question 1, please answer 'not applicable' for the following statements.

Items	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
5. I found the discharge summary information on medications for the person with dementia easy to understand						
6. I found the list of medications for the person with dementia easy to understand						
7. I found the medication guidance explained by the hospital healthcare professional easy to understand						
8. The hospital healthcare professional spent adequate time explaining the medication guidance to me						

Please feel free to comment:

### **Part 3: Carer engagement in discussing the safe use of medications at discharge**

The following statements are about the medication management guidance the hospital provided to ensure that you safely managed medications for the person living with dementia. Medication management guidance could have occurred at, during or after the time of discharge. **This can include receiving guidance/information in written and/or verbal form** on some or all medications. **How much do you agree** with the following statements?

If you answered 'I was not given medication management guidance' in question 1, please answer 'not applicable' for the following statements.



Items	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
9. I was given information about the purpose of the medications						
10. I was given instructions about how to administer medications						
11. I was given information about possible medication side effects						
12. I was given information on medications that can act on the brain and affect the person with dementia's mood and behaviour (e.g. medicines used to treat behaviours or for sleep, also known as psychotropic medications)						
13. I was given information about how long the person with dementia should be using each of their medications						
14. I was given information about any medication changes made in hospital						
15. I was given information about any medications that were ceased in hospital						
16. I was given information about which medications could interact with each other						
17. I was given information about the possible benefits of medications						
18. I was asked if the person with dementia had any problems taking their medications						
19. I was included in decisions about medications for the person with dementia						
20. I had the opportunity to ask questions about medications for the person with dementia						
21. My questions about medications for the person with dementia were answered in a way I could understand						

Please feel free to comment:

**Part 4: Carer preparedness to manage medications after discharge**

The following questions are about how well the hospital provided you with medication management guidance to ensure that you safely managed medications for the person living with dementia.

Medication management guidance could have occurred at, during or after the time of discharge.

**This can include receiving information or instructions in written and/or verbal form** on some or all medications.

If you answered 'I was not given medication management guidance' in question 1, please answer 'not applicable' for the following statements.

Items	Not well at all	Not so well	Neither well or not so well	Well	Very well	Not applicable
22. I felt overwhelmed when receiving medication guidance at discharge						
23. I was satisfied with the medication information provided at discharge						
24. I felt confident to manage the medications for the person with dementia after discharge						
25. I felt satisfied that I was offered the choice of a Dose Administration Aid (e.g. blister pack, dosette box, webster pack) for the person with dementia						

Please feel free to comment:

**Part 5. Co-ordination of medication management guidance after discharge**

The following questions are about your medication-management related activities as the carer for the person with dementia after leaving the hospital. **How much do you agree** with the following statements?

Items	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable	Do not know

26. It was easy to obtain a supply of medications from the local or regular pharmacist after discharge							
27. The General Practitioner (or primary care provider) knew if any medications were changed during hospital stay							
28. The local or regular pharmacist knew if any medications changed at discharge							
29. The residential aged care facility (or long-term care facility) staff knew if any medications changed at discharge							

30. Beyond what the hospital staff had provided, I obtained further information on medication management from (more than one answer is possible):

1. Online websites
2. General Practitioner (or primary care provider)
3. Local/regular pharmacist
4. Residential aged care facility (or long-term care facility) staff
5. Hospital pharmacist
6. I didn't seek or obtain any further information
7. Other (please specify)