Beliefs and attitudes of older adults and carers about deprescribing of medications: a qualitative focus group study

INTRODUCTION
Polypharmacy and inappropriate medication use (use of harmful or unnecessary medications) is common in older adults. Approximately one-third of older adults take five or more regular medications, and one in five medications taken by older adults in primary care is inappropriate. This can have negative clinical and financial consequences. Regular review of medications, with deprescribing (supervised withdrawal) of inappropriate medications, is part of the optimal health care of older adults and may lead to benefits including preventing adverse drug reactions, improved adherence, and reduced costs. There are, however, many barriers to deprescribing in practice. Patient resistance or refusal (or resistance from family members or carers) is often cited by prescribers as a barrier to medication cessation.

Understanding the patient’s experience is a principle of medication optimisation and shared decision making. Shared decision making is advocated not only because it is ethically appropriate and considered a right, but also because it can prevent wastage of time, resources, and medications, and may improve adherence and health outcomes. In two separate studies in Australia (one in an outpatient clinic and one in inpatients) almost 90% of older adults reported being willing to have one or more of their medications ceased. This is in contrast to the aforementioned prescriber perceptions of patient resistance, as well as findings of several interventional deprescribing studies which suggest that patient willingness to have a medication ceased may not be this high.

A recent systematic review identified five main consumer-reported barriers and/or enablers to deprescribing: perceived appropriateness of withdrawal, process of deprescribing, influences on the consumers’ decision to cease a medication, general dislike of medications, and fear associated with medication withdrawal. It is notable that, of the 21 studies identified, all but one focused on a single medication class or therapeutic group and only three focused on older adults. Therefore, it is unknown whether these results are generalisable to older adults’ attitudes towards medications. Additionally, only a single study identified in this review included carers’ or family members’ attitudes and beliefs; this was specific to a single medication (donepezil). Carers are a crucial component of pharmaceutical care in older people, particularly those caring for patients with dementia. Carer agreement with treatment recommendations is pivotal to adhering to recommendations and attainment of goals. As such, carers should be involved in making decisions related to starting, continuing, and stopping medications.

This study aimed to explore the views, beliefs, and attitudes of older adults and carers towards deprescribing with the...
How this fits in

Inappropriate medication use (use of medications where the risks outweigh the benefits for the individual) is common in older adults. GPs report that patient and/or carer resistance is a barrier to deprescribing inappropriate medications. This study confirms that older adults and carers are open to the idea of medication withdrawal if they understand why this is being recommended. In primary care, discussing the reasons for medication withdrawal and addressing any concerns with the patient and/or carer may facilitate deprescribing.

METHOD

Four focus groups were held (purposive sampling) with a total of 28 participants (Table 1) comprising:

- older adults living in the community;
- older adults in a retirement village;
- carers of older adults living in the community; and
- carers of older adults living in a residential aged care facility.

Full methods of focus group conduction and analysis are available from authors on request and are reported according to the COREQ criteria.

Study conduction

All four focus groups were conducted in metropolitan New South Wales, Australia, and were facilitated by the same author, with a second researcher present who took notes. The focus groups lasted approximately 1 hour and all sessions were audiotaped, transcribed verbatim (by a third person), and reviewed for accuracy (by the same author who facilitated the groups).

An interview guide consisting of open-ended questions was used to guide the focus group discussion. Questions centred on how participants felt about their medications in general, medication cessation (in themselves or their care recipient), and what would make them more or less likely to consider cessation or be willing to cease based on a recommendation. Interpretation of the emergent themes was provided informally throughout the focus groups to gain participant checking to improve the validity of the results.

Participant recruitment

Purposive sampling was conducted to reflect the diversity of older adults and carers in different settings (Table 1). The carers and older adult focus groups were not paired.

Analysis

The software program QSR NVivo (version 10) was used to assist with data analysis. Both a directed content analysis (DCA, deductive analysis) and conventional content analysis (CCA, inductive analysis) were conducted in accordance with the methods of Hsieh and Shannon to identify barriers to and enablers of deprescribing. The previously developed thematic framework of consumer barriers to and enablers of deprescribing was used for DCA. Pieces of text were allocated to one, or more, of the five main themes: appropriateness, process, influences, dislike, and fear. Where text was determined to represent a theme that was not previously determined a new theme was created. Once all the four transcripts had been reviewed, the text in each main theme was allocated to subthemes. As each piece of text was placed into a theme or subtheme it was compared and contrasted with the previously existing text in that theme. This process was conducted by one author, with discussion with a second author. Additionally, after completion of coding and theme generation, the second author reviewed all the themes and subthemes, and all the text used to create them.

RESULTS

Directed content analysis

The themes and subthemes of DCA were identified as enablers or barriers to deprescribing, or in some cases as both (it was an enabler if the condition was met, and it was a barrier if it was not).

Appropriateness of deprescribing

Why. There was a strong emergence of the subtheme of ‘why’. Why should the medication be stopped? What will be the benefit of stopping? This subtheme reflects a need to understand the reason for withdrawing the medicine:

’Why … what’s the benefit going to be if we’ve got to stop this?’ [FG3, older adults]

Quality of life was mentioned specifically as the main factor of concern. It was described by some participants as the...
ability to function independently and take part in activities that are important to the individual:

'A person’s quality of life. The older they get whether the withdrawal of that medication means that they have a better quality of life.' [FG1, carers]

The remaining subthemes illustrate older adult and carer understanding of why a medication should or should not be stopped.

**Benefit of medication use (barrier).** Those participants who believed that medication was still necessary or needed, that there was an ongoing benefit to taking it, and who had a memory of benefit or effectiveness when the medication was first started, were less likely to support medication withdrawal:

'Even though I take the anticholesterol pill my cholesterol is still not really that low so I hate to think what it might be without a helping hand.' [FG2, older adults]

'I would have thought that if you have been put on something that was successful it would be a good idea to just continue on with it ...' [FG2, older adults]

**Acceptance of medical condition (barrier).** Medication can be seen as a necessity due to having a medical condition:

'In my case my mother is only on her blood pressure [tablet] ... and her Oroxine [thyroid medication] so she is good to be taking that until the day she goes.' [FG1, carers]

**Long-term use (barrier).** The belief that, because participants had been taking the medication for a long time, it remained appropriate:

'Why was it OK then but, and now it’s not?' [FG1, carers]

'Well the first question would be why is it that I’m going to stop this when I’ve been on it for so long?' [FG3, older adults]

**Lack of current harm (barrier).** Participants are happy to continue taking medication because of a lack of side effects (particularly in the context of long-term use), little concern for future harm (also in the context of limited life expectancy), and express a lack of concern through terms such as ‘only a few tablets’:

'I think they don’t appear to be doing me any harm so I am keeping on with them.' [FG2, older adults]

'If you’ve been on it for 10 years any side effects probably should have shown up by then anyway.' [FG3, older adults]

[Facilitator asks about concerns of future side effects.] 'What future, tell me that.' [FG4, carers]

**Lack of benefit or necessity (enabler).** This incorporates views regarding lack of effectiveness of medication, medication no

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<th>Table 1. Eligibility criteria and participant characteristics</th>
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<td><strong>Carers (focus group 1), n = 8</strong></td>
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<td>Residence (of participant or participant’s care recipient)</td>
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<td>Eligibility criteria</td>
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<td>- currently a non-paid carer for an older adult aged &gt;65 years with ≥1 chronic medical conditions</td>
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<td>- care recipient must be taking ≥1 regular prescription medications</td>
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<td>- conversationally proficient in English</td>
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<td>Age, years (mean ± SD)</td>
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<td>Age of care recipient, years (mean ± SD)</td>
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<td>Number of medications of self or care recipient, (mean ± SD)</td>
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<td>Sex, [n female/n male]</td>
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<td>Comorbidities, % [n] of self or care recipient</td>
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<td>Gastrointestinal disease</td>
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<td>Relationship of carer to care recipient, % [n]</td>
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<td>Son/daughter</td>
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<td>Other non-relative</td>
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<td>Local Health District Index of Relative Socioeconomic Disadvantagea (area where focus group was held)b</td>
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*aAustralian scores are the reference point and are set to 1000 for each index (standard deviation of 100). Scores for local government areas are population-weighted means of the scores of their constituent census collector districts. Centre for Epidemiology and Evidence.*

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longer being needed (condition resolved), and lack of benefit or necessity relevant to end-of-life care (change in treatment goals).

‘I understood that the Alzheimer’s medication was only effective perhaps in the very early stages of dementia.’ [FG4, carers]

‘... but the pain has diminished dramatically now and I have dropped off that pain killer.’ [FG2, older adults]

‘Maybe there’s a point of saying well, stop the medication. What is it going to achieve? Prolonging death, that’s all it’s going to do.’ [FG4, carers]

Alternative available [enabler]. Participants may believe that a better medication or lifestyle is available; however, it was reported that alternatives were not always possible:

‘... medical technology is changing over time, so perhaps over a period of time something else can be taken to replace that one.’ [FG1, carers]

‘There is the other consideration, whether it can be controlled by diet.’ [FG3, older adults]

Drug interactions [enabler]. Concern regarding potential drug interactions may cause participants to favour medication withdrawal:

‘Unless of course you are prescribed new medications and they interact.’ [FG3, older adults]

Side effects [enabler]. Side effects were often the first thing mentioned that could trigger medication withdrawal. Many participants recalled times in the past when they had experienced a side effect (usually soon after the medication was started) and therefore stopped the medication:

‘I took it and had severe side effects, mainly dizzy, it was clearly not suitable for me and it was immediately apparent and I stopped taking it.’ [FG2, older adults]

Process
Discussion. Participants identified that a discussion is required for them to make the decision about withdrawal. Time and support are required and the discussion should involve an explanation of why and what to expect:

‘It would be good [stopping a medication] but you would have to have a discussion about it.’ [FG2, older adults]

‘I think that’s the key thing, communicating to understand why something is going to be stopped, the reason for it and the effect it might have.’ [FG4, carers]

Monitoring and follow-up. Participants expected the GP to inform them what monitoring and follow-up were required (whether it be self-monitoring or returning to the GP). Carers specifically reported that they are the ones who spend the most time with the patient and therefore are in a good position to be involved in monitoring:

‘That’s something your GP should be able to tell you. In 2 weeks if you notice a change, come back. Or he should say I want to see you again in a certain time.’ [FG3, older adults]

Trial. Knowing that withdrawal is on a trial-only basis appeared to increase willingness to have a medication deprescribed:

‘You want it [medication withdrawal] on a trial basis.’ [FG3, older adults]

Additional process considerations. Additional comments were made by participants relating to the process of withdrawal. These included that medications may need to be weaned before cessation, medications should be withdrawn one at a time, and there may be reversal of drug interactions. A lack of liaison between healthcare professionals was also reported as an issue that may influence deprescribing:

‘There is no one person who oversees the whole, they don’t liaise to see the whole picture.’ [FG4, carers]

Influences on willingness to have medications deprescribed
Several person and non-person influences were discussed in relation to deciding to stop or continue a medication. The patient’s regular GP was by far mentioned most often.

Healthcare professionals. The GP can be an influence towards continuation although it is the patient themselves who wishes to stop a medication; participants reported that their GP had used evidence or a ‘warning case’ to convince them to continue:

‘He was sick of taking all this medication ... the doctor said to him, “Don’t do that, you’ll end up like my father who’s gone had
a stroke and he’s just now like a vegetable,” so he kept on taking the medicine.” [FG1, carers]

There was also an assumption reported that, if their GP kept providing repeats, then the medication was still appropriate:

‘Every time I ask for a script for the things that I need ... he [GP] must in his own mind review the need for them and not that we discuss that but I imagine that ... he would be thinking yes will I or won’t I, and then he decides to write the script and that sort of review is good enough for me and I will happily continue to take the two that I need.’ [FG2, older adults]

Overwhelmingly, participants reported that if their GP recommended discontinuation then they would go along with it because of trust and the GP’s medical knowledge. In contrast to this, one carer reported that they thought the GP was unlikely to be the one recommending stopping a medication as they spent very little time with the care recipient in a residential aged care facility.

When asked about medications initiated by a specialist, the participants expected that their GP would check with the specialist or they would be referred back to the specialist to review it. Residential aged care facility nurses and pharmacists were mentioned briefly, although discussion of their role in deprescribing was limited to making recommendations to the GP. Geriatricians and other specialists were also mentioned.

Family and friends. There were mixed opinions on whether or not family and friends were (or should) be an influence or not. It was mentioned by a carer participant that it was important to ensure that all family members were in agreement with withdrawal of medications at end of life:

“You naturally talk to people, to your friends and acquaintances, and I think at our ages particularly, health is often discussed.” [FG2, older adults]

“I know some people do take on board what their friends have to say and what experiences they’ve had with a particular medication.” [FG3, older adults]

Previous bad experiences with stopping. Participants with previous negative experiences of medication withdrawal reported that they would be unwilling to have this medication stopped again:

‘I take Feldene® and I’ve been taking it for years and I went off it once and I was in such pain I had to go back on it again.’ [FG2, older adults]

Other [non-person] influences. These included chronological age, number or complexity of medications, media, family history, regulatory influences, and patient expectation of a prescription when they visit a doctor:

‘Well if she walks on and falls over, she is going to break a bone at 97 and all the tablets in the world aren’t going to do anything for a bone at 97 years old.’ [FG1, carers]

‘A whole lot of people take so many different tablets they wouldn’t know Arthur from Martha ... so sometimes it’s better to say, “Oh damn, I’ll take the lot.”’ [FG2, older adults]

‘From time to time you hear or read adverse comments in press about certain medication, might cause you to want to give it up if possible.’ [FG2, older adults]

‘My mother died of heart attack ... so I hate to think what it might be without a helping hand [taking cholesterol-lowering medication].’ [FG2, older adults]

‘I think people get into a habit of expecting medication ... and the doctors quite often, unfortunately, give it to them.’ [FG2, older adults]

Fear as a barrier to having their medications deprescribed

The subthemes were general or non-specific fear, fear of return of condition (including concern about return of symptoms and missing out on future benefits), and fear of adverse drug withdrawal reactions:

‘I have a concern that what would happen if I stopped this medication?’ [FG3, older adults]

‘[I] stay on it even though it [cholesterol] has settled down to a good level now, but I suppose it could fly up again’ [FG2, older adults]

‘... what are the consequences and the rebound, will this affect something else in that person?’ [FG1, carers]

Return of condition was generally characterised by discussion of biomarkers,
for example, ‘blood levels’ or ‘stability’, although symptoms were also mentioned (for example, pain). These fears, however, are likely to be allayed if the recommendation comes from their GP:

**Facilitator:** ‘Are there any fears that you have about stopping medicine?’

**Participant:** ‘Not if I’m told to do so by someone [the GP] who knows better than me.’ (FG2, older adults)

**Dislike of medications as an enabler to having their medications deprescribed**

**Dislike.** Dislike of medications was reported as a general desire to minimise medication use and there were positive responses to the prospect of stopping a medication:

‘I’d be very grateful to be off it, quite frankly.’ (FG2, older adults)

‘Well that would be good news [if their GP told them they could stop one of their medications].’ (FG2, older adults)

It was generally accepted by both older adult participants and carers that medications were required. However, there were conflicting views on this with some participants believing that most conditions could be managed with lifestyle changes.

**Cost.** The cost of multiple medications was reported as a concern by participants:

‘One month they [a friend] spend $300 on medication … and I said what are you taking, and so she showed me some, and I said reduce it, go to your doctor ask to be reduced.’ (FG1, carers)

‘And I’m OK with that [stopping a medicine] and it is cheaper at the pharmacy.’ (FG1, carers)

It was discussed that reduced cost would be a benefit to stopping a medication but not necessarily the sole motivator for wanting to stop.

**Inconvenience.** The inconvenience to self and care recipient was reported. For care recipients, this was mentioned in the context of their overall condition and goals of care:

‘I see no point in treating [my husband’s] diabetes, because of the difficulty in taking the medication’ (care recipient previously discussed as being combative to medication taking) (FG4, carers)

**Conventional content analysis**

An additional carers-only theme emerged that is relevant to deprescribing (although it was not interpreted as a barrier or enabler): making decisions for others. It included the subthemes of the dynamics of making decisions as a carer (in particular where the care recipient has some level of cognitive function remaining), their level of involvement in making decisions with the doctors (with some carers very involved but others reporting little or no involvement), and the difficulty in making decisions for others. Carers reported taking into account physical and mental factors when making treatment decisions, but that it was often very difficult to do this. One participant acknowledged that their choices for treatment of their care recipient impacted on them:

‘But it’s a real question isn’t it, as the dementia progresses, quality of life for both the person who has the dementia, and the carer; it’s a big issue. They live in a world of their own, it doesn’t worry them, it worries us.’ (FG4, carers)

**DISCUSSION**

**Summary**

The findings of the DCA support the five main barriers and enablers developed after the previous systematic review: appropriateness; process; influences; fear; and dislike. Overall, the beliefs and attitudes regarding deprescribing were similar among older adults and carers. Compared with the older adults’ groups, in the carers’ groups, a discussion of quality of life and recognition of changed care goals at the end of life were more prominent and the theme of ‘making decisions for others’ was unique to this group.

Views about the main themes, appropriateness, process, and fear, were generally agreed by members of the groups. There was some disconcordance between participants in relation to the dislike and influences themes. Disagreements occurred around whether medications were a necessary part of ageing or could be avoided with lifestyle changes. Additionally, there was no agreement on whether certain influences were present or not, in particular cost, whether family members or friends were an influence or not, and the influence that age played on the effectiveness of medications.

**Strengths and limitations**

The present analysis was based on a previous framework developed from the results of 21 original studies, and consistency was
observed in the main themes. The internal validity of this study is strengthened by having the same facilitator conduct all of the focus groups.

The subthemes of the previous framework were not all present in this study and new subthemes were created (information available from authors on request). In many cases, quotes did not directly identify a barrier or enabler, but rather a factor (for example, a discussion) that was required for them to agree to have a medication deprescribed. Some subthemes of the previous framework may not have been identified in this study because of differences between populations and differences in study focus. In this study, the focus groups were in an older population (or carers of older adults) and medications were discussed in general (that is, not medication specific unlike many of the original articles in the systematic review). For example, the subtheme of psychological benefits of withdrawal, which arose from studies looking at neurological medications, was not mentioned in any of the focus groups and neither was the subtheme of stigma associated with medication taking, perhaps because older adults consider medication use to be ‘normal’.

There are several important limitations of this study and the results must be viewed in the context in which the data were collected. First, both of the older adult groups were relatively healthy and high functioning; different views may be held by those with poorer health or those requiring permanent high-level care. One of the present focus groups had only three participants (because one was ineligible and another did not provide consent (information available from authors on request), although interactivity was still observed between participants in the group.

The second group of limitations relate to the methods employed. The benefit of conducting focus groups is that participants can discuss issues among themselves, creating rich data and highlighting conflicts. This can also lead, however, to participants reporting favourable results because of the presence of peers and/or the researcher.

Although it is a strength that a previously developed framework (informed by the literature) was used, knowledge of this before conducting the focus groups can bias the results. The lead investigator was also the primary author on the systematic review in which the framework was developed. No formal attempts were made to achieve data saturation of the subthemes, and analysis occurred only after completion of all four focus groups. This is a limitation of the results that may have biased the results towards agreement with the previously described framework.

Lastly, no attempt was made to determine whether participants (or their care recipients) were taking a medication that could be deprescribed. As such the discussion was based on hypothetical situations. There is no reason to believe that different barriers or enablers would be present in practice, although there may be variation depending on the medication at hand. No attempts were made to ascribe quotes to particular participants nor relate this to the characteristics of the participants. Participants aged ≥65 years were recruited taking at least one long-term medication; however, information was not collected on the types of medications taken by participants (only the number). Further research is required to determine how beliefs and willingness to have a medication deprescribed vary depending on type of medication (for example, symptomatic versus preventive medications).

Comparison with existing literature

The results of this study are consistent with similar previous studies in older adults conducted in different countries with different health systems (not included in, or published after, the original systematic review). Moen et al conducted a focus group study with older adults in Sweden to assess their attitudes towards taking multiple medications and Linsky et al conducted a qualitative study of US veterans in relation to their perception of proactive medication cessation. Both of these studies found that the relationship with their doctor had an influence on their attitudes to medications and willingness to withdraw one or more of them. They also reported the conflicting views on the benefits and/or necessity of medications while wishing to minimise medication use.

Socioeconomic status can affect adherence to medications and therefore may influence beliefs about medication. There was mention of cost as an influence towards deprescribing, although this was generally mentioned as a positive outcome of deprescribing rather than as a motivator for it. This may be because of the population in the present study; three of the four focus groups were conducted in areas of higher than average socioeconomic status in Australia. It should be noted that the cost of medications are subsidised in Australia and the cost spent by the patient on medications in a calendar year is capped to a certain
amount to reduce the burden of medication costs to individuals. Therefore, these results may be vastly different in other countries with different healthcare systems. Possession of a medication discount card (marker of lower socioeconomic status) was found to be associated with reduced willingness to have a medication deprescribed in a single study, also conducted in Australia. However, as this card also enables patients to obtain medications at a lower price this confuses these results. In this same study, private health insurance (a marker of high socioeconomic status) was not associated with willingness to have a medication deprescribed. Further research is required to determine if socioeconomic status affects beliefs about deprescribing and whether the barriers or enablers are different in varying socioeconomic groups.

Implications for research and practice
Box 1 summarises how the results of this study may be applied by healthcare professionals in their practice to enhance deprescribing. There was a variable degree of involvement of older adults and carers in decision making from those who simply did as instructed by their GP without question, to those who actively sought information and voiced their preferences. The expressed need for a discussion may reflect a desire to be respected (integral to the doctor–patient relationship). Previous studies have established that most older adults want to be involved in decision making; however, involvement may be perceived as just being informed of medication changes. Participants in the present study acknowledged that the doctors held the knowledge and expected them to be able to convey information to them in a way that they could understand. Regardless of the patient’s desired level of involvement, patient-centred care can still occur through respect for the patient, making recommendations based on their needs, open communication, and development of a genuine doctor–patient relationship.

The results of this study also highlight the understanding of older adults and carers about medications and how they express the benefits and risks [see theme of ‘appropriateness’]. This language may be used in consultations. This and previous studies have shown that consumers understand competing interests with treatment and that medication use needs to be individualised. Older people may assume effectiveness and indication because the medication is prescribed, as reflected by the subtheme of ‘long-term use’. A formal medication review does not always, however, accompany the provision of repeats in general practice.

There was some mention in the carer focus groups of medication discontinuation in end-of-life care. This is likely to bring unique issues and requires further investigation. Also, the preferences of those with mild dementia (who have been shown to be able to express preferences for treatment) need to be studied.

Future research should focus on the development of a guide to assist GPs in discussing medication discontinuation with older adults and their carers as well as continued efforts towards education and patient-directed deprescribing interventions (which have shown some effectiveness) need to be studied.

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REFERENCES


