



**QUEEN'S
UNIVERSITY
BELFAST**

A qualitative exploration of proxy decision makers' expectations of prescribed medications for people with advanced dementia

McCloskey, B., Hughes, C., & Parsons, C. (2018). A qualitative exploration of proxy decision makers' expectations of prescribed medications for people with advanced dementia. *Palliative Medicine*, 32(6), 1114-1123. DOI: 10.1177/0269216318757163

Published in:
Palliative Medicine

Document Version:
Peer reviewed version

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

Publisher rights

© 2018 the Authors.

This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

General rights

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

Take down policy

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

1 **A qualitative exploration of proxy decision makers' expectations of prescribed**
2 **medications for people with advanced dementia**

3

4 **Expectations of medications in advanced dementia**

5 Bridgeen McCloskey PhD, MPharm, MPSNI. Altnagelvin Area Hospital, Glenshane Road,
6 Londonderry, BT47 6SB, United Kingdom. Email: bmccloskey05@qub.ac.uk

7

8 Carmel Hughes, PhD, BSc, MPSNI. School of Pharmacy, 97 Lisburn Road, Belfast, Queen's
9 University Belfast, BT9 7BL, United Kingdom. Email: c.hughes@qub.ac.uk; Telephone: +44
10 (0) 28 9097 2147; Fax: +44 (0) 28 9024 7794.

11

12 *Carole Parsons PhD, MPharm, MPSNI. School of Pharmacy, 97 Lisburn Road, Belfast,
13 Queen's University Belfast, BT9 7BL, United Kingdom. Email: c.parsons@qub.ac.uk;
14 Telephone: +44 (0) 28 9097 2304; Fax: +44 (0) 28 9024 7794. *Corresponding author

15

16 **What is already known about this topic?**

- 17
- 18 • Patients with advanced dementia often cannot participate in decision-making about
19 their care; proxy decision-makers (family members, friends or next of kin) therefore
20 make decisions on their behalf
 - 21 • Proxy decision-makers' expectations of medications have the potential to influence
22 decisions to prescribe or withdraw medications
 - 23 • The few studies conducted to date which explore proxy decision-makers'
24 expectations of medications for patients with dementia consider all stages of disease
25 and do not focus on the advanced stages of the condition

25

26 **What this paper adds?**

- 27
- 28 • This study is the first to explore and describe proxy decision-makers' expectations of
29 prescribed medications for people with advanced dementia, and to consider how
these expectations may change with changing goals of care and disease progression

- 30 • Proxy decision-makers felt that they had a key role in acting as an advocate and
31 providing information to health care professionals for the person for whom they
32 made decisions, particularly about any symptoms experienced. They reported an
33 expectation for more information about prescribed medicines, and specifically
34 wanted details such as indications, benefits and risks of treatment. Although some
35 expected to be involved in medication-related decisions, the majority preferred to
36 delegate these decisions to healthcare professionals. However, they expected to be
37 informed of any medication-related decisions made
- 38 • Despite uncertainty about the benefits of anti-dementia medications, proxy decision-
39 makers were reluctant for these medications to be withdrawn. Reluctance to stop
40 other prescribed medicines was also expressed, due to fear of potential
41 consequences. However, this reluctance reduced as proxy decision-makers
42 considered changing goals of care and dementia progression

43 **Implications for practice, theory or policy?**

- 44 • Communication between healthcare professionals and proxy decision-makers
45 regarding prescribed medications (indications, risks, benefits) is of critical
46 importance
- 47 • Proxy decision-makers vary in terms of their desire for active involvement in the
48 medication decision-making process. Healthcare professionals should facilitate proxy
49 decision-maker involvement if desired
- 50 • Healthcare professionals must elicit and manage proxy decision-makers'
51 expectations for prescribing medications in advanced dementia and must inform
52 proxy decision-makers of all prescribing decisions made

53

54 **Abstract**

55 **Background:** Proxy decision-makers often have to make decisions for people with advanced
56 dementia. Their expectations regarding prescribed medications have the potential to
57 influence prescription or withdrawal of medications. However, few studies to date have
58 explored this. **Aim:** To explore proxy decision-makers' expectations of prescribed
59 medications for people with advanced dementia, and to consider how these change with
60 changing goals of care and dementia progression. **Design:** Qualitative semi-structured

61 interview study. **Setting/participants:** Fifteen proxy decision-makers of people with
62 advanced dementia were recruited via general practitioners (n=9), Join Dementia Research
63 (JDR) (n=3), and the Alzheimer's Society Northern Ireland (n=3). **Results:** Five key themes
64 emerged: the role as advocate; attitudes to medicines and medicine taking; uncertainty over
65 the benefit of anti-dementia medications; stopping medications; and communication and
66 decision-making. Proxy decision-makers desired more information about prescribed
67 medicines, particularly the indications, benefits and risks of treatment. Despite uncertainty
68 about the benefits of anti-dementia medications, proxy decision-makers were reluctant for
69 these medications to be withdrawn. Reluctance to stop other prescribed medicines was also
70 expressed, but reduced with changing goals of care and dementia progression. Although
71 some proxy decision-makers expected to be involved in medication-related decisions, the
72 majority preferred to delegate these decisions to healthcare professionals. However, they
73 expected to be informed of any medication-related decisions made. **Conclusions:** Proxy
74 decision-makers vary in terms of their desire for active involvement in the medication
75 decision-making process. Healthcare professionals should facilitate proxy decision-maker
76 involvement if desired. Further research is required to consider the impact of proxy
77 decision-maker involvement in decision-making.

78 **Keywords: Dementia, Decision making, Older people, Medication, Prescribing**

79 80 **Introduction**

81
82 Dementia is a progressive, chronic, incurable neurodegenerative condition in which
83 widespread neuronal cell death results in multiple deficits across cognitive domains
84 including: memory, behaviour, language, movement and executive function, and ability to
85 recognise familiar people or common objects.^{1,2} Disease progression is characterised by
86 cognitive and physical decline which can adversely impact on ability to conduct basic and
87 instrumental activities of daily living,³⁻⁵ accompanied by an increasing dependence on others
88 for care.⁶⁻⁸ Stage 7 of the Functional Assessment Staging Test (FAST) (ranging from 7A to 7F,
89 with 7F indicating the most severe dementia) provides a useful description of the features of
90 advanced dementia including profound memory deficits, minimal verbal abilities, inability to
91 ambulate independently, inability to perform any activities of daily living, urinary and faecal
92 incontinence, inability to sit up without assistance and loss of the ability to smile in the very

93 late stages.⁹ Patients with advanced dementia often cannot participate in decision-making
94 about their care.¹⁰ Consequently, decisions are made by proxy decision-makers: family
95 members, friends and next of kin who act in their best interest.¹¹⁻¹⁵

96

97 People with dementia and their caregivers hold high expectations for new medications,¹⁶
98 which may be unrealistic, leading to disappointment and dissatisfaction with care.¹⁷

99 Managing the expectations of proxy decision-makers is an important aspect of treatment in
100 advanced dementia,¹⁸ as they have the potential to influence the prescription or withdrawal
101 of medications in this vulnerable patient group.¹⁹⁻²³ However, despite the importance of
102 expectations in shaping the decision-making process,²⁴⁻²⁶ few studies have explored proxy
103 decision-makers' expectations of medications in advanced dementia; studies considering all
104 stages of disease have reported that anti-dementia medicines (acetylcholinesterase
105 inhibitors [AChEIs] including donepezil, galantamine and rivastigmine, which inhibit
106 breakdown of acetylcholine, an important neurotransmitter for memory) gave people
107 hope,^{20,27-29} and despite lack of clarity about their benefits, were "worth a try",³⁰ with fears
108 about deterioration if these medications were stopped.²⁷ This study aimed to contribute to
109 the limited evidence base.

110

111 **Aim**

112 To explore proxy decision-makers' expectations of prescribed medications for people with
113 advanced dementia. The following objectives were identified:

- 114 • To investigate what information is provided to proxy decision-makers about
115 prescribed medications for people with advanced dementia
- 116 • To explore proxy decision-makers' expectations regarding prescribed medications for
117 the person with advanced dementia
- 118 • To explore proxy decision-makers' experiences of and/or views on decision-making
119 regarding medication use and how these change as dementia progresses
- 120 • To consider how proxy decision-makers would feel about the withdrawal of
121 prescribed medications if goals of care changed due to dementia progression

122

123 **Methods**

124

125 *Setting/participants*

126 Proxy decision-makers of people with advanced dementia in a region of the UK (Northern
127 Ireland [NI]) were recruited. A proxy decision-maker was defined as: an adult family
128 member or friend in regular contact (on at least one occasion per week) with the person
129 with advanced dementia, who was their next of kin, or made decisions about the care of
130 that person in conjunction with healthcare professionals. Further inclusion criteria were as
131 follows:

132 • FAST score of between 7A and 7F for the patient's cognitive function, indicating
133 severe/advanced dementia.⁹ Proxy decision-makers completed this instrument as a
134 proxy measure of function.

135 • Superficial knowledge of medication(s) prescribed (names and broad purpose)

136

137 *Sampling and recruitment*

138 Purposive sampling was undertaken to identify proxy decision-makers of people with
139 advanced dementia. Recruitment was undertaken by mail, telephone or face-to-face via
140 general practitioners, Join Dementia Research (JDR), and the Alzheimer's Society, NI. The
141 researcher (BMcC) only contacted individuals who had returned completed contact consent
142 forms to indicate interest in participation.

143

144 *Ethical approval*

145

146 NHS Research Ethics Committee approval was obtained in February 2016 (West of Scotland
147 Research Ethics Service [WoSRES]; reference 16/WS/0029).

148

149 *Study design and data collection*

150 Face-to-face, semi-structured interviews were conducted by BMcC (a postgraduate
151 researcher and qualified pharmacist) in proxy decision-makers' homes using an interview
152 schedule (Table 1) to facilitate sensitive, flexible, in-depth exploration of individuals' views
153 within an overarching structure by which commonalities of experience could be identified.³¹

154 Interview questions were developed following literature review and discussions within the
155 research team, and refined based on feedback from piloting. No prior relationships existed

156 between participants and the researcher before study commencement. Participants were
157 aware that the researcher was a postgraduate student from the School of Pharmacy,
158 Queen's University Belfast. Participants provided written informed consent. Recruitment
159 continued until analysis revealed no further novel themes emerging.

160

161 *Data analysis and validation*

162 Data collection was undertaken between March 2016 and May 2016. Interviews were
163 digitally audio-recorded and transcribed verbatim. Transcripts were anonymized using a
164 unique code comprising "PDM" (proxy decision-maker) and a number to reflect the
165 sequence in which participants were interviewed.

166

167 Interviews were conducted and analysed by a female pharmacist of Irish descent (BMcC),
168 who had undertaken training in qualitative research methods. Data analysis was iterative,
169 with simultaneous data collection and analysis leading to alterations in the interview
170 schedule in line with emerging themes.³² The framework method of analysis developed by
171 Ritchie and Spencer³³ was applied to the data generated. Microsoft Word was used to aid
172 with data management. Validation of analysis was performed (CP, BMcC) and consensus
173 reached on the final themes.

174

175 **Results**

176

177 Twenty of 35 proxy decision-makers (57.1%) approached expressed interest in the study.
178 Fifteen (42.9%) met the inclusion criteria and agreed to take part; of these nine were
179 recruited via GPs, three via JDR and three via the Alzheimer's Society, NI. Interviews lasted
180 an average of 37.5 minutes (range: 24-60 minutes). Demographic characteristics of
181 participants are detailed in Table 2.

182

183 Five key themes emerged from the interviews: (1) the role of the proxy decision-maker as
184 advocate, (2) attitudes to medicines and medicine taking, (3) uncertainty over the benefit of
185 anti-dementia medicines, (4) stopping medications and (5) communication and decision-
186 making.

187

188 **The role of the proxy decision-maker as advocate**

189
190 Proxy decision-makers reported that they knew the person with advanced dementia better
191 than anyone else, including healthcare professionals. As a result, they felt they had a critical
192 role in interpreting their symptoms.

193
194 *“I feel that the doctor would have a better idea about [my husband’s] symptoms, if*
195 *he asked me about them. I mean I am with him all the time whereas the doctor only*
196 *sees him briefly when we have problems, realistically how can he make good*
197 *conclusions about his symptoms without asking me?” PDM10*

198
199 Proxy decision-makers expected medications to be prescribed for control and/or relief of
200 symptoms and comfort, particularly towards the end of life. They advocated for prescription
201 of medications in some instances, and in other cases, requested withdrawal.

202
203 *“As she approaches the end of life she would need to get the medications that make*
204 *her comfortable, that is really important for me...mummy doesn’t have a voice, she*
205 *has dementia, I am her voice, so it is my responsibility that she gets all the medicines*
206 *that she needs.” PDM3*

207
208 *He is a diabetic as well...and they started him on a drug called metformin but he got*
209 *severe diarrhoea with that and I requested that it be stopped. I mean I would rather*
210 *him have slightly high blood sugar levels rather than diarrhoea because diarrhoea is*
211 *much more upsetting for him and me also... in the future as he approaches the end of*
212 *life, I don't think he will really need the tablet now because he won't be able to eat as*
213 *much...” PDM10*

214
215 Proxy decision-makers placed hope in certain medications and as a result expected to see
216 improvements in their loved one’s condition. However, the side-effects of some medications
217 e.g. antipsychotics, mitigated against this hopefulness. In such cases, proxy decision-makers
218 were keen for medications to be reviewed.

219
220 *“I expected that this drug [risperidone] would make things better for her, you know,*
221 *that she wouldn’t be as scared but I was disappointed and scared myself as it left her*
222 *so drowsy and out of it. I mean I couldn’t even enjoy my visit to the nursing home to*

223 *see her as it just made me so upset. Even the word risperidone makes me feel scared.*
224 *I asked the doctor to review the tablet due to the symptoms [my sister] was*
225 *experiencing.” PDM9*

226

227 **Attitudes to medicines and medicines taking**

228

229

230 Proxy decision-makers highlighted the difficulties associated with trying to administer
231 medications.

232

233 *“Getting them [medicines] down is the problem...the one in the morning goes into*
234 *the porridge but it has to be crushed...but she doesn’t eat all of the porridge, so I*
235 *have no way of knowing how much of the medication [my sister] is actually taking,*
236 *and that could be so dangerous for her...” PDM12*

237

238 When swallowing became problematic proxy decision-makers expected a medication review
239 to determine if the number of medicines could be reduced and to ensure that all
240 medications were prescribed with a clear and current rationale.

241

242 *“[My wife] has to take ten different tablets each morning and night...it is a constant*
243 *struggle for me and a real worry because she has such a poor swallow...it has been a*
244 *while since her tablets have been reviewed and I think now that her swallow is so*
245 *bad, now would be a good time to do it again...I would be relieved if she had to take*
246 *less medicines.” PDM13*

247

248 Proxy decision-makers required more information about the person’s prescribed
249 medications, emphasising the importance of having an appreciation of how medications
250 work and what to expect in relation to benefits and adverse effects. Some held the belief
251 that it was their responsibility to seek such information.

252

253 *“No one gives me any information about the tablets, that is for me to do myself on*
254 *the Internet.” PDM1*

255

256 Others expected details to be provided by the prescribing physician, GP or pharmacist.
257 However, in some cases it was apparent that this information was not provided.

258
259 *"I expect the doctor [GP] maybe to tell me that level of detail [how the medications*
260 *work] and to be honest they don't always provide it...if you had a pharmacist to tell*
261 *you in a common sense kind of way, the important points about medications..."*

262 PDM11

263

264 Proxy decision-makers also discussed specific medications and drug classes. Cardiovascular
265 medications, including β -adrenoreceptor blocking drugs, anticoagulants, statins and
266 angiotensin-converting enzyme inhibitors, were considered essential; proxy decision-makers
267 believed these would prevent major cardiovascular events such as myocardial infarction and
268 stroke.

269

270 *"The statin she needs because her cholesterol is so high, my expectation of it is that it*
271 *will prevent further heart attacks and strokes from happening, so it is really*
272 *important that she takes this tablet."* PDM3

273

274 **Uncertainty over the benefit of anti-dementia medicines**

275

276 Proxy decision-makers appeared uncertain over the benefits of AChEIs and memantine, with
277 many reporting no perceived advantages.

278

279 *"They [doctors] told me a load of nonsense. That this drug [memantine] would help*
280 *her dementia, that it would slow the process down..... I don't think it is helping her*
281 *at all."* PDM2

282

283 *"I would have to say that I don't think [my dad] is getting any benefit from*
284 *donepezil...I therefore suppose that I don't really expect much in the line of that drug*
285 *if I am been honest."* PDM7

286

287 Others were unsure about the effect of these medications because they had no way of
288 telling what their loved one would be like if they were not taking it.

289

290 *"The consultant told me that memantine would slow the dementia down...it is*
291 *difficult to say whether it has slowed it down or not because I can't tell what the*
292 *dementia would be like if he wasn't taking it, you know."* PDM5

293

294 **Stopping medicines**

295

296 Opinions varied regarding stopping anti-dementia medications and other prescribed
297 medications, as detailed below.

298

299 *Anti-dementia medications*

300

301 Some proxy decision-makers were reluctant for these medications to be stopped due to
302 concerns that this could cause deterioration in their loved one's condition.

303

304 *"I wouldn't want to stop them [donepezil and memantine] because I would be afraid*
305 *of what would happen if she stopped them, so we are just happy for her to continue*
306 *to take them until whatever time she passes."* PDM11

307

308 Interestingly, others felt that such medications were making their loved one's condition
309 worse, and conveyed a sense of relief when these medications were stopped.

310

311 *"I was quite happy to get her off them [donepezil and memantine], because she is*
312 *well advanced in her Alzheimer's and I don't see any sense in her being comatosed*
313 *more [sic], because I do think the tablets comatosed [sic] her. To calm her down I*
314 *think they really made her more dysfunctional rather than anything else."* PDM9

315

316 *Other prescribed medications*

317

318 While some proxy decision-makers felt that a review was necessary to reduce the number of
319 prescribed medications, others were reluctant for medications to be stopped, citing
320 concerns over potential consequences. However, as their loved one's condition began to
321 deteriorate, many felt that some medications no longer had a role to play.

322

323 *"If you took it away [temazepam] I don't know if it would make an awful lot of*
324 *difference given how much she sleeps anyway, I mean she basically sleeps for the*

325 same amount of time as she is awake during the day now. Essentially I think it is just,
326 I think it is part of coming to the end of life and closing down.” PDM11

327
328 “We wouldn't protest, if anything, with [my wife], she is not going to get better, I
329 know she is going to get worse. Sometimes I do think that the donepezil is there just
330 because she has dementia, I mean her dementia is so advanced now I wonder is there
331 even any point in her taking it at this stage?” PDM14

332
333 **Communication and decision-making**

334
335 Some proxy decision-makers explained that they found making medication-related decisions
336 extremely difficult.

337
338 “I find it so difficult to make decisions for [my sister] because I know absolutely
339 nothing about the brain...it is different if you break a leg or you break an arm and
340 somebody says will we give her a painkiller, certainly yes, but I don't know what is
341 going on in anybody's mind...because she can't tell me...It is awful hard [sic] making
342 decisions for what tablets people should have for their mind...I hate it. I have to say, I
343 really do.” PDM9

344
345 Decisions were guided by what proxy decision-makers believed the person with advanced
346 dementia would have wanted.

347
348 “I suppose I would think back on the life [we] had together and I know the type of
349 person he is, so I would base my decisions on what I think [he] would decide for
350 himself.” PDM10

351
352 Proxy decision-makers expected any changes in medications to be communicated to them,
353 particularly when medications were stopped.

354
355 “I expect more in the way of communication from healthcare professionals... I mean I
356 expect to be told when there are any changes to my mum's medicines...I believe the
357 reasoning behind why they would be taking her off drugs to be very important to
358 me...” PDM3

359
360 The majority felt that healthcare professionals were equipped with the knowledge and
361 expertise about medications to enable appropriate treatment decisions. Many felt that they
362 did not possess the knowledge to make such decisions themselves. Some explained how
363 they trusted their healthcare professional to make prescribing decisions, and they did not
364 see it as their right to challenge those decisions.

365
366 *"I wouldn't be in a position to challenge them but I appreciate their courtesy at least*
367 *for keeping me in the picture...I have full trust in my doctor, I don't know anything*
368 *about the medicines or how they work on the body, they are the experts and so I just*
369 *let them do their job."* PDM13

370
371 However, despite this trust, proxy decision-makers wished to be kept informed of the
372 decisions made about their loved one's medications. Conversely, some proxy decision-
373 makers desired greater involvement and a more active role in the decision-making process.

374
375 *"I just think that doctors and healthcare professionals need to be involving family a*
376 *little bit more than they do...I know in the care home they say that the medications*
377 *are reviewed annually with the GP but we are never involved in that. They never pick*
378 *up the phone and say, "The GP is coming to review the medications would you like to*
379 *be here, or do you want to know the outcome of that?" If I don't actively go and ask*
380 *can I have a look at my granny's medication list to see what has been added or*
381 *discontinued, nobody would ever tell me."* PDM2

382
383

384 **Discussion**

385

386 *Main findings of the study*

387 Proxy decision-makers felt it was their role to advocate for the person with advanced
388 dementia. They expected healthcare professionals to ask about symptoms, prescribe
389 medications to treat those symptoms, and ensure comfort. The care of people with
390 dementia towards the end of life is often less than optimal,³⁴⁻³⁸ and there is a need for high-
391 quality palliative care for patients with dementia, with palliation of symptoms leading to
392 improved comfort and quality of life.³⁹⁻⁴³

393
394 Proxy decision-makers in the current study expected prescribed medications to be reviewed
395 as swallowing difficulties manifested and dementia progressed, as reported by others.⁴⁴
396 Similar to the present study, the taking of medications in advanced illness has previously
397 been described as a 'daily struggle' by some caregivers.⁴⁵

398
399 Proxy decision-makers viewed cardiovascular medicines as essential to prevent major
400 cardiovascular events. However, studies which have examined medication appropriateness
401 in dementia using expert consensus panels have categorised β -adrenoreceptor blocking
402 drugs as "sometimes appropriate" and statins as "never appropriate" in advanced
403 dementia,^{46,47} anticoagulants as "rarely appropriate"⁴⁶ or "never appropriate"⁴⁷, and ACE
404 inhibitors as "sometimes appropriate"⁴⁶ or "never appropriate".⁴⁷ The recently developed
405 Medication Appropriateness Tool for Co-morbid Health conditions in Dementia (MATCH-D)
406 criteria also suggest that antihypertensive agents, lipid-lowering medications, and anti-
407 platelet, anti-coagulant and anti-thrombotic agents should be ceased in late-stage
408 dementia.⁴⁸ Despite these recommendations, patients with advanced dementia often
409 continue to receive medications of questionable benefit.⁴⁹⁻⁵² Proxy decision-makers'
410 opinions of these medications may help to explain why they continue to be prescribed in
411 advanced disease.

412
413 Many proxy decision-makers in the current study felt they lacked information or access to a
414 reliable source of information about medications prescribed for the person with advanced
415 dementia. Some thought it was their responsibility to actively seek such information, and
416 accessed the Internet to search for details pertaining to prescribed medications. Healthcare
417 professionals should acknowledge the Internet as an information source about prescribed
418 medications, be prepared to offer suggestions for appropriate Internet health resources and
419 assist in evaluating the quality of the information obtained.

420
421 Some proxy decision-makers articulated uncertainty about the benefits of anti-dementia
422 medications because they had no way of measuring their effects, a finding also reported by
423 others.⁵³ Despite this, there was reluctance for these medications to be stopped due to fear
424 that withdrawal could accelerate disease progression or lead to the reintroduction of
425 anxiety, aggression, and challenging behaviours. A qualitative study focusing on AChEIs

426 considered the views of caregivers of people with mild-to-advanced dementia.²⁷ Similar to
427 the present study, carers expected that withdrawal would hasten disease progression.
428 Other studies have suggested that discontinuation of anti-dementia medications may
429 worsen the chronic disease, particularly in those who initially respond to treatment,⁵⁴⁻⁵⁷ and
430 there have been reports of abrupt decline in cognitive or functional abilities in patients or
431 emerging challenging behaviours upon discontinuation. Conversely, others suggest that
432 AChEI discontinuation is safe and well tolerated in the majority of institutionalized
433 patients.⁵⁸ Further studies are required to evaluate the effects of anti-dementia medication
434 discontinuation, adding to the limited evidence base for patients with advanced dementia.

435
436 Proxy decision-makers in this study expressed reluctance over stopping other prescribed
437 medications, which reduced as the condition of their loved one deteriorated, and as end of
438 life approached. This reflects previous work which reported that caregivers could foresee a
439 time when the symptoms associated with memory loss or with another illness might
440 become so severe that taking a medication to treat memory loss was no longer desirable.⁵⁹

441
442 Similar to the study by Caron et al.,⁶⁰ proxy decision-makers expected changes to
443 medications to be communicated to them. Medication management has been defined as
444 one of many domains of care provided by caregivers⁶¹ and includes roles such as:
445 administering multiple medications; avoiding medication errors and possible drug
446 interactions; looking for side-effects; making judgements regarding when to withhold,
447 increase, decrease or discontinue a medication; and trying to make informed decisions
448 about their medication management role by communication with healthcare providers.^{62,63}
449 These roles are often made more difficult by unhelpful structures and practices in different
450 healthcare settings. For example, changes to prescribed medications may not be
451 communicated to caregivers if they were not present during the consultation.⁶⁴ The
452 importance of improving communication between healthcare professionals and caregivers
453 in end of life care settings and for those dying with dementia has been acknowledged.^{65,66}
454 Recent work has identified the potential application of the MATCH-D criteria as a discussion
455 aid or educational tool to facilitate this communication.⁶⁷ The revised Patients' Attitudes
456 towards Deprescribing (rPATD) questionnaire also shows promise as a tool to supplement

457 and guide communication about stopping medications and to highlight proxy decision-
458 maker beliefs and attitudes towards deprescribing.⁶⁸

459

460 Caregivers find decisions around end of life care very difficult. In situations where the wishes
461 of the patient are not known in advance, they are helped by knowing the views held by the
462 person with dementia before losing capacity.¹³ Communication between proxy decision-
463 makers and healthcare professionals is vital to explore and understand the patient's
464 previously stated goals and values, which should then guide and facilitate treatment
465 decisions. Dementia-specific advance directives, which address change in cognition and
466 goals of care as dementia progresses and are completed by patients *before* dementia
467 occurs, would provide proxy decision-makers with even greater reassurance that the
468 treatment they choose is guided by what the patient would have wanted.⁶⁹

469

470 Proxy decision-makers varied in their need to be actively involved in medication-related
471 decisions. The majority were happy to delegate to, and placed substantial trust in,
472 healthcare professionals; they did not feel that they had the appropriate medical knowledge
473 to make such decisions, a finding reported by others.⁶⁰ The integral role of the physician in
474 this regard has emerged in previous studies.^{23,43,60,70} In all cases, being informed of decisions
475 made was essential for reassurance about the care received, and to meet the expectation
476 concerned with the proxy decision-maker's own sense of involvement in such care.

477

478 *Limitations of the study*

479 Limitations must be acknowledged and considered when interpreting the data. This study
480 recruited a sample from a very specific population of proxy decision-makers for people with
481 advanced dementia in one region of the UK (NI); as a result, there is the potential for
482 sampling bias.⁷¹ Selection bias may be present as proxy decision-makers with no
483 understanding of their loved one's medications were not recruited. One approach suggested
484 to address this problem is through the generation of a larger sample size.⁷² However, as this
485 study reached data saturation, this was not considered necessary.^{32,71}

486

487 *Implications for research*

488 In the present study, proxy decision-makers of people with advanced dementia advocated
489 for medicines to be prescribed to ensure their loved one's comfort, especially towards the
490 end of life. Future research should explore the extent to which proxy decision-makers'
491 expectations are met in relation to ensuring comfort as end of life approaches, and their
492 role in the decision-making process regarding initiation, continuation or withdrawal of
493 medications. Further understanding of and insight into communication between healthcare
494 professionals and proxy decision-makers and the complexity of the healthcare professional-
495 proxy decision-maker relationship are critical in the development of an intervention or best-
496 practice model that will serve to facilitate decision-making processes for people with
497 advanced dementia.

498

499 *What this study adds*

500 This study is the first to explore proxy decision-makers' expectations of prescribed
501 medications in advanced dementia, and to consider how these may change with changing
502 goals of care and disease progression. Communication between healthcare professionals
503 and proxy decision-makers regarding prescribed medications is of critical importance.
504 Healthcare professionals should facilitate proxy decision-maker involvement in the
505 medication decision-making process if desired.

506

507 **Conclusion**

508

509 Proxy decision-makers described their role as advocate and providing information to
510 healthcare professionals, particularly about symptoms experienced. They reported an
511 expectation for more information about prescribed medicines, specifically regarding
512 indications, benefits and risks of treatment. Proxy decision-makers expressed reluctance at
513 stopping prescribed medicines due to fear of potential consequences. However, this
514 appeared to reduce with changing goals of care and dementia progression. Although some
515 expected to be involved in medication-related decisions, the majority preferred to delegate
516 these decisions to healthcare professionals. However, they expected to be informed of any
517 decisions made. Further work is required to identify the impact of proxy decision-makers'
518 expectations for prescribed medications on prescribing for people with advanced dementia
519 approaching the end of life.

520

521 **Acknowledgements**

522 The authors would like to thank all research participants, GPs, Join Dementia Research, and
523 the Alzheimer's Society, Northern Ireland, who facilitated and supported this study.

524

525 **Conflicts of interest**

526 The authors have no conflicts of interest to declare.

527

528 **Funding**

529 This research was funded by the Department of Education and Learning (DEL), Northern
530 Ireland, as part of a PhD research degree. The funder had no role in the development,
531 analysis of reporting of the present study.

532

533 **Availability of data and materials**

534 The audiotaped interviews were deleted from the digital recorder following transcription, in
535 accordance with institutional data protection protocols. Transcripts are not available
536 because this would render participants identifiable.

537

538 **References**

539 1. American Psychiatric Association (2013) Diagnostic and statistical manual of mental disorders. 5th
540 Edition. Arlington, VA: American Psychiatric Publishing

541 2. National Institute for Health and Care Excellence (2017) Dementia: supporting people with
542 dementia and their carers in health and social care. NICE clinical guideline 42. [Online] London: NICE.
543 Available at: <https://www.nice.org.uk/guidance/cg42?unlid=9429054072016126125418> [Accessed
544 on 3rd January 2018]

545 3. Liu KPY, Chan CCH, Chu MML, et al. Activities of daily living performance in dementia. *Acta Neurol*
546 *Scand* 2007; 116: 91–95.

547 4. Sikkes SAM, De Lange-De Klerk ES, Pijnenburg YA, et al. A systematic review of Instrumental
548 Activities of Daily Living scales in dementia: room for improvement. *J Neurol Neurosurg Psychiatry*
549 2009; 80: 7–12.

- 550 5. Sikkes SAM, Pijnenburg YA, Knol DL, et al. Assessment of instrumental activities of daily living in
551 dementia: diagnostic value of the Amsterdam Instrumental Activities of Daily Living Questionnaire. *J*
552 *Geriatr Psychiatry Neurol* 2013; 26: 244–250.
- 553 6. Mitchell S, Teno J, Kiely D, et al. The clinical course of advanced dementia. *N Engl J Med* 2009; 361:
554 1529–1538.
- 555 7. Marshall G, Amariglio R, Sperling R, et al. Activities of daily living: where do they fit in the
556 diagnosis of Alzheimer’s disease? *Neurodegener Dis Manag* 2012; 2: 483–491.
- 557 8. Giebel CM, Sutcliffe C, Stolt M, et al. Deterioration of basic activities of daily living and their
558 impact on quality of life across different cognitive stages of dementia: a European study. *Int*
559 *Psychogeriatr* 2014; 26: 1283–1293.
- 560 9. Reisberg B. Functional Assessment Staging (FAST). *Psychopharmacol Bull* 1998; 24: 653–659.
- 561 10. Francis LP. Decision making at the end of life: patients with Alzheimer’s or other dementias.
562 *Georgia Law Review* 2001; 35: 539–592.
- 563 11. Sampson EL, Thuné-Boyle I, Kukkastenvehmas R, et al. Palliative care in advanced dementia; a
564 mixed methods approach for the development of a complex intervention. *BMC Palliat Care* 2008;
565 7:8.
- 566 12. Givens JL, Kiely DK, Carey K, et al. Clinical investigations. Healthcare proxies of nursing home
567 residents with advanced dementia: decisions they confront and their satisfaction with decision-
568 making. *J Am Geriatr Soc* 2009; 57: 1149–1155.
- 569 13. Livingston G, Leavey G, Manela M, et al. Making decisions for people with dementia who lack
570 capacity : qualitative study of family carers in UK. *BMJ* 2010; 341: c4184.
- 571 14. Jones L, Harrington J, Scott S, et al. CoMPASs: IO n programme (Care Of Memory Problems in
572 Advanced Stages of dementia: Improving Our Knowledge): protocol for a mixed methods study. *BMJ*
573 *Open* 2012; 2: e002265.
- 574 15. Prorok JC, Horgan S, Seitz DP. Health care experiences of people with dementia and their
575 caregivers: a meta-ethnographic analysis of qualitative studies. *Can Med Assoc J* 2013; 185: 1195–
576 1195.

- 577 16. Moreira T, Palladino P. Between truth and hope: on Parkinson's disease,
578 neurotransplantation and the production of the "self". *Hist Hum Sci* 2005; 18: 55–82.
- 579 17. Hutchings D, Vanoli A, McKeith I, et al. Good days and bad days: The lived experience
580 and perceived impact of treatment with cholinesterase inhibitors for Alzheimer's disease in
581 the United Kingdom. *Dementia* 2010; 9: 409–425.
- 582 18. Geldmacher DS, Frolich L, Doody RS, et al. Realistic expectations for treatment success in
583 Alzheimer's disease. *J Nutr Health Aging* 2006; 10: 417–429.
- 584 19. Bell RA, Kravitz RL, Thom D, et al. Unmet expectations for care and the patient-physician
585 relationship. *J Gen Intern Med* 2002; 17: 817–824.
- 586 20. Smith A, Kobayashi K, Chappell N, et al. The controversial promises of cholinesterase inhibitors
587 for Alzheimer's disease and related dementias: a qualitative study of caregivers' experiences. *J Aging*
588 *Stud* 2011; 25: 397–406.
- 589 21. Parsons C, McCorry N, Murphy K, et al. Assessment of factors that influence physician decision
590 making regarding medication use in patients with dementia at the end of life. *Int J Geriatr Psychiatry*
591 2013; 29: 281-290.
- 592 22. Deardorff WJ, Feen E, Grossberg GT. The use of cholinesterase inhibitors across all stages of
593 Alzheimer's disease. *Drugs Aging* 2015; 32: 537–547.
- 594 23. Reeve E, Bell JS, Hilmer SN. Barriers to optimising prescribing and deprescribing in older adults
595 with dementia: a narrative review. *Curr Opin Pharmacol* 2015; 10: 168–177.
- 596 24. Webb S, Lloyd M. Prescribing and referral in general practice: A study of patients' expectations
597 and doctors' actions. *Br J Gen Pract* 1994; 44: 165–169.
- 598 25. Cockburn J, Pit S. Prescribing behaviour in clinical practice: patients' expectations and doctors'
599 perceptions of patients' expectations - a questionnaire study. *BMJ* 1997; 315: 520–523
- 600 26. Prosser H, Almond S, Walley T. Influences on GPs' decision to prescribe new drugs — the
601 importance of who says what. *Fam Pract* 2003; 20: 61–68.

- 602 27. Post SG, Stuckey JC, Whitehouse PJ, et al. A focus group on cognition-enhancing medications in
603 Alzheimer disease: disparities between professionals and consumers. *Alzheimer Dis Assoc Disord*
604 2001; 15: 80–88;
- 605 28. Clare L. Developing awareness about awareness in early-stage dementia: the role of psychosocial
606 factors. *Dementia* 2002; 1: 295–312.
- 607 29. Mahoney DF, Clutterbuck J, Neary S, et al. African American, Chinese, and Latino family
608 caregivers' impressions of the onset and diagnosis of dementia: cross-cultural similarities and
609 differences. *Gerontologist* 2005; 45: 783–792.
- 610 30. Hutchings D, Vanoli A, McKeith I, Brothet al. Cholinesterase inhibitors and Alzheimer's disease:
611 patient, carer and professional factors influencing the use of drugs for Alzheimer's disease in the
612 United Kingdom. *Dementia* 2010a; 9: 427–443.
- 613 31. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101
- 614 32. Diccio-Bloom B, Crabtree BF. The qualitative research interview. *Med Educ* 2006; 40: 314–321
- 615 33. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In BRYMAN, A., &
616 BURGESS, R.G. Analyzing qualitative data. London: Routledge, 1994.
- 617 34. Ballard C, Fossey J, Chithramohan R, et al. Quality of care in private sector and NHS facilities for
618 people with dementia: cross sectional survey. *BMJ* 2001; 323: 426–427
- 619 35. Sampson EL, Ritchie CW, Lai R, et al. A systematic review of the scientific evidence for the
620 efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatr* 2005; 17: 31–40.
- 621 36. Roger KS. A literature review of palliative care, end of life, and dementia. *Palliat Support Care*
622 2006; 4: 295–303.
- 623 37. Mitchell SL, Black BS, Ersek M, et al. Advanced dementia: state of the art and priorities for the
624 next decade. *Ann Intern Med* 2012; 156: 45–51.
- 625 38. van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, et al. Caregivers' understanding of dementia
626 predicts patients' comfort at death: a prospective observational study. *BMC Med* 2013; 11: 105.
- 627 39. Birch D, Draper J. A critical literature review exploring the challenges of delivering effective
628 palliative care to older people with dementia. *J Clin Nurs* 2008; 17: 1144–1163.

- 629 40. Luchins D, Hanrahan P. What is appropriate health care for end-stage dementia? *J Am Geriatr*
630 *Soc* 1993; 41: 25–30
- 631 41. Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: A National Survey of
632 Hospice Programs. *J Am Geriatr Soc* 1995; 43: 56–59.
- 633 42. Teno JM, Casey VA, Welch LC, et al. Patient-focused, family-centered end-of-life medical care:
634 views of the guidelines and bereaved family members. *J Pain Symptom Manage* 2001; 22: 738–751
- 635 43. van der Steen JT. Dying with dementia: what we know after more than a decade of research. *J*
636 *Alzheimers Dis* 2010; 22: 37–55.
- 637 44. van Nordennen RT, Lavrijsen JC, Heesterbeek MJ, et al. Changes in prescribed drugs between
638 admission and the end of life in patients admitted to palliative care facilities. *J Am Med Dir Assoc*
639 2016; 17: 514-518
- 640 45. Sheehy-Skeffington B, McLean S, Bramwell M. Caregivers experiences of managing medications
641 for palliative care patients at the end of life: qualitative study. *Am J Hospice Palliat Med* 2014; 31:
642 148–154.
- 643 46. Holmes HM, Sachs GA, Shega JW, et al. Integrating palliative medicine into the care of persons
644 with advanced dementia: identifying appropriate medication use. *J Am Geriatr Soc* 2008; 56: 1306–
645 1311.
- 646 47. Parsons C, McCann L, Passmore P, et al. Development and application of medication
647 appropriateness indicators for persons with advanced dementia: a feasibility study. *Drugs Aging*
648 2015; 32: 67–77.
- 649 48. Page AT, Potter K, Clifford R, et al. Medication appropriateness tool for co-morbid health
650 conditions in dementia: consensus recommendations from a multidisciplinary expert panel. *Int Med*
651 *J* 2016; 46(10): 1189–1197.
- 652 49. Toscani F, Di Giulio P, Villani D, et al. Treatments and prescriptions in advanced dementia
653 patients residing in long-term care institutions and at home. *J Palliat Med* 2013; 16: 31–37.
- 654 50. Tjia J, Briesacher BA, Peterson D, et al. Use of medications of questionable benefit in advanced
655 dementia. *JAMA Intern Med* 2014; 174: 1763–1771.

- 656 51. Matlow JN, Bronskill SE, Gruneir A, et al. Use of medications of questionable benefit at the end of
657 life in nursing home residents with advanced dementia. *J Am Geriatr Soc* 2017; 65: 1535-1542.
- 658 52. Morin L, Vetrano DL, Grande G, et al. Use of medications of questionable benefit during the last
659 year of life of older adults with dementia. *J Am Med Dir Assoc* 2017; 18: 551.e1-551.e7.
- 660 53. Hutchings D, Vanoli A, McKeith, I. et al. Good days and bad days: The lived experience and
661 perceived impact of treatment with cholinesterase inhibitors for Alzheimer's disease in the United
662 Kingdom. *Dementia* 2010; 9: 409-42
- 663 54. Doody RS, Geldmacher DS, Gordon B, et al. Open-label, multicenter, phase 3 extension study of
664 the safety and efficacy of donepezil in patients with Alzheimer disease. *Arch Neurol* 2001; 58: 427-
665 433.
- 666 55. Daiello L, Ott B, Lapane K, et al. Effect of discontinuing cholinesterase inhibitor therapy on
667 behavioural and mood symptoms in nursing home patients with dementia. *Am J Geriatr
668 Pharmacother* 2009; 7: 74-83.
- 669 56. Shega JW, Ellner L, Lau DT, et al. Cholinesterase inhibitor and N-Methyl-D-Aspartic acid receptor
670 antagonist use in older adults with end stage dementia: A survey of hospice medical directors. *J
671 Palliat Med* 2009; 12:779-783.
- 672 57. Howard R, McShane R, Lindesay J, et al. Donepezil and memantine for moderate-to-severe
673 Alzheimer's disease. *N Engl J Med* 2012; 366: 893-903
- 674 58. Herrmann N, O'Regan J, Ruthirakuhan M, et al. A randomized placebo-controlled discontinuation
675 study of cholinesterase inhibitors in institutionalized patients with moderate to severe Alzheimer
676 disease. *J Am Med Dir Assoc* 2016; 17: 142-147.
- 677 59. Lindstrom HA, Smyth KA, Sami SA, et al. Medication use to treat memory loss in dementia:
678 perspectives of persons with dementia and their caregivers. *Dementia* 2006; 5: 27-50.
- 679 60. Caron CD, Griffith J, Arcand M. End-of-life decision making in dementia: the perspective of family
680 caregivers. *Dementia* 2005; 4: 113-136.
- 681 61. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caregivers of older
682 adults and people living with dementia. A review of the literature. *J Clin Nurs* 2013; 23: 3296-3308.

- 683 62. Travis SS, Bethea LS, Winn P. Medication administration hassles reported by family caregivers of
684 dependent elderly persons. *J Gerontol A Biol Sci Med Sci* 2000; 55: 412–417.
- 685 63. Smith F, Francis SA, Gray N, et al. A multicentre survey among informal carers who manage
686 medication for older care recipients: problems experienced and development of services. *Health Soc*
687 *Care Community* 2003; 11: 138–145
- 688 64. Francis SA, Smith F, Gray, N, et al. Partnerships between older people and their carers in the
689 management of medication. *Int J Older People Nurs* 2006; 1: 201–207.
- 690 65. Muders P, Zahrt-Omar C, Bussmann S, et al. Support for families of patients dying with dementia:
691 a qualitative analysis of bereaved family members' experiences and suggestions. *Palliat Support Care*
692 2014; 13: 435-442.
- 693 66. Wallace CL. Family communication and decision making at the end of life: a literature review.
694 *Palliat Support Care* 2015; 13: 815–825.
- 695 67. Page AT, Clifford RM, Potter K, et al. Exploring the enablers and barriers to implementing the
696 Medication Appropriateness Tool for Comorbid Health conditions during Dementia (MATCH-D)
697 criteria in Australia: a qualitative study. *BMJ Open* 2017; 7: e017906.
- 698 68. Reeve E, Low LF, Shakib S, et al. Development and validation of the revised Patients' Attitudes
699 towards Deprescribing (rPATD) questionnaire: versions for older adults and caregivers. *Drugs Aging*
700 2016; 33: 913-928.
- 701 69. Gaster B, Larson EB, Curtis JR. Advance directives for dementia: meeting a unique challenge. *J*
702 *Am Med Assoc* 2017; 318 (22): 2175-2176.
- 703 70. Palagyi A, Keay L, Harper J, et al. Barricades and brickwalls: a qualitative study exploring
704 perceptions of medication use and deprescribing in long-term care. *BMC Geriatr* 2016; 16: 15.
- 705 71. Marshall MN. Sampling for qualitative research. *Fam Pract* 1996; 13: 522–525.
- 706 72. Atkinson R, Flint J. Accessing hidden and hard-to-reach populations: snowball research
707 strategies. *Social Research Update: No. 33*. Guilford, UK: University of Surrey, Department of
708 Sociology, 2001

Table 1. Interview Schedule

Topic	Questions
General information about the participant	1. What age are you? What is your relationship to X? X = Person with dementia for whom proxy decision-maker makes decisions
Discussion about X's medicines	2. On average how many hours per week would you spend with X? a. Is any of this time spent caring for X? If so, can you explain how you care for X? 3. What do you know about X's medicines? 4. Does anyone provide you with information about X's medicines? 5. Is anyone responsible for managing X's medicines?
Proxy decision-makers' expectations towards prescribed medicines for the person with advanced dementia	6. How did you feel when you were told that x would start dementia medications? 7. What information were you given? Who gave it to you? How did you feel about the information you were given? a. Were you given any information about when x might have to stop taking their dementia medications? 8. What do you think this/these medicine(s) is/are doing for X? Why do you think that? 9. What do you hope this/these medicine(s) will do for X in the longer term?
Proxy decision-makers' experiences and views on decision-making regarding medicine use	10. Have you ever had any discussions with the doctor or any other healthcare professional about having medicines started or stopped for X? a. Can you tell me more about this? 11. What are your views on being involved in making decisions about X's medicines as his/her condition gets worse or if the doctor tells you that X has only a few weeks left to live?
Opinions on the withdrawal of prescribed medicines from people with dementia as goals of care change and dementia progresses	12. In the future, if X's dementia was getting more severe how would you feel if this/these medicine(s) was/were to be stopped? 13. In your view, what are the key things you need to be aware of when making decisions about X's medications?

Table 2. Demographic characteristics of participants (N=15)

Demographic characteristic	
Mean age (years) ± SD of proxy decision-maker	71 ± 13.1
Gender of proxy decision-maker	
Female	10 (66.7%)
Male	5 (33.3%)
Mean age (years) ± SD of person with advanced dementia	78.8 ± 9.2
Relationship of proxy decision-maker to person with advanced dementia	
Spouse	8 (53.3%)
Sibling	2 (13.3%)
Child	4 (26.7%)
Grandchild	1 (6.7%)
Place of care	
Patient's own home	7 (46.7%)
Nursing home	5 (3.3%)
Proxy decision-maker's home	3 (20.0%)

SD = Standard deviation