

1 **Research Article**

2

3 **Caregivers' experiences of medication management advice for**
4 **people living with dementia at discharge**

5

6 **Short running title:** Caregiver guidance on medication management
7 for people living with dementia at discharge

8

9 **Authors:**

10

11 Dr Mouna J Sawan PhD ¹, Prof. Yun-Hee Jeon PhD ², Prof. Christine
12 Bond PhD ³, Prof. Sarah N Hilmer PhD ⁴, Prof. Timothy F Chen PhD ¹,
13 Damian Wennekers ⁵, A/Prof Danijela Gnjidic PhD ^{1,6} .

14

15 1) School of Pharmacy, Faculty of Medicine and Health, The University
16 of Sydney Camperdown, NSW, Australia, N347 Pharmacy and Bank
17 Building (A15), The University of Sydney, NSW2006, Australia.

18 2) Sydney Nursing School, Faculty of Medicine and Health, The
19 University of Sydney, Camperdown, NSW, Australia, 88 Mallett Street
20 – Building M02, The University of Sydney, NSW2006, Australia

21 3) Institute of Applied Health Sciences, University of Aberdeen,
22 Aberdeen, UK, School of Medicine, Medical Sciences and Nutrition,
23 Polwarth Building, Fosterhill, Aberdeen, AB25 22D, Scotland United
24 Kingdom

25 4) Clinical Pharmacology and Aged Care, Kolling Institute of Medical
26 Research, Royal North Shore Hospital and Northern Clinical School,
27 Faculty of Medicine and Health, St Leonards, NSW, Australia

28 5) School of Pharmacy, Faculty of Science, University of Utrecht,
29 Utrecht, The Netherlands, Utrecht University Heidelberglaan 8, 3584
30 CS Utrecht, The Netherlands

31 6) Charles Perkins Centre, The University of Sydney, Camperdown,
32 NSW, Australia

33
34 **Corresponding author details:** Mouna Sawan, School of Pharmacy,
35 Faculty of Medicine and Health, The University of Sydney, New
36 South Wales, Australia. Email mouna.sawan@sydney.edu.au.
37 Telephone +6186279109. Twitter: @mouna_sawan

38
39 **Word Count:** Abstract – 249, Main text- 4524, number of references
40 – 37, number of tables- 2

41 **Data Availability Statement:** Data available in article supplementary
42 material

43 **Conflict of Interest :** None

44 **Description of Authors' Roles:** Sawan, Gnjudic: conception and
45 design, acquisition of data, analysis and interpretation of data,
46 drafting, revising the article critically for important intellectual
47 content. Jeon, Bond, Hilmer, Chen: conception and design, analysis
48 and interpretation of data, revising the article critically for important
49 intellectual content. Wennekers: analysis and interpretation of data
50 and revising the article.

51

52

53

54

55

56

57

58

59

60 **Abstract**

61

62 **Rationale, aims and objectives:** Caregivers of people living with
63 dementia play an essential role in managing medications across
64 transitions of care. Adequate caregiver medication management
65 guidance at hospital discharge is important to ensure optimal
66 outcomes from medication use. This qualitative study explores the
67 experiences and perspectives of caregivers about the medication
68 management guidance provided at hospital discharge.

69 **Methods:** A qualitative approach using semi-structured, telephone
70 interviews was conducted with 31 caregivers of people with dementia
71 across Australia. Purposive sampling was used to ensure maximum
72 variation of diverse experiences and perspectives.

73 **Results:** Caregivers' experiences of medication guidance for people
74 with dementia at discharge were described in three themes including:
75 a) inadequate information about medication management at discharge;
76 b) limited caregiver engagement in medication management decisions;

77 and c) difficulties ensuring medication supply post discharge. Most
78 participants indicated they would like to be included in discussions at
79 discharge. However, participation was influenced by caregivers being
80 overwhelmed by discharge processes; proactively seeking information
81 on medication-related harm; and belief in advocacy as part of their
82 caregiver role. Caregivers reported they would like to receive a
83 tailored medication list for people with dementia which included
84 information on medications that may impact on the patient's
85 cognition, and for hospital staff to communicate with both the
86 community pharmacist and primary care physician, to improve co-
87 ordination post transition.

88 **Discussion:** In our study of caregivers of people with dementia, we
89 identified key recommendations to facilitate regular participation of
90 people living with dementia and their caregiver around medication
91 guidance at discharge.

92 **Key Words:** Transitions in care, hospital discharge, carers, caregiver
93 education, decision making
94

95 **1. Introduction**

96 Older people living with dementia often have multiple comorbidities,
97 leading to polypharmacy and frequent use of acute healthcare services
98 ^{1,2}. A recent UK study found that 50% of adults 65 years and over with
99 dementia were admitted to hospital during the first year following a
100 dementia diagnosis ¹. During hospitalisation, patients living with
101 dementia are more likely to be exposed to inappropriate polypharmacy
102 than those without dementia ^{3,4}. Consequently, older people living
103 with dementia are at high risk of experiencing medication-related
104 problems following hospital discharge due to communication failures,
105 delayed, poorly timed discharges leading to reduced quality of life ⁵⁻⁷.
106 Caregivers are often responsible for managing medications for people

107 living with dementia, which is particularly important at hospital
108 discharge to ensure safe use of medications ⁸⁻¹⁰.
109
110 Caregivers play an essential role in managing medications for a person
111 with dementia which is particularly relevant as the disease progresses
112 and medication regimens become complex ^{8,9}. Their responsibilities
113 include decision making, information giving and receiving with
114 healthcare professionals, and managing medications across transitions
115 of care ⁹⁻¹². The complexities of medication management increase at
116 care transitions due to complex dosage regimens, increased
117 medication burden and managing medications without formal training
118 ¹⁰⁻¹². Adequate caregiver medication management guidance at
119 discharge is important to ensure optimal outcomes from medication
120 use and to reduce caregiver burden ^{13,14}. Also, the engagement of
121 individuals living with dementia and caregiver with health

122 professionals to discuss and identify patient's goals, values and
123 preferences ensures medication decisions are person-centred ¹⁵.

124
125 However, care transitions at discharge can be challenging for patients
126 and their caregivers and a vulnerable stage in the patient pathway ¹⁶⁻¹⁸.
127 Studies have reported that caregivers experience poor communication
128 about medication plans and changes in medications, limited
129 opportunities to participate in medication decisions and difficulties in
130 following complicated medication regimens ^{11,19-23}. To date, there has
131 been a limited focus on caregivers' experience of medication
132 management advice for people with dementia and factors that
133 influence caregiver participation in medication plans specifically at
134 discharge ¹⁹⁻²¹.

135
136 The World Health Organisation endorsed Transition of Care as a
137 priority in Medication Without Harm in 2016 to include a set of

138 actions to ensure coordination and continuity of healthcare as patients
139 transfer between healthcare settings, such as hospitals to the home/
140 long term care facilities ¹⁵. Elements of the discharge process include
141 verifying the patient's medication list at the point of hospital
142 discharge, ensuring patients can understand what medications they are
143 taking, for how long and why, and transfer of a discharge
144 summary/referral letter to the patient's primary care physician ¹⁵.
145 Medication management decisions for people living with dementia
146 often require a surrogate decision maker ²⁴. There is a need to identify
147 how existing discharge processes could be further improved to support
148 caregiver medication management for people with dementia. This will
149 inform development of systems of care that optimise the safe and
150 effective use of medications for people living with dementia after
151 discharge from hospital.

152

153 Therefore, the aim of this study was to explore the experiences and
154 perspectives of caregivers for people living with dementia about the
155 medication management guidance provided at hospital discharge. Our
156 specific aims were to: 1) explore caregivers' experiences of medication
157 guidance for people with dementia at discharge; 2) identify factors that
158 influence caregiver participation in medication plans at discharge; and
159 3) identify recommendations to support caregiver medication
160 management post discharge.

162 **2. Methods**

163 2.1 Study design, setting and participants

164
165 This was a qualitative study involving semi-structured interviews with
166 caregivers of people with dementia involved in hospital discharge

167 processes across Australia. Ethics approval was obtained from the
168 University of Sydney Human Research Ethics Committee (2019/578).
169
170 Caregivers were defined as a person who assists and supports a person
171 living with dementia, and: 1) is characterised as the spouse, child, or
172 friend; 2) who are the primary or secondary caregiver; or 4) their
173 caregiving responsibilities may be paid or unpaid ¹². The participant
174 inclusion criteria were: 1) caregivers who care for a person living with
175 dementia discharged from the hospital in the last 12 months; and 2)
176 care recipients living in the community or residing in long term care
177 facilities. Caregivers of care recipients residing in long term care
178 were also included in the study as medication management in this
179 setting is often complex and associated with significant harms ²⁵.
180
181 Caregivers across Australia were invited to participate. Recruitment
182 was undertaken from October 2019 until March 2020 and facilitated

183 by consumer advocacy groups, consumer support organisations and
184 social media (Twitter). In addition, a research engagement service for
185 dementia research known as StepUp for Dementia Research Australia
186 was utilised ²⁶. If a caregiver wished to participate in the study, they
187 were able to contact investigators by phone or e-mail. Purposive
188 sampling was used to ensure maximum variation of diverse
189 experiences and perspectives were covered including caregivers’
190 education level, age, gender and relationship with care recipient, as
191 well as care recipients’ total number of medications and location in
192 Australia. Participant information statement and consent forms were
193 sent based on caregivers’ preferred mode of communication (e-mail or
194 mail) identified at the point of contact. Once written informed consent
195 was obtained, the interviews were conducted by the first author (MS)
196 who has experience in qualitative research over the telephone to allow
197 broader reach of geographically dispersed respondents.

2.2 Study Procedure

The interview guide (see Table S1 published as supplementary material) was semi-structured and included open-ended questions, followed by specific prompts to elicit the details needed to understand the topic. It comprised three sections. The first section explored if and what medication resources caregivers received at hospital discharge and how useful were they to caregivers. The second section explored caregivers' experiences of medication management guidance at hospital discharge and their perceptions of the barriers and facilitators that influenced their involvement. The third section explored the types of support about safe medication administration and use at home which caregivers wanted. Medication management was defined as the supply, assistance with administration, communicating with health care professionals, monitoring for medication related harm and making decisions about medications²⁷. Caregiver and care recipient

215 demographic characteristics were collected at the time of the
216 interviews. The interview guide was piloted with the first two
217 interviews. A preliminary analysis was undertaken by the research
218 team (MS, DG) to assess responses and minor changes to the
219 interview guide were made. Data from the first two interviews were
220 included in the final analysis.

221
222 Interviews took place between October 2019 and March 2020 until
223 thematic saturation was reached, whereby additional interviews did
224 not yield any new insight relevant to the study, and representation of
225 key characteristics was achieved²⁸. All interviews were recorded, and
226 the median duration of the interview was 37 minutes (inter-quartile
227 range (IQR) 18).

228 229 2.3 Analysis

230

231 Interviews were audio taped, transcribed verbatim, and reviewed for
232 accuracy by comparing transcription with the audio file by MS.
233 Transcripts were de-identified and entered into QSR NVivo (version
234 12) for data management. Content analysis was conducted using an
235 inductive approach to identify categories and themes that emerged
236 from the data which answered the purpose of our inquiry without the
237 restraint of a structured framework ^{29,30}. The method for content
238 analysis was informed by Downe-Wamboldt ³¹. This approach focuses
239 on achieving trustworthiness of the results throughout the steps of
240 analysis. Researchers (MS and DW) began with line by line coding of
241 transcripts. Subsets of the coded texts were analysed further to provide
242 quantification of the codes/terms. The codes were also sorted into
243 categories using aims 1 and 2 as a guide. The research team met to
244 review samples of the transcribed data representing the full range of
245 categories and coding framework and discuss emerging themes. These
246 were reviewed and refined to reconcile differences in interpretation

247 until no new categories emerged, and all researchers agreed on the
248 final interpretation of the data. Reflexivity was facilitated by the by
249 on-going dialogues with the research team throughout data collection
250 and analysis.

251
252 To address aim 3, the first author (MS) aligned the codes which
253 described proposed recommendations, derived from aligning
254 participant quotes with the themes identified for study aims 1 and 2
255 using a pragmatic approach to qualitative analysis.

257 **3. Results**

258
259 A total of thirty-one caregivers across Australia participated in semi-
260 structured interviews (Table 1). The majority of participants were
261 female and cared for their parent, nine cared for their spouse/partner,
262 and two were friends of the care recipient. Twenty caregivers who

263 expressed interest in participating were not able to be interviewed
264 because they did not meet the inclusion criteria or data saturation had
265 been reached.

266

267 Caregivers' experiences of medication guidance for people living with
268 dementia at discharge were described in three themes: a) inadequate
269 information about medication management at discharge; b) limited
270 caregiver engagement in medication management decisions; and c)
271 difficulties ensuring medication supply post discharge. Three
272 categories emerged which explained the facilitators and barriers to
273 caregiver participation in medication management guidance and
274 decisions at discharge. Table S2 published as supplementary material
275 contains a summary of themes with additional participant quotes and
276 participant identifier.

277 **3.1 Caregivers' experiences of medication guidance at discharge**

278

279 **a) Inadequate information about medication management at**
280 **discharge**

281 Many caregivers reported that they received no information
282 concerning medication management at discharge such as changes in
283 medication, duration of therapy, indications for treatment or drug-drug
284 interactions. Upon discharge, caregivers felt they were not counselled
285 on discharge medications that could impair cognition or exacerbate
286 symptoms of dementia, which was important in addressing care needs
287 (e.g. behaviour, cognition, delirium, constipation) post transition. The
288 absence of specific advice about medications administered during
289 admission (e.g. anaesthesia during surgery) was also mentioned.

290
291 *I think it was very distressing because he was all over the place,*
292 *the anaesthesia took days to wear off, he was stumbling a lot,*
293 *even getting him from the ward down to the car, so he was*
294 *stumbling and it was quite traumatic for me. (Caregiver 1)*

295

296 Of the caregivers who received medication information, participants

297 reported receiving up to three modes of communication: written

298 discharge summary, medicines list and explanation by the registered

299 nurse, hospital physician or pharmacist (in-person or via the phone).

300 Over half of caregivers reported to have communicated with a

301 healthcare professional at discharge and described that the

302 conversation was brief, focused on supply of medication and scripts

303 and did not include specific medication information such as the

304 risk/benefit of medications, potential adverse effects or duration of

305 treatment. Many caregivers reported that the discharge summary was

306 too long, dense, included technical jargon which made it difficult to

307 read and that they had limited time to go through it.

308

309 *There were five medications initially one to keep him calm, to*310 *elevate his mood and to manage his restlessness, aggression.*

311 *They did not give specific information other than ‘ we've tried to*
312 *give him this tablet but he wouldn't take it’. (Caregiver 8)*

313
314 Some caregivers noted there was a lack of timely exchange between
315 the hospital and primary care physician or long term care facility, and
316 others reported that the information on the discharge summary was
317 inconsistent or not updated with the hospital treatment plan for
318 discharge. Inadequate documentation on medication was reported to
319 result in caregivers making up recipient medication lists post
320 discharge without the help of a healthcare professional.

321
322 *While he was in hospital, he developed delirium, when the*
323 *geriatrician spoke to them she said we are going to stop with the*
324 *oxycodone because that could be causing it. On the discharge*
325 *summary which you know, we got two weeks later, they actually*
326 *discharged him with oxycodone. (Caregiver 13)*

327

328 A number of caregivers reported receiving medication lists and
329 described that the content was useful as it outlined medications which
330 were initiated and/or changed at discharge, indications for the use of
331 medications and instructions which were easy to understand. The
332 medication list was considered a valuable reference as it elucidated
333 medication administration schedules and highlighted medication
334 changes and possible side effects; information that was not received
335 from the physician or registered nurses during hospitalisation.

336

337 **b) Limited caregiver engagement in medication management**
338 **decisions**

339 A number of caregivers reported that they felt included in treatment
340 discussions with physicians and received information on the risk and
341 benefits of medications and explanations for treatment changes.

342 However, many caregivers felt that they were not given opportunities
343 to be involved in medication decisions throughout hospitalisation.
344

345 *I stopped in to see him, and he was very sleepy. The nurse told me*
346 *that because of his agitation he had been given risperidone, and*
347 *this was without any consent. Nobody called me, nobody asked*
348 *about this at all, I know what the side effects are, and you have*
349 *got to be very careful about not giving risperidone because of the*
350 *dementia and the heart problems. (Caregiver 7)*
351

352 Some caregivers felt that there were limited efforts by the hospital
353 staff to listen to them during hospitalisation and at discharge regarding
354 concerns with potential medication adverse effects.
355

356 *He was literally sleeping that whole time, we didn't think it was*
357 *necessary for him to probably be on melatonin at the time. In*

358 *hospital we didn't get too many answers to be honest. It was sort*
359 *of, well this is what he's taking, there was really no*
360 *communication regarding that. (Caregiver 3)*

361

362 Many caregivers also reported at discharge, that the hospital staff
363 spent limited or no time to ask if they had preferences or concerns that
364 included how to improve medication adherence or supervise the
365 person with dementia managing their medication in light of their
366 declining cognitive ability.

367

368 *There was no real assistance given in terms of any method I*
369 *should employ to ensure that she was in fact taking them but also,*
370 *you know, how to sort of organise the taking of them. All the sort*
371 *of actual administration was kind of basically up to me.*

372 *(Caregiver 14)*

373

374 In several cases, caregivers felt to have been overlooked by hospital
375 staff as they were not the recognised as the primary care giver or the
376 communication (discharge letter/instructions) was provided to the
377 long term care facility. This left several caregivers to perceive that
378 their voice did not matter as they experienced limited communication
379 with health professionals, which presented a challenge to caregivers to
380 ensure follow-up of medication post transition/discharge.

381

382 *There is no discussion at all, you're not given any details, you're*
383 *irrelevant. They just tell the nursing home. I feel that they if*
384 *you're not a blood relation or next of kin, you could say you're the*
385 *carer you don't get the respect you deserve. (Caregiver 20)*

386

387 **c) Difficulties ensuring medication supply post discharge**

388 Many caregivers highlighted they experienced challenges ensuring
389 continuity of medication supply post discharge as the hospital

390 provided three days supply of medication. If the discharge took place
391 before or during the weekends, caregivers had difficulty organising an
392 immediate appointment with the primary care physician to obtain
393 prescriptions and ensure medications were purchased from the
394 pharmacy and administered. The pressure to ensure the timely
395 administration of medications contributed to the caregiver stress and
396 burden.

397

398 *They only gave me some of his medication, they told me that was*
399 *all, and they only give you like three days' worth. For somebody*
400 *with dementia and they discharge you on a Friday and the*
401 *medication takes you to Monday morning. That's not good*
402 *because you can't get the doctor, I have a lot of trouble getting*
403 *him anywhere, you know. (Caregiver 16)*

404

405 Some caregivers reported reasons for delayed visits to the primary
406 care physician (General Practitioner) to follow-up on medications and
407 prescriptions post discharge. These included feeling tired from their
408 involvement in their care recipient's hospital admission, difficulties
409 associated with managing behavioural symptoms of the person with
410 dementia during transportation or unable to take time off work. One
411 caregiver reported a positive experience at discharge as they obtained
412 additional supply of medications from the hospital upon request to
413 ensure continuity of care post discharge.

414
415 *After spending five weeks in hospital. I was tired from going in*
416 *and out. That was the reason they gave me extra medication*
417 *because I thought she was too dangerous to get in and out of the*
418 *car. They gave me enough medication for a couple of weeks.*
419 *(Caregiver 22)*

421 Caregiver burden from ensuring immediate supply of medications also
422 extended to several caregivers who utilised dose administration aids
423 (DAA) packed by community pharmacists. A number of caregivers
424 reported a positive experience, with the hospital pharmacy
425 communicating directly with the community pharmacists to ensure
426 medication changes be implemented in the DAA. Some caregivers
427 reported that medication changes were not communicated to the
428 community pharmacist resulting increased responsibility to ensure
429 medication supply.

430 **3.2 Factors that influence caregiver participation in medication** 431 **management plans at discharge**

432

433 **a) Caregivers overwhelmed by discharge processes**

434 Many caregivers felt overwhelmed by the nature of the hospital
435 discharge processes because of multiple competing responsibilities at

436 the time of and post discharge, including managing medications. A
437 number of caregivers reported that the discussion at discharge
438 revolved around the suitability of discharging the patient leaving
439 limited or no time to discuss important information about medications.

440
441 *We were given 24-hours notice to prepare how we were going to*
442 *take her home. And so suddenly, I'm given all this paperwork,*
443 *and somebody is just flicking through these pages. The sheer*
444 *volume of information was very confusing to me and it all came*
445 *at discharge. It was too much information at that point in time,*
446 *which was highly emotionally charged. (Caregiver 31)*

447
448 Several participants reported that that they were not able to be present
449 at the time of discharge because the discharges were unplanned,
450 abrupt, or the timing conflicted with their work commitments. A
451 number of caregivers reported that they were contacted by hospital

452 staff via telephone and received information to support medication
453 management post transition. Caregivers reported that the experience
454 was positive as they felt involved even though they had not been
455 present at discharge.

456

457 Some caregivers reported that the hospitalisation caused caregivers'
458 tiredness and stress from managing the emotional needs of the person
459 with dementia and addressing exacerbation of symptoms triggered by
460 the unfamiliar hospital environment. The stress created by the
461 discharge process limited the caregiver's ability to ask questions about
462 their care recipients' medications at discharge. As a result, caregivers
463 reported that they required additional support at the time of and post
464 discharge to facilitate engagement and planning of medication
465 management post transition.

466

467 *I'm happy to ask, but I don't always think of the right questions to*
468 *ask. I'm confident to ask, but it's just thinking of what to ask. I*
469 *don't know, and then you sometimes you're tired and you've been*
470 *there a long time and you just want to go home. You get home*
471 *and you think I should have asked them. (Caregiver 22)*

472

473 **b) Caregivers proactively seeking information to ensure avoidance**
474 **of medication harm**

475 Most participants reported involvement in several activities to ensure
476 medication safety at discharge. Some caregivers questioned hospital
477 staff during admission or at discharge about the benefit of
478 medications. This included raising concerns about medications that
479 may be impacting on the patient's cognition or exacerbating
480 symptoms of dementia, and querying the use of medications, such as
481 psychotropics and opioids, with hospital staff due to concerns about
482 side effects and/or multiple medications (i.e. polypharmacy).

483

484

He started to show signs of hallucination. And I remembered one

485

of my colleagues saying she had been given strong painkillers

486

that made her hallucinate. So that's when I said to them, what is

487

it exactly that you're giving him (Caregiver 27)

488

489

Post discharge, many caregivers reported seeking information about

490

the indication, duration of therapy and potential adverse effects of

491

medications initiated by the hospital. Caregivers wanted to gain more

492

understanding of medications to increase confidence in managing

493

medications to ensure medication safety post transition and preparing

494

for triggers that exacerbate confusion in people living with dementia.

495

Sources of information included the internet search engines, education

496

materials accessible through support organisations (e.g. the Wicking

497

Dementia Centre and National Prescribing Service MedicineWise)

498

and on-line courses on dementia, medicines information provided by

499 the community pharmacists, primary care physician and long term
500 care facility staff.

501

502 *Well the internet gave me an idea for how long the medication*
503 *would be given, it's almost like it's only like a short thing, like a*
504 *short term measure and the dangers of what's to come, like*
505 *possibilities of heart attacks and compromised health and all that*
506 *sort of stuff. (Caregiver 21)*

507

508 **c) Belief in advocacy as part of the caregiver role**

509 For some caregivers, involvement in medication guidance during
510 discharge related to their belief in their role as an advocate on the
511 patients' behalf. Caregivers perceived that it was their duty to fill in
512 gaps in the healthcare system such as limited hospital resources in
513 staffing. The belief in advocacy was evident when caregivers

514 participated in medication decisions or objected to the use of
515 medications in patients.

516

517 *I'm absolutely aware of the threat that hospital staff are under. I*
518 *am aware of putting a lot of pressure on them, but at the same*
519 *time, I want to advocate for myself and my mother. I kind of try*
520 *more to tread a fine line between being pushy and also getting*
521 *information that we need. (Caregiver 5)*

522

523 Other caregivers did not see it as their responsibility to fill in gaps
524 within the healthcare system, relying on health professionals (primary
525 care physician, pharmacist or the long term care facility) to make
526 medication-related decisions or accepted the status quo.

527

528 *I was so fed up with the situation that she was discharged in the*
529 *way she was. And then I gave up and just thought what's the*

530 *point. You know, I've got to there's no point, they're just going to*
531 *do what they want and I've trusted the aged care home so I*
532 *thought well I'm just going to wait till she's back there to talk*
533 *with them. (Caregiver 4)*

534 **3.3 Recommendations identified to support caregiver medication** 535 **management post discharge**

536
537 Table 2 outlines proposed recommendations identified to support
538 caregiver medication management post discharge. Recommendations
539 were derived from the analysis of participant quotes and aligned with
540 the themes identified in sections 1 and 2.

541 **4. Discussion**

542 This qualitative study provides insights into the experiences and needs
543 that are specific to caregivers of people living with dementia.

544 Caregivers reported they received limited information on medication

545 management guidance and experienced limited engagement in
546 medication management decisions at discharge. Factors that
547 influenced participation in medication management plans at discharge
548 included caregivers overwhelmed by the discharge process,
549 caregivers' proactively seeking information to ensure avoidance of
550 medication harm and belief in advocacy as part of the caregiver role.
551 In addition, the study identified targeted recommendations that could
552 be incorporated into existing discharge processes to support caregivers
553 in medication management for people with dementia.
554
555 Many participants highlighted the lack of information regarding the
556 management of medications provided at discharge. This is consistent
557 with previous studies that have shown that standard discharge
558 consultation with patients and their caregivers are seldom provided
559 ^{20,21,32}. Several studies involving caregivers of patients living with or
560 without dementia reported that caregivers receive limited medication

561 information at discharge. This study further revealed that specific
562 discharge information for duration of therapy and potential adverse
563 effects important for people living with dementia were absent. The
564 limited information is a factor that places older adults living with
565 dementia at increased risk of medication-related harm due to potential
566 confusion and inaccuracies in medication management ³³. In
567 particular, older individuals with dementia receiving high-risk
568 medications, which are prescribed for short term can further
569 compound the situation. ^{4,34} The findings in Table 2 highlight the need
570 for tailored information for caregivers of people with dementia to be
571 provided during discharge to inform safe monitoring and appropriate
572 use of medications.

573
574 This study revealed some caregivers did not engage in medication
575 guidance at discharge because they felt that there were no
576 opportunities for engagement, or they relied on other community

577 healthcare professionals. These issues are also experienced by
578 caregivers of patients with chronic conditions during discharge^{20,21,35}.
579 In addition, for caregivers of people living with dementia, the study
580 found that limited communication from hospital staff can be
581 complicated by not recognising the caregivers as the person
582 responsible to receive all relevant information about the individual's
583 medication. Our study highlights the need for patients and caregivers
584 tools, such as question prompt, to enhance communication between
585 the caregiver and hospital staff to improve medication management at
586 discharge (Table 2).

587

588 Additionally, this study revealed caregivers of people living with
589 dementia experienced emotional and psychological burden linked to
590 the lack of medication guidance post discharge and feeling unprepared
591 to conduct adequate medication management post transition.

592 Caregivers requested that they were advised of discharge processes at

593 admission so that they had time to process the information and think
594 about what questions to ask. Early discharge planning (initiated during
595 the acute phase of an illness or injury) delivered to caregivers of older
596 adults has been shown to be effective in improving outcomes in older
597 adults ^{36,37}. Given that caregivers of people with dementia experience
598 a higher degree of burden than the caregiver of a person without
599 dementia ³⁸, early pre-discharge intervention delivered to caregivers of
600 people with dementia may improve medication management activities
601 post discharge.

602
603 We also found caregivers experienced challenges with ensuring
604 continuity of medication supply post discharge and communication
605 with the community pharmacist to ensure dose administration aides
606 were available. Complex medication regimens and ensuring
607 medication supply are factors which also contribute to burden on
608 caregivers and increase the risk of medication-related problems and

609 rehospitalisation ^{8,39}. Previous studies recommend communication
610 with the primary care physician to improve co-ordination post
611 transition ^{10,40}. In addition, our study highlights the important role of
612 pharmacists to provide medication guidance post discharge.
613 Pharmacist-led medication review and caregiver education at the time
614 of discharge, as well as ongoing medication management support from
615 community pharmacists could ensure the safe use of medications in
616 people with dementia ^{9,41,42}. This aligns with recent calls for more
617 advanced roles of pharmacists, such as working within the primary
618 care physician practice, to ensure the successful transition of care ⁴³⁻⁴⁵.
619
620 The strength of this qualitative study was the use of maximum
621 variation sampling and analyst triangulation to enhance the credibility
622 of the findings. However, the results may not be transferable to other
623 countries, as the data was collected from participants who only resided
624 in Australia, other studies indicate that the issues with guidance at

625 discharge for people living with dementia are not unique to Australia
626 ^{19,20}. While the study captured a broad range of perspectives from
627 caregivers of people located in different regions of Australia, the
628 transferability of the findings to metropolitan/rural/remote areas may
629 be limited. In addition, the study included participants who were
630 primarily European as the findings may not be transferable to all
631 Australians. Although this study described the perspectives and
632 experiences of caregivers regarding medication management guidance
633 for people with dementia, future studies should consider including
634 participants living with dementia. Another study limitation was that
635 several months elapsed between the care recipient hospital admission
636 and qualitative interviews due to study design. The time delay would
637 have potentially influenced participant recollection of their
638 experiences at hospital discharge regarding medication management
639 and may not reflect what was reported. Further research using
640 participant observation and audio-recordings of discussions between

641 patients, their caregivers and health professionals is needed to evaluate
642 discharge processes. Another limitation was that interviews were
643 conducted over the telephone which may have limited in-depth
644 discussion of the topic ⁴⁶. However, telephone interviews allowed a
645 broad reach of geographically dispersed responses.

646

647 **5. Conclusions**

648 The findings of this study revealed that there are opportunities to
649 improve the processes in discharge medication management guidance
650 for caregivers of people living with dementia. Caregivers reported
651 that they would like to receive tailored medication information for
652 people with dementia to manage medications safely. Future studies are
653 needed to improve the implementation of existing resources, such as
654 medicines lists, and explore the development of additional resources
655 to encourage participation and alleviate caregiver stress during
656 medication guidance at discharge.

657

658 Conflict of Interest : None

659

660 Description of Authors' Roles: Sawan, Gnjidic: conception and
661 design, acquisition of data, analysis and interpretation of data,
662 drafting, revising the article critically for important intellectual
663 content. Jeon, Bond, Hilmer, Chen: conception and design, analysis
664 and interpretation of data, revising the article critically for important
665 intellectual content. Wennekers: analysis and interpretation of data
666 and revising the article.

667

668 Acknowledgments: StepUp for Dementia Research, which is funded
669 by the Australian Government Department of Health and implemented
670 by a dedicated team at the University of Sydney.

671

672 Funding : The project and DG was supported by the Australian
673 National Health and Medical Research Council Dementia Leadership
674 Fellowship.

675

676 Compliance with Ethical Standards: Ethics approval was obtained
677 from the University of Sydney Human Research Ethics
678 Committee (2019/578).

679

680 **References:**

- 681 1. Shepherd H, Livingston G, Chan J, Sommerlad A. Hospitalisation rates and
682 predictors in people with dementia: a systematic review and meta-
683 analysis. *BMC Medicine*. 2019;17(1):130.
- 684 2. Amjad H, Carmichael D, Austin AM, Chang CH, Bynum JP. Continuity of
685 Care and Health Care Utilization in Older Adults With Dementia in Fee-for-
686 Service Medicare. *JAMA Intern Med*. 2016;176(9):1371-1378.
- 687 3. Prudent M, Dramé M, Jolly D, et al. Potentially inappropriate use of
688 psychotropic medications in hospitalized elderly patients in France: cross-
689 sectional analysis of the prospective, multicentre SAFEs cohort. *Drugs*
690 *Aging*. 2008;25(11):933-946.
- 691 4. Gnjjidic D, Hilmer SN, Hartikainen S, et al. Impact of high risk drug use on
692 hospitalization and mortality in older people with and without Alzheimer's
693 disease: a national population cohort study. *PLoS One*. 2014;9(1):e83224.
- 694 5. Mullan J, Burns P, Mohanan L, Lago L, Jordan M, Potter J. Hospitalisation
695 for medication misadventures among older adults with and without

- 696 dementia: A 5-year retrospective study. *Australas J Ageing*.
697 2019;38(4):e135-e141.
- 698 6. Simonson W, Feinberg JL. Medication-related problems in the elderly :
699 defining the issues and identifying solutions. *Drugs Aging*. 2005;22(7):559-
700 569.
- 701 7. Sakiris MA, Sawan M, Hilmer SN, Awadalla R, Gnjdjic D. Prevalence of
702 Adverse Drug Events and Adverse Drug Reactions in Hospital among Older
703 Patients with Dementia: A Systematic Review. *Br J Clin Pharmacol*. 2020.
- 704 8. Lim RH, Sharmeen T. Medicines management issues in dementia and
705 coping strategies used by people living with dementia and family carers: A
706 systematic review. *International journal of geriatric psychiatry*.
707 2018;33(12):1562-1581.
- 708 9. Gillespie R, Mullan J, Harrison L. Managing medications: the role of
709 informal caregivers of older adults and people living with dementia. A
710 review of the literature. *J Clin Nurs*. 2014;23(23-24):3296-3308.
- 711 10. Maidment ID, Aston L, Moutela T, Fox CG, Hilton A. A qualitative study
712 exploring medication management in people with dementia living in the
713 community and the potential role of the community pharmacist. *Health
714 expectations : an international journal of public participation in health care
715 and health policy*. 2017;20(5):929-942.
- 716 11. Manias E, Bucknall T, Hughes C, Jorm C, Woodward-Kron R. Family
717 involvement in managing medications of older patients across transitions
718 of care: a systematic review. *BMC geriatr*. 2019;19(1):95.
- 719 12. Brodaty H, Green A. Defining the role of the caregiver in Alzheimer's
720 disease treatment. *Drugs Aging*. 2002;19(12):891-898.
- 721 13. Travis SS, Bethea LS, Winn P. Medication Administration Hassles Reported
722 by Family Caregivers of Dependent Elderly Persons. *The Journals of
723 Gerontology: Series A*. 2000;55(7):M412-M417.
- 724 14. El-Saifi N, Moyle W, Jones C, Alston-Knox C. Determinants of medication
725 adherence in older people with dementia from the caregivers'
726 perspective. *International Psychogeriatrics*. 2019;31(3):331-339.
- 727 15. World Health Organization. Transitions of Care: Technical Series on Safer
728 Primary Care. 2016;
729 [https://apps.who.int/iris/bitstream/handle/10665/252272/978924151159](https://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-9-)
730 [9-](https://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-9-)

- 731 [eng.pdf;jsessionid=2C39DB4F75CCB94DBF362BEA92CC6128?sequence=1.](https://www.stepupfordementiaresearch.org.au/)
732 Accessed 14/4/2020.
- 733 16. Kanaan AO, Donovan JL, Duchin NP, et al. Adverse drug events after
734 hospital discharge in older adults: types, severity, and involvement of
735 Beers Criteria Medications. *J Am Geriatr Soc.* 2013;61(11):1894-1899.
- 736 17. Forster AJ, Clark HD, Menard A, et al. Adverse events among medical
737 patients after discharge from hospital. *Cmaj.* 2004;170(3):345-349.
- 738 18. Waring J MF, Bishop S, et al. An ethnographic study of knowledge sharing
739 across the boundaries between care processes, services and organisations:
740 the contributions to 'safe' hospital discharge. In. Southampton (UK): NIHR
741 Journals Library2014.
- 742 19. Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K. "We are doing it
743 together"; The integral role of caregivers in a patients' transition home
744 from the medicine unit. *PLoS one.* 2018;13(5):e0197831-e0197831.
- 745 20. Hesselink G, Flink M, Olsson M, et al. Are patients discharged with care? A
746 qualitative study of perceptions and experiences of patients, family
747 members and care providers. *BMJ Qual Saf.* 2012;21 Suppl 1:i39-49.
- 748 21. Bauer M, Fitzgerald L, Koch S. Hospital discharge as experienced by family
749 carers of people with dementia: a case for quality improvement. *Journal*
750 *for Healthcare Quality.* 2011;33(6):9-16.
- 751 22. Coleman EA, Smith JD, Frank JC, Min SJ, Parry C, Kramer AM. Preparing
752 patients and caregivers to participate in care delivered across settings: the
753 Care Transitions Intervention. *J Am Geriatr Soc.* 2004;52(11):1817-1825.
- 754 23. Tobiano G, Chaboyer W, Teasdale T, Cussen J, Raleigh R, Manias E. Older
755 patient and family discharge medication communication: A mixed-
756 methods study. *J Eval Clin Pract.*n/a(n/a).
- 757 24. Reeve E, Bell JS, Hilmer SN. Barriers to Optimising Prescribing and
758 Deprescribing in Older Adults with Dementia: A Narrative Review. *Current*
759 *clinical pharmacology.* 2015;10(3):168-177.
- 760 25. Barber ND, Alldred DP, Raynor DK, et al. Care homes' use of medicines
761 study: prevalence, causes and potential harm of medication errors in care
762 homes for older people. *Qual Saf Health Care.* 2009;18(5):341-346.
- 763 26. Jeon YH. StepUp for Dementia Research.
764 <https://www.stepupfordementiaresearch.org.au/>. Accessed 01/05/2020.

- 765 27. A spoonful of sugar: medicines management in NHS hospitals. 2001;
766 [http://www.eprescribingtoolkit.com/wp-](http://www.eprescribingtoolkit.com/wp-content/uploads/2013/11/nrspoonfulsugar1.pdf)
767 [content/uploads/2013/11/nrspoonfulsugar1.pdf](http://www.eprescribingtoolkit.com/wp-content/uploads/2013/11/nrspoonfulsugar1.pdf). Accessed 01/01/2020.
- 768 28. Morse JM. The Significance of Saturation. *Qualitative health research*.
769 1995;5(2):147-149.
- 770 29. Bazeley P. *Qualitative data analysis: Practical strategies*. Sage; 2013.
- 771 30. Patton MQ. *Qualitative Research and Evaluation Methods*. California: Sage
772 Publications Inc; 2002.
- 773 31. Downe-Wamboldt B. Content analysis: method, applications, and issues.
774 *Health Care Women Int*. 1992;13(3):313-321.
- 775 32. Allen J, Hutchinson AM, Brown R, Livingston PM. User experience and care
776 for older people transitioning from hospital to home: Patients' and carers'
777 perspectives. *Health Expect*. 2018;21(2):518-527.
- 778 33. Kaufmann CP, Stämpfli D, Hersberger KE, Lampert ML. Determination of
779 risk factors for drug-related problems: a multidisciplinary triangulation
780 process. *BMJ Open*. 2015;5(3):e006376.
- 781 34. Eshetie TC, Nguyen TA, Gillam MH, Kalisch Ellett LM. A narrative review of
782 problems with medicines use in people with dementia. *Expert opinion on*
783 *drug safety*. 2018;17(8):825-836.
- 784 35. Jamieson M, Grealish L, Brown J-A, Draper B. Carers: The navigators of the
785 maze of care for people with dementia—A qualitative study. *Dementia*
786 (14713012). 2016;15(5):1112-1123.
- 787 36. Fox MT, Persaud M, Maimets I, Brooks D, O'Brien K, Tregunno D.
788 Effectiveness of early discharge planning in acutely ill or injured
789 hospitalized older adults: a systematic review and meta-analysis. *BMC*
790 *geriatr*. 2013;13:70.
- 791 37. Wagle KC, Skopelja EN, Campbell NL. Caregiver-Based Interventions to
792 Optimize Medication Safety in Vulnerable Elderly Adults: A Systematic
793 Evidence-Based Review. *J Am Geriatr Soc*. 2018;66(11):2128-2135.
- 794 38. Brodaty H, Donkin M. Family caregivers of people with dementia.
795 *Dialogues Clin Neurosci*. 2009;11(2):217-228.
- 796 39. Garcia-Caballos M, Ramos-Diaz F, Jimenez-Moleon JJ, Bueno-Cavanillas A.
797 Drug-related problems in older people after hospital discharge and
798 interventions to reduce them. *Age and Ageing*. 2010;39(4):430-438.

- 799 40. Boustani MA, Sachs GA, Alder CA, et al. Implementing innovative models
800 of dementia care: The Healthy Aging Brain Center. *Aging Ment Health*.
801 2011;15(1):13-22.
- 802 41. Cross AJ, Le VJ, George J, Woodward MC, Elliott RA. Stakeholder
803 perspectives on pharmacist involvement in a memory clinic to review
804 patients' medication management and assist with deprescribing. *Res*
805 *Social Adm Pharm*. 2019;07:07.
- 806 42. Terayama H, Sakurai H, Namioka N, et al. Caregivers' education decreases
807 depression symptoms and burden in caregivers of patients with dementia.
808 *Psychogeriatrics*. 2018;18(5):327-333.
- 809 43. Cardwell K. Reducing medication errors and transitions of care. *Age*
810 *Ageing*. 2020;49(4):537-539.
- 811 44. Alosaimy S, Vaidya A, Day K, Stern G. Effect of a Pharmacist-Driven
812 Medication Management Intervention Among Older Adults in an Inpatient
813 Setting. *Drugs Aging*. 2019;36(4):371-378.
- 814 45. Sawan M, Wennekers D., Sakiris M., Gnjidic D. Interventions at Hospital
815 Discharge to Guide Caregivers in Medication Management for People
816 Living with Dementia: a Systematic Review. *J Gen Intern Med*. 2020;In
817 Press.
- 818 46. Novick G. Is There a Bias Against Telephone Interviews In Qualitative
819 Research? *Research in nursing & health*. 2008;31(4):391-398.
- 820

821

Table 1. Participant characteristics (N= 31)

Characteristics	<i>n (%) or Median (IQR)</i>
<i>Caregivers</i>	
Female	25 (81%)
Age (years), Median (IQR)	60 (14)
Education Status	
Less than 12 years of education	2 (6%)
Completed high school	3 (6%)
Completed Certificate III or advanced diploma	6 (19%)
Bachelor's degree or above	20 (65%)
Ethnicity	
Australian	10 (32%)
European	19 (61%)
Asian	1 (3%)
New Zealand	1 (3%)
State and Territory	
New South Wales	19 (61%)
Victoria	5 (16%)
Northern Territory	1 (3%)
Western Australia	3 (10%)
Tasmania	3 (10%)
Relationship with Care recipient	
Married/partner	9 (29%)
Adult child	20 (65%)
Friend	2 (6%)
Time elapsed since care recipient hospital admission and qualitative interview (months), Median (IQR)	4 (8)
<i>Information about care recipient (n=31)</i>	
Female	17 (55%)
Age (years), Median (IQR)	81 (14)
Place of residence	
Community	20 (65%)
Long term Care Facility	10 (32%)
Assisted Living Facility	1 (3%)
Total Number of Medications (including when required medications)	
1-9	24 (77%)
10-14	6 (19%)
15+	1 (3%)

Table 2. Alignment of themes to identify recommendations to support caregiver medication management post discharge

Theme	Proposed intervention	Quote
1. a) Inadequate information about medication management at discharge	<p>Provide caregivers with a summary that is clear, easy to read and includes: diagnosis, medication changes and reason for changes, indications, adverse effects and duration of therapy.</p> <p>Provide an accurate list of medications and administration schedules at the time of discharge.</p> <p>Ensure caregivers have a medication list that incorporates tailored specific alerts/advice for people with dementia post-transitions on medications that may impact on the patient's cognition and information on appointments to follow-up.</p>	<p>'It would be good to have the name of the medication and generic synonyms and what it's supposed to do. In the final column and why it's important or how important it is, it's vital if it's taken or if you don't notice any symptoms. Something written simply explaining what things are, what it's supposed to do. You need a printed resource really in my opinion. (Caregiver 6)</p> <p>I think comprehensive a written report would have been good ... also, regarding medications whether this medication that she's currently on is a permanent thing or if it was just temporary thing. (Caregiver 5)</p> <p>It would have been nice if someone had said, you know, his next lot of tablets are due at whatever time and be aware of the anaesthetic and that it might take some time to wear out of him. (Caregiver 1)</p> <p>Written information which could have been given to the home and sort of say, this has the instructions. This is when the, this is the day needs to go to see her general practitioner and there'll be a follow up appointment is scheduled by the rooms in three weeks. That would have been so much superior than verbal instruction. (Caregiver 24)</p>

	Timely communication of the discharge letter to the primary care physician, pharmacist, and long term care	
b) limited caregiver engagement in medication management decisions	<p>The role of the caregiver who ‘provides decision-making support’ to the person living with dementia needs to be acknowledged and respected.</p> <p>Organise meetings with caregivers during admission to discuss diagnosis, treatment decisions, medication changes and caregiver concerns and preferences.</p> <p>Discharge information needs to be communicated shared among caregivers (there may be more than one).</p> <p>Communicate information effectively to the patient and caregivers e.g. clarify medication concerns, explain rationale behind treatment decisions strategies to improve adherence in people with dementia (dose administration aids, simplifying dosage regimens).</p>	<p>I liked more consultative approach rather than a ‘follow my advice’ approach and the more, how did you come to the diagnosis approach? Because at the end of the day, I live with my husband for 30 years day in, day out. (Caregiver 12)</p> <p>I would like for any person that as soon as they walk into a hospital and they’re given they are acknowledged. I would like them to be put into the loop from the get go. I think too often you’re dismissed by nursing staff. (Caregiver 20)</p> <p>If it was at all possible, to have a particular time to meet with the doctor. The staff of the hospital can ask family ‘when is the best time for you to come to the hospital’ ... If there was some kind of systematic more formal way that fitted the needs of the family I think rather than the family having to fit around the hospital staff. (Caregiver 7)</p> <p>Maybe they could have just made some suggestions you know about how to organise the actual taking of them given my wife’s dementia. (Caregiver 14)</p>

<p>1. c) Difficulties ensuring medication supply post-discharge</p>	<p>Provide more than 3 days supply of medications.</p> <p>Hospital staff to communicate with Community Pharmacist to organise dose administration aids and update on medication changes.</p> <p>Plan appointment with primary care physician ahead of time to obtain prescriptions and ensure medication supply.</p>	<p>They gave him three days' supply on a Friday. So if you can't get an appointment on the Monday, or the doctors are not working on a Monday, you have to the creek without a paddle. So I think that one of the things would also help the carer a lot is if they gives five days' supply of the medication to be discharged with. (Caregiver 13)</p> <p>I did get an appointment with the doctor the next day and then I had to go there and wait forever and then I had to go out to the pharmacy and wait forever so the whole thing was a bit traumatic just trying to get it organised and get him there to be seen. (Caregiver 16)</p>
<p>2. a) Caregiver overwhelmed by discharge processes</p>	<p>Provide caregiver information earlier during admission as opposed to just prior discharge so that the caregiver can have more time to reflect on the information and then clarify medication information with the physician or registered nurses before transition.</p> <p>Caregiver question prompt to enhance communication between the caregiver and hospital staff regarding medications.</p> <p>Caregivers who are unable to make discharge to be contacted via telephone</p>	<p>The doctors can come in the early morning and then you'd have and they'd tell you information, you'd have time to think about it and then we could ask the nurses or the doctor if available so we could ask the nurses if we could speak to the doctor. It is just time to think through your thoughts and know that there was someone there to ask once you'd digested the information. (Caregiver 26)</p> <p>It's like the first time your sewing machine breaks down, it takes you a long time to put a new needle in and find out why the tension isn't right. You don't really know the right questions to ask. You don't know why it's jumping stitches. It's a bit like that with a patient, trying to deal with doctors, you don't know the right questions to ask. (Caregiver 6)</p>

	to be informed on changes to medication at discharge.	I think they need to arrange with the family or carer to have someone with the person at the time of consultations to give the person any information ...If the person is not able to do, they can make a phone call and tell them, "This is what we're going to do. Are you happy about that, do you have any questions?". (Caregiver 13)
2. b) Caregivers proactively seeking information to ensure avoidance of medication harm	Review of medications post-discharge. Refer caregiver to reliable internet resources to refer to further information.	I think it's important to keep monitoring medication and making sure that what is given is correct. Because sometimes things can change. In that case, I think medication needs to be re-evaluated a lot more regularly. Because things change and you cannot become complacent. I think 'he should be right' is probably not a good right approach. (Caregiver 3) You can look at that up on the internet too. You have a look on the internet when there's a crisis, because there are too many things to do. (Caregiver 22)
2. c) Belief in advocacy as part of caregiver role	Empower patients and caregivers to communicate with healthcare providers during and after discharge.	We all family members have a right to be able to ask questions and receive proper information. (Caregiver 7) My mum can't ask questions, she can't follow instructions, she can't respond to things, she can't make decisions. So, you have to have a representative or an advocate at the bed side. (Caregiver 25)