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BMJ Open  

Shared decision-making about cardiovascular disease medication in older people: a qualitative study of patient experiences in general practice

Jesse Jansen,1,2 Shannon McKinn,1 Carissa Bonner,1,2 Danielle Marie Muscat,1 Jenny Doust,3 Kirsten McCaffery1,2


ABSTRACT

Objectives To explore older people’s perspectives and experiences with shared decision-making (SDM) about medication for cardiovascular disease (CVD) prevention.

Design, setting and participants Semi-structured interviews with 30 general practice patients aged 75 years and older in New South Wales, Australia, who had elevated CVD risk factors (blood pressure, cholesterol) or had received CVD-related lifestyle advice. Data were analysed by multiple researchers using Framework analysis.

Results Twenty-eight participants out of 30 were on CVD prevention medication, half with established CVD. We outlined patient experiences using the four steps of the SDM process, identifying key barriers and challenges: Step 1. Choice awareness: taking medication for CVD prevention was generally not recognised as a decision requiring patient input; Step 2. Discuss benefits/harms options: CVD prevention poorly understood with emphasis on benefits; Step 3. Explore preferences: goals, values and preferences (eg, length of life vs quality of life, reducing disease burden vs risk reduction) varied widely but generally not discussed with the general practitioner; Step 4. Making the decision: overall preference for directive approach, but some patients wanted more active involvement. Themes were similar across primary and secondary CVD prevention, different levels of self-reported health and people on and off medication.

Conclusions Results demonstrate how older participants vary widely in their health goals and preferences for treatment outcomes, suggesting that CVD prevention decisions are preference sensitive. Combined with the fact that the vast majority of participants were taking medications, and few understood the aims and potential benefits and harms of CVD prevention, it seems that older patients are not always making an informed decision. Our findings highlight potentially modifiable barriers to greater participation of older people in SDM about CVD prevention medication and prevention in general.

INTRODUCTION

One of the biggest challenges of our time is optimising health and quality of life for our rapidly growing ageing population. Up to 70% of older people have two or more chronic conditions which complicates decision-making.1 2 Treatments that improve one condition might make another worse, may have long-term benefits but short-term harms, and multiple medications (and their interactions) must be balanced.3 In addition, taking multiple medicines, frequent healthcare visits, refilling prescriptions, making lifestyle changes and self-managing care can be a significant burden on patients and their family/carers.4 A patient-centred approach to healthcare decision-making can help to ensure that the benefits outweigh the harms, they serve the larger aims of the older person’s life and impose the smallest possible burden. Shared decision-making (SDM) can help achieve this.

SDM aims for clinicians and patients to collaboratively make a health decision after discussing the options and benefits and harms, and considering the patient’s values, goals, preferences and circumstances.3-7 The case for SDM among older adults, especially those with multimorbidity, is particularly strong6; decisions in this context can be considered highly preference sensitive, evidence around potential benefits and harms of treatments for older people is often limited, and involves the weighing of many factors (eg, patient capacity, social support, carers, burden of treatment). The best option therefore strongly depends on which...
outcomes matter the most to the individual older patient and what option best suits their circumstances. Further, older people’s preferences will vary widely depending on factors such as their frailty, level of education, cognitive and health status and tolerance of side effects, providing another argument for a tailored and shared approach to decisions. However, the same factors that increase the importance of SDM in older people also make it more complicated, not to mention the additional challenges of age-related cognitive changes and communication barriers such as hearing loss.

Medication for the primary and secondary prevention of cardiovascular disease (CVD), including statins and antihypertensives, are among the most commonly prescribed medications in people aged 75 years and older. At the same time, the evidence around potential benefits and harms of these medication for older people is limited because they are poorly represented in clinical trials and most CVD guidelines are based on cohorts with an age cut-off. For example, many CVD risk prediction models are not well validated in older people. The widely used Framingham risk equation that is used in the Australian primary CVD prevention guidelines, for instance, is based on a patient cohort with an upper age of 74. For a large proportion of older people, the decision to start CVD medication was made at a younger age and could therefore be informed by evidence-based guidelines, however once people reach the age cut-off for trials, they enter the ‘non-evidence-based zone’. Even where evidence suggests benefits of preventive medication for older people, as is the case for secondary prevention, the evidence becomes uncertain in the context of complex interactions between multiple conditions and medications, the generally higher risk of side effects, declining health and limited life expectancy as trial data is not available for these groups. It is therefore not a surprise that general practitioners (GPs) are uncertain about CVD prevention in older age, and there is evidence of overtreatment and undertreatment of CVD risk in this group. This is why an SDM approach to CVD management has now been universally advocated, in particular for those who are older, frail or have comorbidities.

The literature has started to address some of these challenges, and changes have been proposed to adapt existing SDM models for older patients. However, studies describing the experience of older patients with health decisions are still scarce. In this paper, we explore older people’s perspectives and experiences with decisions about medication for CVD prevention and describe the implications of our findings for SDM in the context of preventive medicine in older people.

METHODS

Design
A qualitative study using semi-structured interviews with 30 general practice patients aged 75 years and above in New South Wales, Australia in 2012.

Recruitment and participants
Patients were recruited through their GPs from multiple clinics throughout Sydney and regional New South Wales; the GPs participated in a separate interview study. Participating GPs (n=16) invited up to four patients aged 75 years and above who had elevated CVD risk factors at the time of recruitment (eg, blood pressure, cholesterol) or had recently received CVD-related lifestyle advice; the latter criterion was aimed at targeting lower risk patients. The age cut-off was determined based on the evidence gap for this group in the Australian CVD guidelines. In line with the qualitative approach, we aimed to recruit a diverse, purposive sample rather than a representative sample by selecting patients with varying CVD risk factors (eg, gender, blood pressure), CVD history, medication use and experience of CVD events. Thirty eight patients returned expression of interest forms, and 30 participated in the interviews. Recruitment was stopped when initial data analysis indicated that meaning saturation had been reached (ie, no new concepts were being identified in the data).

Patient and public involvement
Patients were not involved in the development of research questions, the design, the recruitment to or the conduct of this study.

Data collection
Semi-structured interview schedules were developed by the research team, piloted with a convenient sample of two older persons and revised (see supplementary file). One author, trained in public health qualitative methods (SM), conducted interviews between February and August 2012. Participants signed a consent form before being interviewed over the phone (n=25) or in person (n=5), according to their preference. Interviews lasted from 8 to 55 min. The interviews were audio-recorded and transcribed verbatim. The guidelines for CVD prevention in Australia have not changed substantially since this data was collected.

Data analysis
A Framework analysis method was used to analyse the interview transcripts, which involved 5 steps (table 1).

RESULTS
Demographic and health characteristics of participants are presented in table 2. Twenty eight participants out of 30 were on CVD prevention medication,
14 of whom had established CVD (quotes marked est. CVD). As a result, there was comparatively less data about the experiences of people who were not taking CVD medication. Participants defined their health in terms of presence or lack of serious illness and disability, level of independence, whether medical conditions were controlled or uncontrolled and relative to one’s own previous health as well as relative to others of a similar age. We report on older patient’s experiences with decision-making about medication for CVD prevention as involving a decision. Medication was generally perceived as ‘needed’ without a sense that there may be different options to consider. This attitude appeared heightened in participants who had experienced a CVD event or had a family history. Lifestyle approaches were perceived as an optional addition rather than an alternative to medication.

It’s good for your, your health (…) well fair enough you do it. You don’t even ask any questions. (ID72 est. CVD)

The majority of participants in our study had been on CVD medications for at least 5 years with the expectation of taking them for the rest of their lives. Participants described how taking CVD medication is not ‘a big deal’ (ID28) and a part of their routine to stay healthy as they get older so they ‘don’t think about it anymore’ (ID19, est. CVD). One exception was when people experienced side effects. This triggered the consideration of alternative options including stopping, reducing or changing medication or trying lifestyle changes. Side effects and concerns were often not discussed with the GP, and some participants specifically mentioned barriers around raising the option of stopping medication. For example, a patient who was keen to try non-medication approaches to lower his cholesterol felt discouraged by his GP’s attitude:

You can, can do away with all these medications to do with cholesterol (…) But you talk to your doctor, they said, they don’t, they don’t seem to believe in it. (ID 89)

**Step 2: Discussing the different treatment options and their potential benefits and harms**

Several participants demonstrated limited understanding of the aim of CVD medication (ie, reducing the risk of a future CVD event), assuming that elevated blood pressure or cholesterol are diseases needing treatment rather than risk factors. Many did not make the connection between taking antihypertensives/statins and CVD and reported that their GP had not discussed heart disease or stroke with them, while at the same time mentioning discussions they had about their blood pressure and cholesterol:

When he takes my blood pressure, I always ask him what it is and write it down so that I’ve got a record but no we don’t generally discuss heart things. (ID85)

Understanding was not necessarily great in people who had experienced a CVD event. For example, one participant with an extensive history of CVD (2x stroke, hole in the heart, type 2 diabetes) displayed limited understanding of his increased CVD risk:

I’m never worried about me heart at all. It’s not too bad as far as I, I’m aware. (ID90 est. CVD)

Others expressed a better understanding, mentioning for example, how family history, stress, age and diabetes increase risk or referring to antihypertensives/statins as ‘heart tablets’ (ID75). However, this was by no means comprehensive.
My doctor knows I’m diabetic, he has been watching me. But obviously that must have something to do with the heart. (ID48 est CVD)

Table 2  Participant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
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<td>Good, very good or excellent</td>
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</tr>
</tbody>
</table>

My doctor knows I’m diabetic, he has been watching me. But obviously that must have something to do with the heart. (ID48 est CVD)

Step 3: Exploring patient preferences for the different treatment options

Values, goals and preferences around CVD prevention varied widely across participants and included improving quality of life or length of life, preventing illness or disability, reducing treatment burden, reducing worry about CVD or anxiety about taking multiple medications and maintaining a strong self-identity. See table 3 for a detailed overview and illustrative quotes. Even though the vast majority of participants could articulate what was important to them, only a few mentioned discussing their goals and preferences with their GP, and mostly in the context of side effects of CVD medication. The general attitude was that age is not a reason to not start, stop or change medication. However, some mentioned the financial and opportunity costs involved in looking after an ageing society. Others commented that CVD prevention should be ‘appropriately suitable for the age’ (ID44 est. CVD) or acknowledged the importance of considering the older person’s ‘attitude and their own state of health’ (ID9) when making decisions.

Step 4: Making the decision and involving the patient to the extent they wish

Participants often equated being informed with being involved in decisions about CVD medication, and patient-centred communication (eg, listening to concerns, being caring, thorough, being non-ageist) seemed to be valued more than active involvement. Many just wanted to know the reason why CVD medication was recommended, or changes to medication were suggested. They were happy to then follow their GP’s recommendations, generally preferring a directive approach. The involvement of others (family, carers) in medication decisions was mentioned by several people.

Oh yes, I’d like to be completely involved, yes. INTERVIEWER: When you say completely involved you mean (…) PARTICIPANT: Getting as much information as what I can get. (ID40)

The majority of participants described how they wanted ‘as much information as possible’ about their CVD medication; however there were exceptions:

There are people who know, seem to know more about the pharmaceutical industry than the pharmacist. I’m not in that category, I do as I’m told. (ID31 est. CVD)

Only three participants described being actively involved in the decision-making process; for two this was triggered by severe side effects of their CVD medication.

My muscles ached and I didn’t do well on them (a lipid lowering medication) and I hated taking them so... we’ve come to make a pact, as my HDLs and LDLs are a reasonable balance, I just go along with my high cholesterol which is monitored on a regular basis and lived with. (ID3)
For some participants, trust was mainly expressed long-standing, positive and trusting relationships with their GP (see Step 4). Some participants described the burden of taking multiple medications together with their general practitioners (see Step 3), contributing to a feeling of self-worth. In contrast, several participants had the more fatalistic view that heart disease is just 'part of the course' (ID83) of getting older, however this did not dissuade them from taking medication.

Participants varied in how they valued quality of life versus length of life. Some focused-on longevity for example, because they wanted to see their grandchildren grow up or fulfil other future goals. Other participants prioritised quality of life and stressed the importance of providing care for older people that does not ‘grasp with (sic) straws’ (ID44 est. CVD). According to one participant, cardiologists in particular put too much emphasis on prevention when death is inevitable in older age. For others, there was an acceptance that the end of life is near and unavoidable. Some referenced religious beliefs when making such statements.

Some participants perceived that you cannot stop yourself from getting older, but by taking medication you have some control over your health and future. Others talked more generally about how prevention is better than cure. Many referred to having the responsibility to do 'what you have to do' (ID58 est. CVD) to look after your health and how taking CVD prevention is an inherent part of this as you get older. Some participants had the more fatalistic view that heart disease is just 'par for the course' (ID22) of getting older, however this did not dissuade them from taking medication.

Participants discussed potential harms of antihypertensives (eg, feeling faint and weak, low energy, headaches) and statins (muscle aches). A few described how they had experienced side effects that were so severe that they decided to stop their medication together with their general practitioner (see Step 4). Some participants described the burden of taking multiple medications and the confusion it could cause. However, most participants accepted the benefits of medication as being worth the nuisance.

A directive decision-making preference was also related to high levels of trust in the GP. Many participants expressed long-standing, positive and trusting relationships with their GP, assuming they ‘should know what’s best for me’ (ID89). For some participants, trust was mainly based on the expertise of medical professionals in general: ‘she has far more knowledge than I have’ (ID19 est. CVD). According to these participants doctors make the decisions and patients should follow their recommendations:

That’s what they’re there for, that’s their job. My job is to, to do what they tell me. (ID90 est. CVD)

For others, trust was also about the personal relationship they have with their GP and their shared history,
with an implicit assumption that GPs are not only medical experts but also know and understand what matters to their older patients.

He refers to me, like, he’ll tell me, his mother’s the same age as me and he, he tells me what he tells his mother. It’s a very intimate consultation. (ID82, est CVD)

Used to say he [previous GP for 35 years] was more of a friend than a Doctor because I had been with him for so long. (ID43)

**DISCUSSION**

This qualitative investigation into older people’s (75+) experience of decision-making in the context of CVD prevention medication revealed that although the majority of participants were taking medications, only a few seemed to fully understand their purpose and potential benefits and harms. Participants varied widely in their goals and preferences related to CVD, and defined involvement in decision-making less in terms of making the final decision, and more in terms of being informed. There was surprising commonality in the experiences of these patients and across primary and secondary prevention.

In our study, most people had been taking CVD medication for a very long time, had faith in the importance of prevention, and were taking medication because it was the apparent default decision. Cognitive biases such as status quo bias, cognitive dissonance and confirmation bias may provide an explanation. However, several of our findings suggest that older patients are not always in a position to make an informed health decision. Most participants conveyed limited knowledge about the aims and potential benefits and harms of CVD medication and often held the assumption that CVD prevention is effective regardless of age. They demonstrated limited choice awareness regarding alternatives (not starting, stopping, reducing or changing medication or trying lifestyle change) unless they were experiencing side effects or had a strong negative attitude towards medication. Other studies have similarly found what is often referred to as ‘low choice awareness’ or ‘low decision awareness’ in older people. A systematic review of studies using the Observing Patient Involvement in Decision Making (OPTION) Scale to assess SDM found that only in 1 in 3 studies clinicians made it clear that there was more than one option to consider. This is problematic given that older people may have different preferences for CVD prevention when fully informed. Fried et al, for example, have shown in an experimental study with hypothetical scenarios that older people are less willing to take medication for primary prevention of CVD when provided with information about potential harms in addition to benefits compared with benefit information only.

Our results also suggest that decisions may not always be concordant with goals, values and preferences. The health goals and priorities of participants in our study varied widely. This occurred across different categories of goals, including fundamental goals (eg, living as long as possible vs as healthily as possible); functional goals (eg, staying active vs being free of worry) and disease/symptom specific goals (ie, avoiding symptoms or side effects, reducing risk of stroke). A quantitative study revealed similarly variable health goals and preferences in older patients; half of the older participants identified reducing the risk of cardiovascular events as more important than reducing their combined risk of fall injuries or medication symptoms, whereas the other half of the participants identified the opposite priorities. Few participants in our study mentioned discussing their goals with their GP and demonstrated trust in the GP’s understanding of their preferences and circumstances. This is in line with other qualitative studies which have found that older patients may not start conversations because they assume the clinician knows what matters to them. Clinicians, similarly, do not initiate these discussions and may assume they know the patient’s preferences. However, unless actively discussed, there is likely to be a mismatch between the clinician’s perception of patient preferences and the patient’s actual preferences. Patients may also think that their preferences or concerns are irrelevant to the decision-making process because the clinician does not enquire about it. Combined, these findings suggest that these decisions are highly preference sensitive and that preferences and goals cannot be assumed and need to be explicitly discussed.

**Directions for research and practice**

In our study and others, older people valued a caring, person-centred approach to healthcare where they felt heard and understood by their GP. Older people also defined involvement less in terms of making the final decision and more in terms of being informed. This aligns with a general finding that most (but not all) older people prefer a more passive role in decision-making. These results seem to be partly due to a cohort effect, and together with the ageing of the baby boomer generation, suggest that there is a growing space for using a SDM approach with older people. In addition, both in our study and in previous work, older people were heterogeneous regarding their desired involvement in decision-making, which emphasises that older patients’ preferences should not be assumed. Rather, patients should be encouraged and supported by GPs to be involved, but ultimately it is up to the patient to decide how much they want to participate. Even if the final decision is made by the GP, if patients are actively engaged in the information exchange and discussion of preferences, it should still be considered a shared decision.

Strategies to address barriers and challenges of SDM about CVD medication are presented in table 4. Decision aids for CVD prevention are available and might be a good starting point for information-exchange. However, in order to be effective, decision aids should be developed...
with older people and comorbidities in mind. Clinicians also need an understanding of how to adapt the evidence for older people. Additional guidance on how long CVD medication should be prescribed and circumstances in which it can be reduced or stopped, both in clinical guidelines and patient education materials, is also needed to support these conversations. In addition to decision aids, question prompt lists have been developed and have successfully empowered patients to discuss the potential benefits and harms of different options; our results suggest that similar interventions may be needed to encourage patients to share what matters to them with their health provider. These tools will need to be supported by specific discussions around preferences during consultations, a necessary step, given that preferences and values described by participants in our study (eg, avoiding being a burden) differ from what is typically reported in clinical guidelines for primary CVD prevention and broader health goals and preferences for universal health outcomes (eg, staying alive longer) only modestly predict people’s preferences for CVD medication.

### Strengths and limitations

This is a selective patient sample with only two people not on preventive CVD medication. Although this limits interpretation of the findings, it is representative of this population. A clear strength of this study is the diverse sample of older patients who vary in terms of primary and secondary prevention, how long they had been taking CVD medication but also their age, education and comorbidities. There was a time gap between data collection (2012) and publication (2019); however a recent systematic review suggests that the same barriers to SDM in CVD care in general practice still apply, with limited support and guidance available for GPs. As this is a qualitative study, the generalisability of these findings may be limited. We have taken steps to enhance transferability by describing the research context and methods and relating our results to existing models and evidence.
from the literature. A follow-up quantitative survey could be carried out to confirm our findings are generalisable to the older population at large.

Most participants in our study had been taking CVD medication for over a decade, around half of them for established CVD. In other words, this is not the typical SDM context of new decisions about new medication. However, it is a common scenario for older people, in particular those with multimorbidity. Rather than being a limitation of the study, this speaks of the need to reframe SDM in this context to include a periodic re-evaluation of decisions that have been made in the past. This would include ongoing conversations about medication to ensure treatments are still of benefit and remain feasible and might include discussions around reducing or stopping CVD medication. This approach may also improve adherence to essential CVD medication. Especially in the absence of triggers such as acute side effects, it may be challenging and counterintuitive for older patients to initiate these discussions and health providers might be reluctant to ask because they perceive they lack time or skills.

CONCLUSIONS
Our aim in this study was to explore older people’s perspectives and experiences with decisions about medication for CVD prevention. Our results suggest that decision-making for many older patients might be more about re-evaluating and adjusting medication decisions made in the past than about new medication. To ensure that decisions are informed and aligned with patient preferences and goals, GPs may need to spend extra time regularly reviewing medications, explaining the aims of prevention, explaining that there are different options to consider and importantly, eliciting personal goals and preferences. Clearly this can be a time-consuming process. Protected time, more dedicated resources, and even specific remuneration for discussions around goals and preferences and monitoring and reviewing medication may be needed.

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Contributors JJ contributed to the conception and design of the study, the analysis and interpretation of data, drafting and critically revising the manuscript. SM contributed to the acquisition, analysis and interpretation of data, drafting and critically revising the manuscript. CB contributed to the conception and design of the study, analysis and interpretation of data, and critically revising the manuscript. DM contributed to interpretation of data, and critically revising the manuscript. JD contributed to the conception and design of the study, and critically revising the manuscript. JH contributed to the conception and design of the study, interpretation of the data, and critically revising the manuscript. All authors approved the final version for publication, and all authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Competing interests None declared.

Patient consent for publication Not required.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Data underlying our findings cannot be made publicly available for ethical reasons; public availability would compromise our participants’ privacy. Data requests may be sent to the corresponding author at shannon.mckinn@sydney.edu.au.

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