

Multidisciplinary perspectives on medication-related decision-making for people with advanced dementia living in long-term care: a critical incident analysis

Authors:

Miss Domenica Disalvo (Corresponding author)

IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney, Ultimo, NSW, Sydney, Australia

235 Jones St, Ultimo NSW 2007 (PO Box 123)

domenica.m.disalvo@student.uts.edu.au

T. +61 (02) 9514 4861

Dr Tim Luckett

IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney, Ultimo, NSW, Sydney, Australia

tim.luckett@uts.edu.au

Dr Alexandra Bennett

NSW Therapeutic Advisory Group, Sydney, NSW, Australia

sasha.bennett@svha.org.au

Prof Patricia M. Davidson

School of Nursing, Johns Hopkins University, Maryland, Baltimore, USA

pdavidson@jhu.edu

Prof Meera Agar, MBBS, MPC, FRACP, PhD

IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney, Ultimo, NSW, Sydney, Australia

South Western Sydney Clinical School, University of New South Wales, NSW, Australia

Ingham Institute of Applied Medical Research, NSW, Australia

meera.agar@uts.edu.au

Acknowledgements

Authors would like to thank all participants who participated in focus groups as part of this study.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. DD was supported by a UTS Doctoral Scholarship.

Abstract

Purpose: This study aimed to explore medication-related decision-making by health professionals from different disciplines and specialties caring for people with advanced dementia living in long-term care facilities, focusing on dilemmas associated with starting, continuing or deprescribing medications commonly regarded as potentially inappropriate.

Methods: Four focus groups were undertaken, each on a different medication type (antibiotics, lipid-lowering agents, opioids and acetylcholinesterase inhibitors). Transcripts underwent qualitative analysis using line by line inductive coding and then a person-centred framework to highlight themes across medication types.

Results: Sixteen participants participated in focus groups. Regardless of medication type or dilemma, results suggested decision-making for residents with advanced dementia should begin with discussing goals of care and engaging with families, and be viewed as an iterative process involving regular monitoring and adjustment. Decision-making was seen as requiring a dialectical approach involving multiple perspectives, with an emphasis on establishing communication between health professionals, family and the person with dementia to better understand goals/preferences for care.

Conclusion: Inter-professional collaboration enables sharing of clinical experience/expertise, differing disciplinary perspectives, and knowledge about the resident. Continuing a medication should be considered an active decision that carries as much responsibility as starting or deprescribing.

Keywords: decision-making, potentially inappropriate prescribing, long-term care, deprescribing, dementia, interdisciplinary collaboration

Multidisciplinary perspectives on medication-related decision-making for people with advanced dementia living in long-term care: a critical incident analysis

Introduction

Guidance from the European Association for Palliative Care (EAPC) recommends that care for people with advanced dementia requires a palliative approach which emphasises quality of life and comfort [1]. However, identifying when a given individual should transition to a palliative approach requires a person-centred approach which takes into account the trajectory, goals of care and context that are unique to each person. Most people with advanced dementia live in long-term care (LTC) [2], where care is often inconsistent with a palliative approach [3]. LTC residents with advanced dementia often have symptoms that go under-recognised and under-treated and may receive medications that are focused on prolonging life rather than comfort, and cause harms through adverse effects [4].

A multidisciplinary approach, whereby an integrated team of professionals from different disciplines and specialties comes together to reach a combined decision on a complex situation, is considered the gold standard for care of people with advanced dementia living in LTC [1]. Only two survey studies have sought to understand the process of medication-related decision-making in this context [5, 6]. Whilst providing some insight into the decision-making process, further qualitative research is needed to provide a more in-depth and nuanced understanding of factors influencing decision-making to inform best practice.

Key medicine decisions for LTC residents with advanced dementia are commencing new medications for symptom control, and deprescribing any for which potential benefit no longer outweighs potential risk of harm. However, decisions are not always straight forward. For example, while antibiotics might not be considered appropriate for extending life, they are sometimes used in palliation to treat significant discomfort of pneumonia and other infections in this population [1]. While acetylcholinesterase inhibitors (AChEI) may provide cognitive and functional benefits, long-term preventive medications like lipid-lowering agents can reduce risk of vascular events or mortality, these may no longer be primary goals of care in advanced dementia [7].

An issue of concern in LTC is prescribing inertia i.e. continuing to prescribe medications that a resident no longer needs [8], which has prompted a movement to deprescribe, with new organisations formed specifically to optimise quality use of medicines (QUM) in older adults e.g. Australian Deprescribing Network (ADeN) [9]. However, little is known about the factors in decision-making that contribute to prescribing inertia in LTC residents with dementia.

A recent systematic review found the most prominent enablers to deprescribing in people with life-limiting disease were organisational support, and a multidisciplinary approach to medication review [10]. Further research is needed to better understand factors impacting appropriate deprescribing in palliative care.

A methodology used with promising results to explore medication-related decision-making in other clinical populations is the 'critical incident technique' (CIT) which focuses on 'dilemmas' and factors influencing their resolution [11]. Two separate studies used CIT to explore physician decision-making with regard to prescribing opioids and benzodiazepines to patients in primary healthcare [12, 13]. In both studies, considerations other than pharmacological contributed to decision-making, including concern about maintaining a therapeutic relationship with patients.

This study aimed to explore medication-related decision-making by health professionals from different disciplines and specialties caring for people with advanced dementia living in LTC facilities, with a special focus on the dilemmas associated with starting, continuing or deprescribing medications commonly regarded as potentially inappropriate.

Method

Study design

The study used a qualitative approach modelled on the CIT [11]. Ethics approval was from the University of Technology Sydney (UTS) Human Research Ethics Committee (Approval Reference No. ETH16-0291). All participants gave written informed consent to participate. The consolidated criteria for reporting qualitative research (COREQ-32) [14] guided reporting (see Appendix A2 published as supplementary material online).

Participants

Sampling

Eligible participants were health professionals with experience of medication-related decision-making and management for people with advanced dementia. Participants were purposively sampled from health professions most commonly involved in medication-related decisions for people with advanced dementia including medicine, nursing and pharmacy. Because of the central role played by medical professionals in prescribing medicines, we included physicians from the three specialties for whom advanced dementia is a major focus, namely general practice, palliative care, geriatrics and old age psychiatry. Nursing participants needed to be a registered nurse (RN) and have a scope of practice that included medication management.

Recruitment

An email invitation was circulated through professional body newsletters, the team's established clinical networks and professional interest groups.

Data collection

Data were collected using focus groups, as follows.

Pre-session

One week prior to the focus groups, participants were sent a questionnaire including questions on number of years in occupation and experience in making medication decisions in advanced dementia. Participants were also emailed two different vignettes on each specific medication of interest (see Appendix A1 published as supplementary material online attached to the electronic version of this paper), including AChEIs, antibiotics, opioid analgesics and lipid-lowering agents. These have been identified from the literature as being medications that are commonly started or continued in LTC residents with advanced dementia but are of questionable net benefit due to risk of adverse effects, further accentuated in those with advanced dementia due to physiological changes that accompany this condition impair medication metabolism and clearance. Antipsychotic medications were not included due to significant recent research in Australian LTC in this area [15, 16].

Key parameters of interest were altered across vignettes in terms of clinical and socio-demographic variables including age, sex, comorbidities, cognitive and functional status, a medication list and a short description of the dilemma. Participants were asked to read vignettes prior to the scheduled meeting and encouraged to make notes to use as an aide during focus groups. Vignettes were also intended to prompt health professionals' memories of similar encounters when prescribing or managing medications for people with advanced dementia. Participants were asked to have their notes and the vignettes in front of them during the focus group meeting.

Focus groups

Four focus group sessions were undertaken, with each session focusing on a different medication of interest, with participants telephoning into a teleconference call at the scheduled time. Focus groups were audio recorded and lasted approximately 90 minutes.

Three focus groups were facilitated by MA, a female palliative care physician with experience in leading palliative care services including in-reach to LTC; as well as leading an extensive program of research that includes use of the CIT and studies focused on the care of LTC residents with advanced dementia. One focus group was facilitated by TL, a male social scientist with experience in research on improving palliative care for LTC residents with

advanced dementia. A female PhD Candidate (DD) with a background in medical sciences acted as assistant moderator, taking notes and running the audio recorder during focus groups.

Many participants knew the focus group facilitators prior to the study through established professional bodies and/or previous collaborative research. Participants were made aware that this research made up part of a PhD programme within the email invitation and information sheet.

The CIT was operationalised in each focus group as exploration of dilemmas in the vignettes, including sources of information useful for informing decision-making and the variables resolving or worsening equivocation in decision-making [17] (see Table 1). Participants were also asked “can you think of experiences you have had where similar or different issues occurred in relation to this medication?” Similar to the ‘think aloud’ method used in cognitive interviews, we encouraged participants during focus groups to verbalise their decision-making process as they answered questions [18]. Open discussion and debate was encouraged to make explicit any discipline/specialty-specific assumptions and perspectives that might otherwise be too embedded for participants to recognise and report.

[insert Table 1 here]

Questions were sometimes opened to any participant but at other times asked to each participant in turn to ensure perspectives from different disciplines/specialties were included and manage group dynamics. It was explained to participants that there were no ‘right’ or ‘wrong’ responses and focus groups were aimed at capturing complexity and diversity rather than concordance among perspectives.

Data analysis

Content analysis was first employed to extract generalised principles from the individual vignettes presented and offered by participants. Initially, DD independently coded all four transcripts and developed a coding structure. The structure was coded inductively, grouping text/themes which were found between all medications of interest, and also identifying points of interest which were specific to each medication. The narratives of each vignette were of interest to identify common features that prompt recall by participants and offer insight into the decision-making process. Areas of disagreement between different disciplines/specialties were regarded as focal points for highlighting dilemmas and contextual considerations.

DD, TL and MA met to discuss and clarify common themes between medications of interest as well as defining features and points of difference. Themes from a review of reviews of person- and patient-centred care [19] were used to transition to interpretive themes. QSR NVivo 11 software was used to manage data. For verification purposes, a one page summary of themes found throughout all focus groups was emailed to participants, which also invited them to identify any they disagreed with.

Results

Participant characteristics

The study was conducted between September 2016 and February 2017. A total of 16 participants were recruited, ten of whom were female. Participants’ clinical experience is summarised in Table 2. Six participants were involved in the focus group on antibiotics, five in AChEI focus group, five in lipid-lowering agent focus group and four in the opioid focus group. All four focus groups included medical representation from general practice, a representative from geriatric and/or palliative medicine and nursing representation from aged care and/or palliative care. A heart failure nurse practitioner attended the lipid-lowering agent focus group to give a relevant specialist perspective. A clinical nurse specialist working with a hospital rapid response team participated in the antibiotic focus group to provide insight into use of this medication in LTC residents transferred to acute care. Pharmacists attended three of the focus groups, but a pharmacist who was scheduled to attend the focus group on lipid-lowering agents cancelled at the last minute due to unforeseeable circumstances and could not be replaced.

[insert Table 2 here]

Participants had experience in a range of activities related to medication decision-making for LTC residents with advanced dementia, including medication reviews and case conferencing with other health professionals and

family to decide medication management, as well as other assessments such as falls risks. There was also many overlaps in experience by specialty and disciplines.

Themes

Participants saw medication-related decision-making for LTC residents with advanced dementia as a focus of concern for patient care with equal potential for significant consequences regardless of whether starting, continuing or deprescribing a medication. Participants attributed prescribing inertia to apathy, a desire not to be seen to threaten the status quo, and/or a concern that changing medication might confer responsibility for negative consequences. However, they emphasised that taking no action should be viewed as an equally active decision that carried equal responsibility.

“The last thing a GP wants to do is change things around and then something bad happens, then it would be very easy for people to blame the GP for the decision on retrospect...if the patient is stable and there is no side effects, the tendency of many GPs is to just continue going.” (GP2, lipid-lowering agents)

Concerns were also raised about a perceived trend in LTC by which a dementia diagnosis was seen as a reason to deprescribe indiscriminately, without due individual assessment.

“The implication that just because a person who has a cognitive impairment deteriorates from a cognitive perspective in an aged care facility, that that means that they’re dying and the best treatment for that situation is comfort care with opioids and benzodiazepines without further thought is just a concerning one sometimes.” (Geriatrician 1, opioids)

“He’d stopped eating or drinking and they thought he must be dying...it turned out he had a mouth full of ulcers...there was this presumption that he was deteriorating from his dementia, and he wasn’t. You have to have a really careful approach; is it actually deterioration from dementia, or is it something else that could be really easily resolved?” (Nurse 1, opioids)

Above all else, focus group discussions highlighted the complex interplay of diverse factors specific to each individual resident that health professionals needed to consider when making decisions about potential harm versus potential benefit for medications in LTC residents with advanced dementia. Rules-of-thumb and guidelines were seen as useful, especially for health professionals who did not deal with dementia and palliative care regularly.

“I love guidelines because when it’s off my scope it helps me to know what to do, and somebody else has already digested the complexities of the literature and given me a frame to work around. The heart failure guidelines specifically, I use them a lot, and certainly we contribute to those working at a high level in the heart failure area, but when I’m off my scope on something like dementia which you know many heart failure patients have, I just don’t have a really good knowledge. So for me, a guideline is gold.” (Nurse 3, lipid-lowering agents)

However, concerns were raised that they were often over-applied without due reference to individual resident variability. Participants stressed that proper understanding of each resident’s case required collaborative input from a range of professional and personal perspectives, including the person with dementia and their family.

“The guidance is important but it’s only one part of what should be a complex management approach involving other professionals” (Old age psychiatrist 1, AChEI)

“It should be a multidisciplinary approach including the resident and their family in the discussion. I think that happens most of the time but sometimes it doesn’t. Yes, we can have guidelines and algorithms and everything, but it needs to be individualised, looking at all of their medicines and all of their health conditions.” (Pharmacist 2, AChEI)

Themes from the focus groups could therefore be grouped within two broad categories as follows: i) Applying a person-centred approach to medication-related decision-making for LTC residents with advanced dementia, and ii) Decision-making as a dialectic process requiring multiple perspectives in which layers of clinical factors are considered, reflected upon as a team and integrated to reach a quality medication-related decision.

Applying a person-centred approach to medication-related decision-making for LTC residents with advanced dementia

Go slow in the face of unpredictability and unknown individual variability

The unpredictability of the dementia trajectory for each individual resident was seen to make medication related decisions difficult for clinicians in terms of a) establishing whether overall goals of care were palliative and b) appraising whether a medication would have a net benefit within the person's lifetime.

"It's completely unpredictable ... I mean I would be completely shocked if the patient survived another 12 months, but whether this person would die tomorrow, or whether they live for another 6 months, I can't tell." (GP 2, antibiotics)

A high prevalence of polypharmacy in LTC residents with advanced dementia added complexity to multi-morbidity to make it difficult to determine what was causing symptoms, especially in the context of cognitive impairment and limited functioning.

"He's on numerous medications...so it would be really hard to work out what was doing what." (Nurse 1, AChEI)

"You really have to use your skills to assess that this is not the usual resident we know, something is wrong, and then we have to do a proper head to toe check of the patient, and stop to find out what is going on." (Nurse 2, lipid-lowering agents)

Many participants highlighted the necessary need for caution and gaining all the appropriate resident information when changing medication, regardless of the medication type or decision as the repercussion for making the wrong decision was seen as potentially dangerous given the vulnerability associated with dementia and frailty. Possible repercussions described included drug interactions, kidney and liver damage, over-sedation and lethargy, increased falls risk, delirium, bradycardia, gastrointestinal effects and nausea.

"So it's really for me, stop and think before acting... I don't see much point in prescribing something for the sake of feeling like you've done something as a clinician. I think it's important to have the correct information." (Nurse 4, antibiotics)

Due to individual variability, it was difficult for clinicians to give a definitive answer as to when to change medications, especially deprescribing long-term treatments. Only when there was an obvious decline in function or cognition could medication-related decisions be easily made for a resident.

"If the person's functional ability is pretty impaired, then it's probably time to stop." (GP 3, AChEI)

A holistic approach is required

Regardless of the medication in question, the overarching consensus was that decisions about a specific medicine should never be made in isolation, but should also take into account all their other medications and a comprehensive range of clinical and personal considerations. Rather than focus on a single decision, clinicians saw medication management as a continuing process of regular review, monitoring and adjustment.

"Looking at his list of drugs, none of us would ever just look at donepezil in isolation." (Pharmacist 2, AChEI)

Weighing up the potential harms and benefits of starting, continuing or ceasing medications needed to take account of the context of each particular person and their individual goals.

"Benefits of continuing those medications have to really outweigh the side effects. How burdensome is it for the resident? If the benefits are much larger, at what stage do we stop it? (Nurse 2, lipid-lowering agents)

"Is there a patient sign or symptom to support either benefit, or harm from the drug, or lack of benefit." (Pharmacist 2, AChEI)

Clinicians emphasised the need for comprehensive assessment before making medication-related decisions. Considerations listed by participants that needed to be taken into account included the resident's history of adverse effects or drug interactions, whether some medications were potentially negating the effects of another, severity

of symptoms, swallowing capacity, illness trajectory, incontinence level, anticholinergic load, evidence of cardiovascular abnormalities, if the resident was completely bedbound or were newly admitted to the LTC facility.

“There is a couple of other medications with anticholinergic effects that he’s on which would be counteracting the donepezil anyway, so that’s another issue.” (GP3, AChEI)

“If it gets to that point where they can’t swallow anything, then obviously that’s a different conversation, because that means this patient is incapable of feeding themselves, and eating and drinking...I think, if it gets to that stage where they can’t even swallow the tablet, then I think it’s a different conversation.” (GP 2, antibiotics)

It was important to view the resident as a person with needs, and that other factors should be looked at, not just medication, in order to improve care and the person’s overall quality of life. Non-pharmacological approaches were considered a better approach in many instances to minimise adverse effects from medicines including massage and heat packs.

“The most likely and the most effective strategy you would have here would be non-pharmacological to be honest...that would be my first line of intervention rather than a pharmacological one in this situation.” (Old age psychiatrist 1, AChEI)

Try to clarify the purpose of each medication

Participants frequently focused on distilling the purpose of medications, though sometimes this was challenging. Those that controlled symptoms and maintained quality of life (e.g. analgesics) were likely to be continued, provided the benefits outweighed associated risk of adverse effects. Some medications (e.g. antibiotics) were more ambiguous with regard to purpose. Starting antibiotics was seen as only beneficial if it was being used to maintain quality of life and to treat symptom burden associated with infection rather than to sustain life.

“Certainly from a benefits perspective and quality of life, I think pain management is a critical aspect to consider...In terms of the risks, well that comes back to what we’ve talk about, being what dose we start with, with what route, how its monitored...pain management has got to be your first priority though.” (Pharmacist 1, opioids)

“An infection like this is often a pre-terminal event with someone with advanced dementia and the likely benefits of any treatment with antibiotics may just be prolonging her terminal stage.” (Palliative care physician 1, antibiotics)

Lipid-lowering agents were seen as clear candidates for deprescribing where this was seen as safe and no longer aligned with the resident’s therapeutic goals of care which may be focused on palliative principles for strictly comfort. While the prescribing of AChEI’s may also no longer align with the resident’s goals of care, participants reported clinical experience of seeing rapid decline in cognitive and functional status in residents when AChEIs were stopped, therefore ceasing was seen as needing to be approached with caution in LTC residents with advanced dementia.

“I think the difficulty if we start altering his medications is that we run the risk of pushing him into delirium. Certainly, I think there is evidence that shows that if you take people off anticholinesterase inhibitors they can acutely decline as well, so you’ve got to be really careful here.” (Old age psychiatrist 1, AChEI)

“I’ve seen people deteriorate rapidly...people do deteriorate very rapidly sometimes.” (GP 3, AChEI)

Decision-making is a dialectic process requiring multiple perspectives

Diverse professional perspectives may need negotiating

Decision-making in the focus groups proceeded via a dialectic process wherein participants with their different perspectives iteratively added layers of factors for consideration. Inter-professional collaboration was stressed as important to share both clinical experience/expertise and knowledge about the individual resident to reach the best decision. Medical practitioners and pharmacists often provided expertise on medicines while nurses from the LTCF contributed an understanding of the resident and his/her family.

“I just know that my knowledge about this medication is so limited that you would want someone...to come along and actually have an understanding of how this drug works, and why it’s given... you really want someone in your team like that to explain it.” (Nurse 1, lipid-lowering agents)

Pharmacists’ knowledge of pharmacology was seen as helpful to inform medication-related decisions, especially in a palliative care context where reducing medication load was a key priority.

“From clinical practice when I’ve had difficult situations with deprescribing, when patients have been on medications for long periods of time, I found working with a pharmacist extremely beneficial because often it’s beyond my expertise, then together we put together regimens to deprescribe successfully.” (Old age psychiatrist 1, AChEI)

There were very few points of contention during discussion between focus group participants. However, perspectives sometimes differed due to disciplinary or specialty scope of practice. For example, in relation to antibiotic use, the GP placed more emphasis than other participants on their relationship with the family as a consideration in deciding whether antibiotics should be administered.

Palliative care physician 1:

“Reflecting on my practice and comparing with your practice, it seems it’s so much the case that it’s default treatment...I guess as a palliative care physician I would like to offer a really strong alternative that not treating a patient like this with antibiotics is a very appropriate option. You know, it should be at least equal to the option of treatment. I guess it’s pushing against the tide a lot, but I think it’s a really important point to state for a patient like this.”

GP 2:

“I think the issue here though is it’s in the context of my practice...If the family wants it quite strongly, there is no way I am going to say ‘there is no way I can give it’ because it’s used enough and you know, it’s just not worth having that sort of conflict with the family I think because it [antibiotic] is unlikely to do a lot of harm.” (antibiotics)

Communication should be iterative to align medication decisions with the changing illness trajectory and goals of care

Ideal communication and collaboration was seen as iterative rather than one-off, given the likelihood that goals would change in light of disease progression and acute events. Participants saw medication decisions as likely to change over time. Much of the discussion revolved around the due process of decision-making, rather than the resulting decision.

“The concept of planning I think is key and that is the progressive series of conversations that happens from the beginning right through...and is readdressed each time there is a change.” (Nurse 4, antibiotics)

“What’s appropriate now, is not going to be appropriate down the track...” (Geriatrician 3, antibiotics)

View family and resident goals as focal

Focus group participants portrayed shared decision-making as a process that started and finished with resident/family goals. Emphasis was placed on establishing good communication between health professionals, family and (wherever possible) the person with dementia to better understand goals and preferences of care.

“The question is very much around the concept of goals of care, focus of care, expectations of care, having not seen evidence of a discussion around care planning for me that’s going to be the key in terms of moving forward with any decision making.” (Nurse 4, antibiotics)

Engaging with family members early on was seen as optimal to enable a gentler transition toward accepting their loved one’s prognosis.

“It becomes a conversation that’s had in a controlled and advanced way, rather than in a crisis and in the middle of the night... if we’ve done a good job they shouldn’t be surprised either. It’s kind of like they’re a bit prepared for this too.” (Palliative care physician 1, antibiotics)

Participants emphasised the need to inform families properly to enable them to participate in shared decision-making.

“Sometimes families can be quite directive about what should be given without the understanding of how things work...discussion needs to happen to clarify all the issues that could be going on in people’s minds.” (Nurse 1, opioids)

“I often find people don’t have a very clear understanding of medications that are going to make a difference today and tomorrow, or make me feel better in a few hours versus medications that make a big difference over 10 years.” (Geriatrician 1, lipid-lowering agents)

When families were resistant to a palliative approach, their perspective was carefully balanced against participants’ clinical judgement regarding the resident’s interests.

“If the family are adamant that one thing is the way forward, I try to work with it as long as there are no severe risks...I am guided a lot by what the family say...If something is plainly unsafe, having assessed capacity in the patient, I would go with what is safer. But generally, if there’s not a major safety issue, I’ll go with what the family say.” (Old age psychiatrist 1, AChEI)

“My sense is that if you know the aim of palliative care is to try and make sure that each day is a little bit better due to what you do. So if ceasing a medication causes harm to everybody around you from doing it, then it’s not a great palliative act to do that, so that would certainly influence my continuing it.” (Geriatrician 1, lipid-lowering agents)

As well as integral to high quality care, ensuring that decision-making shared with family and aligned with their goals was also seen as necessary to prevent litigation. There was concern that families might perceive even the most appropriate decisions as grounds for litigation if these did not accord with their understanding of what was best for the resident. As highlighted above, participants were also acutely aware of risks associated with starting or deprescribing medications and emphasised the need to communicate these to family members to ensure they accepted these within the context of likely benefits.

“You know the family’s view on this, getting that wrong and having the family or the patient in a different context feeling that the medications are not right for them is another harm, is another risk, and so it needs to be considered within getting this balance right for that person at that time.” (Geriatrician 1, opioids)

The contribution of research evidence

Participants regularly referenced research evidence in their discussions or else highlighted its scarcity. A lack of research evidence was especially highlighted regarding the safety of deprescribing in LTC residents with advanced dementia, with available evidence suggesting mixed results.

“In palliative care and in geriatrics I guess the question of when to deprescribe medications comes up a lot, and there’s relatively recent evidence to suggest that for people whose prognosis is quite poor who might be within the last 12 months of life, that if you stop the lipid-lowering agent that they’re on, even if they’re on it for initially very good reasons, there may actually be a quality of life benefit.” (Geriatrician 1, lipid-lowering agents)

Discussion

The current study is the first to explore case-based medication-related decision-making by multidisciplinary health professionals in relation to LTC residents with advanced dementia. The focus groups conducted in this study suggest that medication-related decision-making in this context, regardless of discipline, may share common features regardless of the medication in question or whether the decision concerns starting, continuing or deprescribing.

Findings from the focus groups are consistent with previous studies that found interdisciplinary decision-making improved care in the management of residents with medication problems and behavioural difficulties (pain- and dementia-related) in high level LTC facilities [20] and at end of life [21]. In the focus groups, health professionals worked together iteratively to reach the best approach to therapeutic management. Previous research has found

that 'collective intelligence' of more than one health professional working together outperforms a single health professional in diagnostic decision-making due to reduced human error (e.g. due to cognitive bias) and sharing of experience [22]. The current focus groups add that different perspectives based on scope of practice may diversify the range of factors under consideration and so contribute to a more holistic decision-making process. In particular, current findings echoed those previously in finding the scope of practice and expertise of community pharmacists to be appreciated in LTC [23].

In the current study, regardless of discipline, participants viewed clinical decision-making as a continuing process requiring regular monitoring and review, with due process in managing medications for people in their care just as important as the decision itself. There was an acceptance that any decision was tentative, pending review of the consequences, and that the balance between harm and benefit would alter over time in light of changes in clinical status and context. Previous work to develop a toolkit of heuristics to aid practitioners making end-of-life care decisions for people with dementia similarly encouraged an iterative process to medication management [24]. Similar to previous findings, participants also identified that the level of vulnerability and unpredictability in trajectory may be higher for those with advanced dementia [25], adding impetus for close monitoring.

A finding well documented in the literature, participants expressed the difficulty of broaching the subject of deprescribing with families as it confronted families with their loved one's deteriorating health [26]. However, a qualitative study found older adults and carers were open to the idea of medication deprescribing if they understood why this was being recommended [27]. Consistent with previous results [13, 12], maintaining a therapeutic relationship with the resident was of paramount importance. Participants in the current study reported that having an established trusting relationship with families provided a foundation for helping them to understand that deprescribing might be the best course of action for their loved one's wellbeing.

While participants acknowledged that there was widespread advocacy in relation to initiating and deprescribing certain medicines, they were surprisingly cautious in following this advice. Most participants agreed with recommendations stating appropriate antibiotic use is to improve symptoms associated with infection [1]; however, considerations relating to duty of care towards the family were sometimes considered to 'trump' recommendations where families could not be persuaded not to use antibiotics and these posed minimal risk of harm. Considerations of this kind might partly explain why, while many clinicians see antibiotics as futile treatment and unlikely to improve symptoms at later stages of dementia, results of a study found 40% of LTC residents with advanced dementia receiving them in the last two weeks of life [28].

Given promotion of the need to actively manage symptoms, particularly pain in people with advanced dementia in the literature [29], it was surprising how cautious participants were to commence opioids. Similarly, a previous study found GPs feeling uneasy about prescribing opioids, even when the indication was appropriate [13]. Whilst participants did indeed consider symptom management important, they equally stressed the importance of making careful selections regarding opioid type and dosage, and monitoring adverse effects.

Participants reported being conscious of a trend among some practitioners to deprescribe medications in LTC residents with a dementia diagnosis indiscriminately, without proper assessment. Recent guidelines and recommendations encourage the process of deprescribing long-term medicines in patients with limited life expectancy [30], but participants described the rapid functional/cognitive decline in their patients when AChEIs were stopped. Previous survey studies found physicians were less likely to recommend discontinuation of AChEIs if there was any indication they stabilised cognition, reduced challenging behaviours or maintained patient function [31, 6]. If discontinuation is attempted, clinicians need to taper the dose slowly, and monitor for signs of cognitive/functional decline. Similarly, many participants saw continuing medications in LTC residents with advanced dementia as a reasonable course of action, instead of running the risk of adverse withdrawal effects from deprescribing.

As in some previous research, participants in the current study were also hesitant to deprescribe medications in frail older populations due to limited evidence to support this practice [26]. They expressed concern on how to best approach this process, and uncertainty around its consequences i.e. medication withdrawal effects. However, participants seemed more confident in deprescribing lipid-lowering agents due to recent evidence supporting the safety and improvement in quality of life and cognition in older patients with limited life expectancy [32].

Quality evidence in the form of clinical trials to support deprescribing practices for people with advanced dementia, while growing is still limited [33]. Most studies looking to test the safety of deprescribing of medicines and the barriers and enablers of this process are focused on the broader context of older adults with normal life expectancy [34]. These results are not transferrable to LTC residents with advanced dementia who have a limited life expectancy and goals are focused on a palliative approach.

Consistent with earlier findings [35], participants in the current study saw single disease guidelines of limited usefulness for multi-morbid frail LTC residents with advanced dementia. Guidelines were seen as helpful when a particular drug or comorbidity fell outside of their usual scope of practice, but viewed as only one contribution towards a complex management approach involving other health professionals.

Participants in the current study empathised with less experienced health professionals who might be reluctant to leave themselves open to blame when negative consequences followed a decision to deprescribe. Consistent with past findings [36], participants acknowledged the risk of liability as a barrier to deprescribing. Participants emphasised the decision to continue a medication in a person with advanced dementia should be considered an active decision with the same responsibility inherent in deprescribing, given the increased risk of adverse drug reactions [8].

Limitations

Study findings are limited by the risk of bias due to group effects common to all focus groups, including the potential for participants perceived to be of greater authority to influence the responses of other participants (i.e. a 'halo' effect) [37]. Also, responses may have been constrained by continuing professional relationships with the facilitators. To reduce this risk, the facilitator began by stating that the purpose of the groups was to tease out equivocal considerations rather than reach consensus. Moreover, the CIT enabled probing about decision-making which would have made bland agreement difficult [17]. Though DD has a non-clinical background this offered the opportunity to minimise the risk of clinical biases during analyses. Results of the study may also be limited by focusing on only certain medication types, use of only one focus group for each, and consideration of only two vignettes on each occasion. While discussion on vignettes were discussed till exhaustion by participants, and resident parameters were altered to see if decision making would change, it is nonetheless noted that results will not be transferrable to disparate cases. Finally, the hypothetical nature of the vignettes meant that our method omitted contributions that would be forthcoming if participants were discussing residents who they had real-world knowledge of.

Conclusion

The current study highlights the need for a team approach to medication-related decision-making for LTC residents with advanced dementia, which should include the person with dementia where possible and their family, as well as health professionals from a range of disciplines. Consensus on the resident's goals of care should be viewed as the starting point for all decisions. Findings also suggest that decision-making should be viewed as carrying similar responsibility and requirements for justification and review regardless of whether initiating, continuing or deprescribing medications. Further evidence is needed to guide the safety of medication changes, especially deprescribing in palliative care residents nearing the end of life i.e. LTC residents with advanced dementia.

Acknowledgements Authors would like to thank all participants who participated in focus groups as part of this study.

Funding This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. DD was supported by a UTS Doctoral Scholarship.

Conflicts of interest None.

Authors' contributions DD contributed to the development of the research questions, conducted the search, analysed the articles, and drafted the manuscript. TL and MA contributed to the development of research questions, analysis of data, and helped to draft the manuscript. AB and PD contributed to analysis of data. All authors contributed to and approved the final manuscript.

References

1. Van Der Steen J, Radbruch L, Hertogh C, De Boer M, Hughes J, Larkin P et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014;28(3):197-209.
2. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future. 2016.
3. Birch D, Draper J. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing.* 2008;17(9):1144-63.
4. Parsons C, Hughes C, Passmore A, Lapane K. Withholding, discontinuing and withdrawing medications in dementia patients at the end of life: a neglected problem in the disadvantaged dying? *Drugs & Aging.* 2010;27(6):435-49. doi:http://dx.doi.org/10.2165/11536760-000000000-00000.
5. Parsons C, McCorry N, Murphy K, Byrne S, O'sullivan D, O'mahony D et al. Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life. *International Journal of Geriatric Psychiatry.* 2014;29(3):281-90.
6. Shega J, Ellner L, Lau D, Maxwell T. Cholinesterase inhibitor and N-methyl-D-aspartic acid receptor antagonist use in older adults with end-stage dementia: a survey of hospice medical directors. *Journal of Palliative Medicine.* 2009;12(9):779-83.
7. Holmes H. Rational prescribing for patients with a reduced life expectancy. *Clinical Pharmacology & Therapeutics.* 2009;85(1).
8. Ostini R, Hegney D, Jackson C, Tett S. Knowing how to stop: ceasing prescribing when the medicine is no longer required. *Journal of Managed Care Pharmacy.* 2012;18(1):68-72.
9. NHMRC Cognitive Decline Partnership Centre UoS, in collaboration with the Australian Deprescribing Network and NPS MedicineWise. Quality Use of Medicines to Optimise Ageing in Older Australians: Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy Sydney, NSW, Australia 2018.
10. Paque K, Vander Stichele R, Elseviers M, Pardon K, Dilles T, Deliens L et al. Barriers and enablers to deprescribing in people with a life-limiting disease: A systematic review. *Palliat Med.* 2018;33(1):37-48.
11. Flanagan J. The critical incident technique. *Psychological Bulletin.* 1954;51(4):327.
12. Bendtsen P, Hensing G, McKenzie L, Stridsman A-K. Prescribing benzodiazepines—a critical incident study of a physician dilemma. *Social Science & Medicine.* 1999;49(4):459-67.
13. Bendtsen P, Hensing G, Ebeling C, Schedin A. What are the qualities of dilemmas experienced when prescribing opioids in general practice? *Pain.* 1999;82(1):89-96.
14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care.* 2007;19(6):349-57.
15. Westbury J, Gee P, Ling T, Brown D, Franks K, Bindoff I et al. RedUSE: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities. *Medical Journal of Australia.* 2018;208(9):398-403.
16. Brodaty H, Aerts L, Harrison F, Jessop T, Cations M, Chenoweth L et al. Antipsychotic deprescription for older adults in long-term care: The HALT study. *J Am Med Dir Assoc.* 2018;19(7):592-600.
17. Kempainen J. The critical incident technique and nursing care quality research. *Journal of Advanced Nursing.* 2000;32(5):1264-71.
18. Nielsen J, Clemmensen T, Yssing C, editors. Getting access to what goes on in people's heads?: reflections on the think-aloud technique. *Proceedings of the second Nordic conference on Human-computer interaction; 2002: ACM.*
19. Eklund JH, Holmström I, Kumlin T, Kaminsky E, Skoglund K, Högländer J et al. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling.* 2018.
20. Crotty M, Halbert J, Rowett D, Giles L, Birks R, Williams H et al. An outreach geriatric medication advisory service in residential aged care: a randomised controlled trial of case conferencing. *Age and Ageing.* 2004;33(6):612-7.
21. Connor S, Egan K, Kwilosz D, Larson D, Reese D. Interdisciplinary approaches to assisting with end-of-life care and decision making. *American Behavioral Scientist.* 2002;46(3):340-56.
22. Kurvers R, Wolf M, Naguib M, Krause J. Self-organized flexible leadership promotes collective intelligence in human groups. *Royal Society Open Science.* 2015;2(12):150222.
23. Gheewala P, Peterson G, Curtain C, Nishtala P, Hannan P, Castelino R. Impact of the pharmacist medication review services on drug-related problems and potentially inappropriate prescribing of renally cleared medications in residents of aged care facilities. *Drugs & Aging.* 2014;31(11):825-35.
24. Davies N, Mathew R, Wilcock J, Manthorpe J, Sampson E, Lamahewa K et al. A co-design process developing heuristics for practitioners providing end of life care for people with dementia. *BMC palliative care.* 2016;15(1):68.

25. Reeve E, Bell S, Hilmer S. Barriers to optimising prescribing and deprescribing in older adults with dementia: a narrative review. *Current Clinical Pharmacology*. 2015;10(3):168-77.
26. Turner J, Edwards S, Stanners M, Shakib S, Bell S. What factors are important for deprescribing in Australian long-term care facilities? Perspectives of residents and health professionals. *BMJ Open*. 2016;6(3):e009781.
27. Reeve E, Low L-F, Hilmer S. Beliefs and attitudes of older adults and carers about deprescribing of medications: a qualitative focus group study. *Br J Gen Pract*. 2016;66(649):e552-e60.
28. D'Agata E, Mitchell S. Patterns of antimicrobial use among nursing home residents with advanced dementia. *Archives of Internal Medicine*. 2008;168(4):357-62.
29. McLachlan A, Bath S, Naganathan V, Hilmer S, Le Couteur D, Gibson S et al. Clinical pharmacology of analgesic medicines in older people: impact of frailty and cognitive impairment. *Br J Clin Pharmacol*. 2011;71(3):351-64. doi:<http://dx.doi.org/10.1111/j.1365-2125.2010.03847.x>.
30. Reeve E, Farrell B, Thompson W, Herrmann N, Sketris I, Magin P et al. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine in People with Dementia. Recommendations, The University of Sydney, Sydney, Australia. 2018.
31. Parsons C. Withdrawal of antidementia drugs in older people: who, when and how? *Drugs & Aging*. 2016;33(8):545-56.
32. Narayan S, Nishtala P. Population-based study examining the utilization of preventive medicines by older people in the last year of life. *Geriatrics & Gerontology International*. 2018;18(6):892-8.
33. Van Der Cammen T, Rajkumar C, Onder G, Sterke C, Petrovic M. Drug cessation in complex older adults: time for action. *Age and Ageing*. 2014;43(1):20-5.
34. Page A, Clifford R, Potter K, Schwartz D, Etherton-Beer C. The feasibility and effect of deprescribing in older adults on mortality and health: a systematic review and meta-analysis. *Br J Clin Pharmacol*. 2016;82(3):583-623.
35. Ailabouni N, Nishtala P, Mangin D, Tordoff J. Challenges and enablers of deprescribing: A general practitioner perspective. *PloS one*. 2016;11(4):e0151066.
36. Anderson K, Stowasser D, Freeman C, Scott I. Prescriber barriers and enablers to minimising potentially inappropriate medications in adults: a systematic review and thematic synthesis. *BMJ Open*. 2014;4(12):e006544.
37. Nisbett R, Wilson T. The halo effect: evidence for unconscious alteration of judgments. *Journal of Personality Social Psychology*. 1977;35(4):250.