

# “I simply don't know, because I don't know which drugs I get”: Perspectives on deprescribing among older adults with limited life expectancy and their relatives

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## Funding information

Velux Fonden, Grant/Award Number: 00018248

## Abstract

Use of medications of questionable benefit is common in end of life care. In order to effectively carry out deprescribing, it is important to gain insight into the perspectives of patients and their relatives. Thus, our objective was to explore perspectives on deprescribing among older adults with limited life expectancy and their relatives. We conducted semi-structured interviews with ten nursing home residents and nine relatives. Interviews were analysed using systematic text condensation. Four main themes were identified: “*Medication as a necessity and to feel well,*” “*Frailty as a barrier for taking responsibility,*” “*Patient autonomy and faith in authority*” and “*A wish for being involved.*” Most participants had not considered the possibility of deprescribing but were open towards medication change if proposed by a healthcare professional. Most participants did not have in-depth knowledge about medication but would like to be informed or involved in decisions. The participants generally had faith in healthcare professionals despite limited contact. Our study implies that older adults with limited life expectancy and their relatives are generally interested in deprescribing activities; however, the initiative of deprescribing lies with the healthcare professionals.

## KEYWORDS

deprescribing, end of life, frailty, interview, perspectives

## 1 | INTRODUCTION

Use of medications of questionable benefit is common among the older population<sup>1-3</sup> and might lead to excess frailty and hospitalization.<sup>4-6</sup> In older adults with limited life expectancy, goals of care often shift from preventing disease to maintaining functional level and sustaining quality of life.<sup>7</sup> Further, in the last years of life, even more medication may be considered of questionable value for the patient as the time to benefit for prophylactic medications can exceed the life expectancy.<sup>8</sup> Deprescribing, defined as supervised withdrawal of medications of questionable benefit to improve outcome,<sup>9</sup> could be a solution to this,<sup>10,11</sup> as deprescribing aims at reducing risk of harm by reducing or stopping medication with a low benefit-to-harm ratio.<sup>12</sup> However, deprescribing is a complex process influenced by many barriers and enablers, and to enable a patient-centred process, it must be accepted by the concerned individuals and not only decided by the healthcare professionals. Therefore, in order to effectively carry out deprescribing, it is important to gain insight into the perspectives of the patients and relatives affected by it.

There is no clear guideline to assess when an older person has a life expectancy of 1-2 years. However, as the median survival in Danish nursing homes is approximately 26 months,<sup>13</sup> it was decided in this study to use residency in nursing home as a proxy for limited life expectancy. In Denmark, all citizens can apply for nursing home residency, but appointment is reserved to the frailest individuals needing all-day care. Residency is appointed by the local municipality based on functional and social capacity.

Studies of older adults in general and their relatives reveal barriers as well as enablers towards deprescribing. Reported barriers include not having enough time with a physician to review medication<sup>14-16</sup> and fear of what will happen after deprescribing.<sup>14-18</sup> Reported enablers include overwhelming trust in the physician's decisions<sup>14,16,19-22</sup> and a general dislike of taking medication.<sup>14,15,19,22</sup> The knowledge of and interest in medication among older adults vary.<sup>14,16,20</sup> For older adults with limited life expectancy, many of the same barriers and facilitators exist<sup>23</sup>; however, the perspectives of older adults with a life expectancy of 1-2 years are not covered exhaustively. Further, although relatives often have a pronounced role in the care of these patients, only a few studies investigate the perspectives of relatives towards deprescribing in the context of end of life treatment.<sup>24-28</sup> Thus, the aim of this study was to qualitatively explore perspectives on deprescribing among older adults with limited life expectancy and their relatives.

## 2 | METHODS

### 2.1 | Design and theoretical framework

In this qualitative study, we used semi-structured individual interviews to facilitate in-depth knowledge<sup>29</sup> about the research question: How do older adults with limited life expectancy and their relatives experience deprescribing in their everyday life? We used a hermeneutic-phenomenological approach, where the phenomenology openly explores the phenomenon of deprescribing from the perspectives of the participants, and the hermeneutic approach incorporates the preunderstandings of the researchers to interpret the explored experiences.<sup>30,31</sup> We used our preunderstanding, consisting of both our medical knowledge, our own lived life experiences and our clinical experiences from working with older adults and their medication, to explore the participants' experiences with medication and deprescribing. By using the hermeneutic approach, our preunderstandings and the new understandings from the interview situation were merged in a circular process, and a fusion of horizons as described by Gadamer took place between the interviewer and the participant.<sup>32</sup> The study is reported in accordance with the COREQ criteria (see Appendix 1).

We developed thematic interview guides for older adults and their relatives (see Appendix 2) based on previous literature on deprescribing perspectives in end of life.<sup>23</sup> The interview guides contained open-ended questions about everyday life, medication use, knowledge of medication, attitudes towards medication and perspectives concerning deprescribing. The interviews were guided by the interview guide, but not followed strictly. All interviews were explorative, giving the participants the opportunity to speak freely about their perspectives, but under consideration of the frailty of the participants. All interviews were conducted in Danish, audio-recorded and transcribed verbatim.

### 2.2 | Setting and participant recruitment

The interviewer and moderator visited three nursing homes. All residents receiving medication and deemed able to sign an informed consent were eligible for inclusion. We used convenience sampling in the selection of participants as the frailty of the participants necessitated inclusion of every eligible resident on the specific day of the interview. After each interview at the nursing home, the resident pointed out a relative to be asked for participation in the study. TG conducted all the interviews, and CL participated as moderator in the first interviews (see Appendix 3). The interviews were conducted from March to August 2018. The interviews with older adults took place in their living room

at the nursing homes. The interviews with relatives were held in their homes or in a hospital meeting room according to the participants' choice.

Most residents lived a quiet life at the nursing home, as they had difficulties seeing, walking, hearing, etc. As study inclusion required residents to provide informed consent, no residents suffered from dementia. However, they were all frail and suffered from minor to moderate cognitive impairment. None of the residents dispensed their medication themselves. None of the relatives lived together with the residents.

## 2.3 | Data collection

A total of 20 residents and 12 relatives were asked to participate. Five residents and one relative declined, while five residents and two relatives withdrew their consent prior to interview, leaving ten residents and nine relatives to participate. Two relatives (relative 2a and 2b) of the same resident were interviewed together. The older adult was present during the interview of two of the relatives (relative 1 and relative 10). The median age of the residents was 87 years (range 72-96 years) and of the relatives 60 years (range 45-82 years). The median number of medications prescribed to the residents was 11 (range 4-15), and the median number of daily tablets was 16 (range 3-31). The interviews lasted from 7 to 55 minutes (median 12 minutes for residents and 31 minutes for relatives).

## 2.4 | Data analysis

TG listened to the audio recording and wrote a short summary of the most important topics immediately after each interview. Data analysis was performed in NVivo 11 (QSR International) using systematic text condensation described by Malterud<sup>33</sup> and based on Giorgi's psychological phenomenological analysis.<sup>34</sup> The analysis consisted of four steps performed by TG. Firstly, all summaries were read to obtain an overall impression of data and to develop preliminary themes. Hereafter, each transcription was examined line by line to identify meaning units and sort them into codes. Next, codes were grouped into code groups, and all meaning units within each code group were condensed to reflect the content. Finally, the condensates within each code group were synthesized to describe the identified themes. The cited quotes from the interviews were translated into English. A decision trail was made to keep track of decisions made during data analysis. See Table 1 for examples of data analysis. The whole process was conducted as an iterative process and discussed between TG, CL and DSN.

## 2.5 | Ethics

Due to the qualitative study design, The Regional Committees on Health Research Ethics waived registration of the study. The study was approved by the Danish Data Protection Agency (approval 17/34563). The study was conducted in accordance with the principles of the Declaration of Helsinki.

**TABLE 1** Schematic example of the steps in the analysis from meaning units to main themes

Meaning units	Code	Condensation	Main theme
Interviewer: If the physician came to you and said that they think you should take more medication, what would you think? Resident 9: Well, first I would object if they don't think I get too much already. And what could possibly be taken away.	Attitude towards medication change	If the physician said I should have more medication, I would object and ask if they didn't think I get enough medication already and if anything could be taken away.	Medication as a necessity and to feel well
Relative 2b: I have sometimes asked: "Which medication do you actually get?" "Well, I get this one in the morning" she says, but she doesn't know what it is.	Knowledge about medication	I have sometimes asked the resident which medication she gets, and then she says that she gets one in the morning, but she doesn't know what it is.	Frailty as a barrier for taking responsibility
Interviewer: Would it be the same if the physician came to you and said that there should be put more medication on top? Relative 1: Yes, because then I assume there must be a reason why he thinks like this. And we would of course also like to question that. Interviewer: So it is important for you to be informed? Relative 1: Well, definitely. Of course, we would know why no matter if it is something that is imposed or deprived.	Willingness to change	I assume the physician has a reason to suggest changes, and I would like to question that. Of course, we would appreciate to know why, whether medication is imposed or deprived.	Patient autonomy and faith in authority

Inclusion of participants was based on informed and written consent. Participants were informed that participation was voluntary. Participants gave consent for their data to be published in a scientific journal securing that efforts would be made to conceal their identity.

### 3 | RESULTS

Four main themes emerged during the analysis: *“Medication as a necessity and to feel well,” “Frailty as a barrier for taking responsibility,” “Patient autonomy and faith in authority” and “A wish for being involved.”* The main themes and codes within them represent important aspects to consider around deprescribing for older adults with limited life expectancy and their relatives (see Figure 1).

#### 3.1 | Medication as a necessity and to feel well

Both residents and relatives generally considered taking medication a necessity, something they were accustomed to or simply had to do, because the physician had told them to.

Resident 3: “I think I get a lot [of drugs]. [...] But it must be a necessity.”

Some residents thought they took too much medication, regardless of how much medication they actually took. The

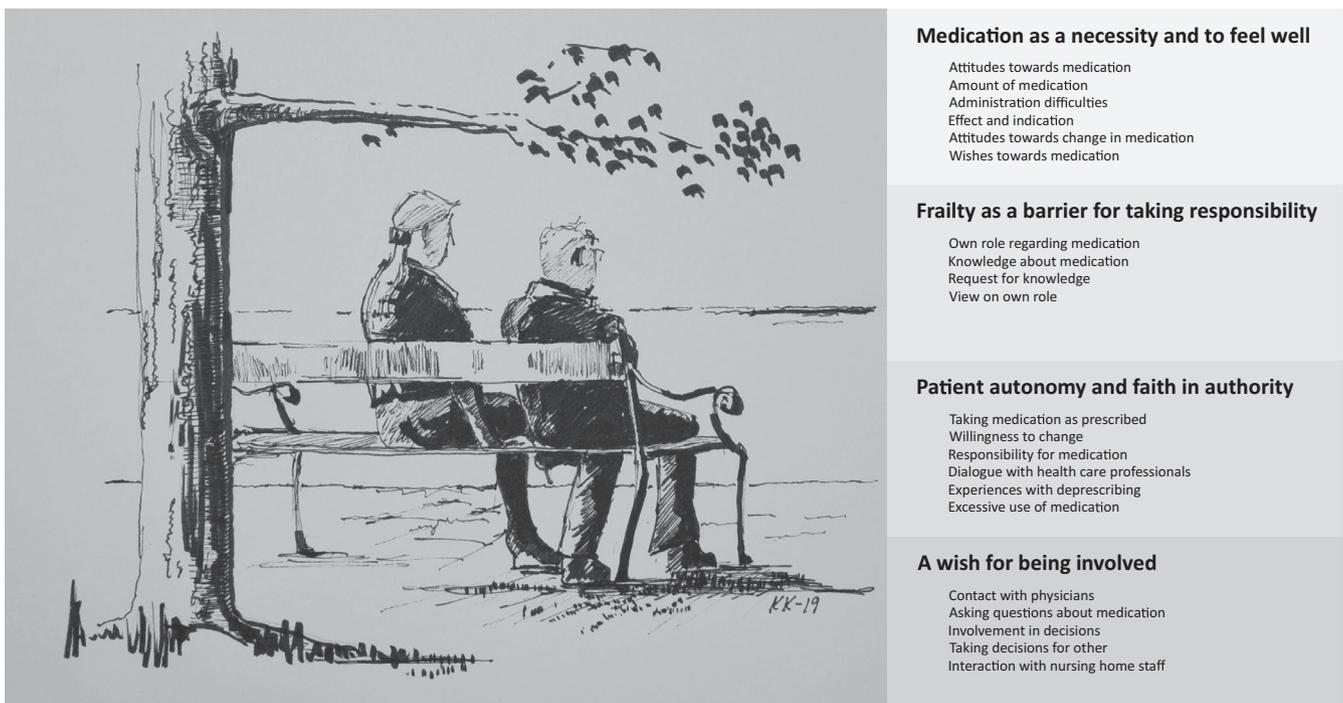
residents did not consider it challenging to administer their medication as either tablets or other formulations, and they mostly did not experience any side effects. Only a few residents experienced troubles with swallowing tablets, and the relatives seldom heard the residents complain about discomfort.

Resident 6: “Well, I down them [the pills] while drinking a lot of water. Sometimes it is difficult. [...] But I must have it, and then I take it.”

Most residents and some of the relatives had no opinion as to which medications were most important. On the other hand, some relatives pointed out medication to prevent the residents from having a blood clot as most important. Quality of life and functional level were generally considered more important among the relatives than prolonging life. Despite this, a general perception among both residents and relatives was that all the medication was important; otherwise, it would not have been prescribed.

Relative 8: “No, they [the pills] must be important all of them, well, otherwise she wouldn't get them. I don't think you'd give unnecessary medication. That would be foolish.”

Some residents expressed a desire to do without medication, if possible. Likewise, most relatives stated an interest in the residents having as little medication as possible. Some even wondered if it could be an advantage to stop all medication to



**FIGURE 1** Aspects of deprescribing among older adults with limited life expectancy and their relatives within the four identified themes

see whether the residents could do without or even get better. Some residents had tried reduction of medication with favourable results.

Relative 5: “Then we suggest to the neurologist if we could cease my dad’s medication, which he agreed to, and my dad became better almost every day. [...] He is not so cut off from the outside world as he was before.”

Both residents and relatives stated that the indication for treatment was to recover from disease or to feel well and therefore a reduction in medication would mean that the residents were in good health. Only a few residents and relatives were sceptical about stopping a medication because the medication could have effects that they would then miss out on. Finally, a few relatives would interpret that end of life was approaching if the physician recommended reduction of all medication or specific prophylactic medication.

Relative 2b: “Well, if they take the cholesterol medication away from her, I would probably think... [...] I would think, well, then it must be because they think there is not much time left.”

### 3.2 | Frailty as a barrier for taking responsibility

The residents were all frail in the way that they were no longer able to look after themselves and they lost their energy quickly just by keeping up with daily routines such as getting dressed and having meals. Most residents did not know the name of their drugs; however, they knew their daily number of tablets and some also knew what the tablets looked like or what time of day they should take them.

Resident 2: “Well, I don’t know the name. But I get three pills in the morning and one in the evening, at dinnertime.”

A few residents knew the type of medication they took, such as blood thinners, antihypertensives and diuretics. It was difficult for the relatives to have exact knowledge about the residents’ medication and they generally had an idea about the type of medication the residents took, but not the drug name or strength.

Relative 8: “I could ask how much she gets, but if she tells me she gets a pill and a half... Well, I wouldn’t know if it is too much or too little, so it wouldn’t really make sense to ask.”

Both residents and relatives expressed that they wanted to know which medication they received, and many felt they were sufficiently informed. Residents spontaneously mentioned that they would like to have a reason for medication change, even when they were not fully aware of the types of medication already taken. As such, their cognitive challenges due to frailty made it difficult for them to take responsibility for their medication treatment. Likewise, most of the residents had not by themselves thought about the option of having less medication.

Resident 1: “Well, [if the physician suggests medication reduction] I would... I simply don’t know, because I don’t know which drugs I get.”

Some relatives expressed that they were happy about the nursing home staff helping with the medication because they had felt insecure earlier when the residents had tried to cope with dispensing themselves. If the residents happened to forget their medication, the staff now would remind them to take it.

### 3.3 | Patient autonomy and faith in authority

Most residents expressed faith in authorities by stating that they would always use their medication as prescribed by the physician. Some residents said that if they were ill or the medication was inconvenient, then they could ask the staff for allowance for not taking their tablets at that time.

Patient autonomy towards healthcare professionals was expressed by some residents hesitating to increase their amount of medication, whereas all residents would welcome a reduction if suggested by their physician or staff at the nursing home. However, most residents and relatives stated they would not notice if a medication was changed, and as such, they would not worry about an actual change.

Most residents trusted the physician and did what they were told without questioning it. Some relatives expressed no fear of taking a conversation with the physician or the staff about the medication of the residents, while others felt incompetent to do so or were unsure of whether they should.

Relative 4: “The physician has assessed it would be wisest to give him [the resident] a blood thinner. [...] And I have to say, I have no medical education, and I don’t think I have the expertise to say, well, he shouldn’t have that.”

When asked about the responsibility for their medication, most residents pointed out the physician or the staff at the nursing home. Some relatives expressed that they did not think the staff could have the responsibility, as many different nurses were involved in the care of the residents. Some residents and

relatives expressed that they were not sure where the responsibility lays. Some relatives pointed out the resident in collaboration with the physician and the relatives as responsible for the medication.

Most residents could not recall an experience where the physician had suggested stopping a medication; however, some residents had tried withdrawal of primary painkillers as recommended by the nursing home staff. Some residents and relatives had tried to suggest stopping medication themselves, sometimes resulting in fewer medications but other times rejected by the physician.

Resident 9: “I have tried to have it [the medication] reduced. I did that by addressing the physician. But he didn't agree. In his opinion I didn't get more than I should have.”

Relatives' and patients' confidence in the health professionals was in some situations challenged as the healthcare professionals were in a position of authority. A few relatives had the experience that healthcare professionals could sometimes use excessive medication to keep the residents calm or to avoid arranging activities for the residents.

Relative 4: “My impression is that older people are getting too much medication, and I think it's alarming. Unfortunately, I have the impression that it's easier to give a pill than to find time to give them what they need.”

### 3.4 | A wish for being involved

Most residents and relatives were frustrated about the limited contact with physicians. Residents expressed they had sparse contact with their physician, and some stated that they had never met their physician, whereas others only talked with their physician on the telephone. Further, most residents stated they did not discuss medicine with their physician. Some relatives were satisfied with the amount of contact, as they told that the physician would visit the nursing home once a year to review the medication.

Only a few residents and relatives had experienced asking questions about medication, and most were unsure who to ask. If the residents had problems with their medication, they assumed they would ask the staff at the nursing home, whereas others would ask the physician directly. Some relatives would ask the residents first, and if they could not explain the problem, they would ask a healthcare professional.

Both residents and relatives expressed a desire to be informed about decisions regarding the medication, in order not to feel decisions being made over their heads.

Resident 5: “I'm very aware of which medication I get. I would like to know what I put in my body. [...] Why I take it, and what it does. That is, what the purpose is with it.”

Although most residents would like to be informed, they were generally not interested in being involved in the decisions, as they thought they did not have enough knowledge and that the physician must know better. Some residents felt insecure when being asked to make a choice and found it easier if the physician took the decision for them. The relatives, however, would generally like to be involved in decisions and to have their voice heard.

Relative 1: “But I would not take a risk, so he [the physician] has to convince us that there isn't any, right? Otherwise we wouldn't dream of changing anything.”

Some relatives felt they were quite involved in decisions, because they knew the residents better than the physician or if they passed on information in case the residents' memory failed.

Relative 7: “I'm also humbled by their [the physicians] knowing better about the medication. I, on the other hand, know my mum better than they do, and that's why we should work together.”

The difficulty of making decisions for others was illustrated as some relatives doubted whether they ought to be more involved in the residents' medication, whereas other relatives were glad not to be too involved as it gave them a sense of freedom. Further, some relatives did not think the staff at the nursing home would let them be involved in the medication of the resident, even if the residents needed their involvement. Some relatives were afraid to interfere with the staff, because they feared that annoying or agitating the staff would negatively affect the care for the residents.

Relative 8: “Then she [the resident] was really incorrectly medicated. [...] I must admit I had an argument with them [the staff] there. [...] My mum has to be there every day, and she has to be around them. [...] My mum was afraid she would be kicked out of the nursing home if I made too much trouble.”

## 4 | DISCUSSION

In this qualitative study, we explored perspectives on deprescribing among older adults with limited life expectancy and

their relatives. Generally, medication was perceived as a necessity by residents and relatives and in-depth knowledge about medication was sparse among both. Most residents had not considered the possibility of deprescribing themselves but were willing to change their medication if proposed by the healthcare professional. Most residents did not find medication challenging to take and would not notice if their medication was changed. Both residents and relatives saw the physician or the staff at the nursing home as responsible for the medication, and they trusted the healthcare professionals, even though the contact with physicians was limited. Finally, both relatives and residents would like to be informed and to a varying extent involved in medication decisions.

## 4.1 | Strengths and limitations

As most of the participants were not aware of the term deprescribing and had not been giving reduction in medication many thoughts beforehand, the primary strength of our study is that the participants were asked about their perspective on medication use in general and hereafter asked about specific experiences around medication change together with imaginary episodes. In this way, we ensured that all aspects of the topic were explored.

Some limitations to our study should also be acknowledged. Firstly, we used residency in nursing home as a proxy for limited life expectancy but two of the interviewed residents had been living in a nursing home for more than five years. Furthermore, the older adults had to be able to sign an informed consent before the interview. The latter excluded older adults with dementia, which is very common in Danish nursing homes.<sup>13</sup> As such, a limitation to this study is inclusion of residents less frail than expected for older adults with limited life expectancy. For these reasons, we believe that in regard to medication, the residents were representative of older adults with a life expectancy of 1-2 years outside nursing home as well. Another limitation could be that some of the interviews were relatively short, as the residents were quickly worn out due to their frailty. However, the participants' perspectives on medication were not difficult for them to talk about, and therefore, their perspectives were elaborated even when the interviews were relatively short. For two residents, however, hearing problems and delay in answering required the interview questions to be made simpler and the data from these interviews were consequently less rich. In two of the interviews with relatives, the older adults were present during the interview. This could possibly have limited the expressions from the relatives. However, these older adults were by far the frailest of the included residents and it did not seem as if they took any notice of the interview going on. Furthermore, the relatives were comfortable with participating in an interview in front of the residents. Relative

2a and 2b were interviewed together; however, this did not affect the analysis as relative 2b primarily led the conversation. Even though each relative was selected by a resident, we analysed them separately. This means that we have not compared specific statements, such as type of medication taken, between residents and relatives, but instead accepted the meaning of each individual.

## 4.2 | Our findings compared to existing literature

The participants in our study had relatively limited experience with deprescribing, which is consistent with a previous qualitative study among older adults exploring patient perceptions of deprescribing.<sup>22</sup> According to the literature, previous poor experiences with deprescribing can be a barrier to the patients' willingness to try deprescribing.<sup>15</sup> However, the few unfavourable episodes of deprescribing explored in this study were about symptom relief, whereas episodes with deprescribing of preventive medication had left a good impression among both residents and relatives.

Enablers of deprescribing among older adults have been described as a high medication burden, side effects and a perception of no indication for treatment.<sup>15,25,27,35,36</sup> However, even though these enablers were not experienced by the residents in this study, the residents were still willing to try deprescribing. It appeared that the residents welcomed a reduction in their daily number of medications, mostly just because of the number of pills. Some residents and relatives stated that fewer medications must mean the residents are healthier, whereas others were simply not interested in taking a high number of medicines. This general dislike of taking medication is consistent with findings from previous reviews stating that older adults expressed a strong dislike of using medications long-term,<sup>14</sup> felt that medication was unnatural<sup>15</sup> or did not want to use more medication than they already did.<sup>19</sup>

An important aspect of deprescribing includes involvement of patients and relatives in decisions around medication change. As in other studies discussing shared decision-making within medication use,<sup>16,20,22,26-28,37</sup> the older adults and relatives in our study wanted to be involved in varying degrees. The residents primarily wanted to be informed and given an explanation, which was also found in a recent systematic review about attitudes towards deprescribing in older adults with limited life expectancy.<sup>23</sup> In an interview study about communication between patients and physicians, the trust of older adults in their physician could prevent them from asking questions or seeking information,<sup>16</sup> and few of the residents in our study had actually tried to question their medical treatment. Another Danish study found that nursing home residents found it difficult to imagine being part of a discussion of deprescribing and

that they could not identify topics to be discussed.<sup>38</sup> Our study suggests that relatives are willing and confident to engage in discussions with healthcare professionals about deprescribing. However, few studies have investigated whether involvement can be a burden on the relatives, for example by worrying about the choice of care<sup>27</sup> or feeling guilty for stopping treatment.<sup>26</sup> This needs to be studied in more detail.

Studies of perspectives among healthcare professionals suggest that they fear older adults with limited life expectancy feel given up upon or confused if healthcare professionals recommend deprescribing.<sup>39</sup> The opposite is found in this study where both residents and relatives thought that increase in medication meant deterioration and reduction in medication meant better health, unless all medications were stopped at once.

Finally, in this study, the residents and relatives stated to have quite sparse contact with the physician and not many discussions about medication during their appointments. This is also mentioned in other studies,<sup>14,15</sup> where older adults also fear to take up too much of the physician's time<sup>16</sup> or feel that their voices are not being heard.<sup>35</sup> This could be a possible barrier for deprescribing.

### 4.3 | Relevance for clinical practice

The marked trust in authority seen in our study can be relevant for deprescribing initiatives, as most residents and relatives do not suggest deprescribing themselves but are willing to try deprescribing if recommended by the physician or the staff at the nursing home. This places a considerable responsibility with healthcare professionals caring for older adults with limited life expectancy to be observant on possibilities for deprescribing. Further, as the residents and relatives in this study felt that there was insufficient time to discuss medication changes with the physician, deprescribing initiatives could benefit from creating more room and developing tools for healthcare professionals discussing medication with older adults and their relatives. These discussions should ensure the perspectives of older adults with limited life expectancy being heard, hereby making better opportunities for involvement of the individuals who demand shared decision-making.

### 4.4 | Conclusion

The findings of our study suggest that many factors are involved in deprescribing at end of life; however, as starting point, the willingness of older adults with limited life expectancy and their relatives to try deprescribing is considerable, if they are supported by healthcare professionals. To facilitate deprescribing, healthcare professionals need to initiate

more discussions about deprescribing among older adults with limited life expectancy and their relatives to ensure possibilities for their involvement in decision-making.

### ACKNOWLEDGEMENT

The authors wish to thank all participants for their participation in the study, Ann-Louise Hald and Malene Nissen for transcription of the interviews and Karsten Kiehn for sketching Figure 1.

### CONFLICT OF INTEREST

All authors declare that they have no conflicts of interest.

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### REFERENCES

1. Storms H, Marquet K, Aertgeerts B, Claes N. Prevalence of inappropriate medication use in residential long-term care facilities for the elderly: a systematic review. *Eur J Gen Pract.* 2017;23(1):69-77.
2. Nyborg G, Brekke M, Straand J, Gjelstad S, Romøren M. Potentially inappropriate medication use in nursing homes: an observational study using the NORGE-PH criteria. *BMC Geriatr.* 2017;17(1):220.
3. Paque K, Elseviers M, Vander Stichele R, et al. Associations of potentially inappropriate medication use with four year survival of an inception cohort of nursing home residents. *Arch Gerontol Geriatr.* 2019;80:82-87.
4. Maher RL, Hanlon J, Hajjar ER. Clinical consequences of polypharmacy in elderly. *Expert Opin Drug Saf.* 2014;13(1):57-65.
5. Cheong V-L, Sowter J, Scally A, Hamilton N, Ali A, Silcock J. Medication-related risk factors and its association with repeated hospital admissions in frail elderly: a case control study. *Res Soc Adm Pharm.* 2020;16(9):1318-1322.
6. Wallace E, McDowell R, Bennett K, Fahey T, Smith SM. Impact of potentially inappropriate prescribing on adverse drug events, health related quality of life and emergency hospital attendance in older people attending general practice: a prospective cohort study. *J Gerontol A Biol Sci Med Sci.* 2017;72(2):271-277.
7. Hilmer SN, McLachlan AJ, Le Couteur DG. Clinical pharmacology in the geriatric patient. *Fundam Clin Pharmacol.* 2007;21(3):217-230.
8. Holmes HM, Min LC, Yee M, et al. Rationalizing prescribing for older patients with multimorbidity: considering time to benefit. *Drugs Aging.* 2013;30(9):655-666.
9. Reeve E, Gnjjidic D, Long J, Hilmer S. A systematic review of the emerging definition of "deprescribing" with network analysis: implications for future research and clinical practice. *Br J Clin Pharmacol.* 2015;80(6):1254-1268.

10. Wouters H, Scheper J, Koning H, et al. Discontinuing inappropriate medication use in nursing home residents: a cluster randomized controlled trial. *Ann Intern Med.* 2017;167(9):609-617.
11. Potter K, Flicker L, Page A, Etherton-Beer C. Deprescribing in frail older people: a randomised controlled trial. *PLoS One.* 2016;11(3):e0149984.
12. Scott IA, Hilmer SN, Reeve E, et al. Reducing inappropriate polypharmacy: the process of deprescribing. *JAMA Intern Med.* 2015;175(5):827-834.
13. Reilev M, Lundby C, Jensen J, Larsen SP, Hoffmann H, Pottegård A. Morbidity and mortality among older people admitted to nursing home. *Age Ageing.* 2019;49(1):67-73.
14. Gillespie RJ, Harrison L, Mullan J. Deprescribing medications for older adults in the primary care context: a mixed studies review. *Health Sci Rep.* 2018;1(7):e45.
15. Reeve E, To J, Hendrix I, Shakib S, Roberts MS, Wiese MD. Patient barriers to and enablers of deprescribing: a systematic review. *Drugs Aging.* 2013;30(10):793-807.
16. Schöpf AC, von Hirschhausen M, Farin E, Maun A. Elderly patients' and GPs' perspectives of patient-GP communication concerning polypharmacy: a qualitative interview study. *Prim Health Care Res Dev.* 2018;19(4):355-364.
17. Thompson W, Black C, Welch V, Farrell B, Bjerre LM, Tugwell P. Patient values and preferences surrounding proton pump inhibitor use: a scoping review. *Patient.* 2018;11(1):17-28.
18. Luymes CH, van der Kleij RMJJ, Poortvliet RKE, de Ruijter W, Reis R, Numans ME. Deprescribing potentially inappropriate preventive cardiovascular medication: barriers and enablers for patients and general practitioners. *Ann Pharmacother.* 2016;50(6):446-454.
19. Bokhof B, Junius-Walker U. Reducing polypharmacy from the perspectives of general practitioners and older patients: a synthesis of qualitative studies. *Drugs Aging.* 2016;33(4):249-266.
20. Weir K, Nickel B, Naganathan V, et al. Decision-making preferences and deprescribing: perspectives of older adults and companions about their medicines. *J Gerontol B Psychol Sci Soc Sci.* 2018;73(7):e98-e107.
21. Clyne B, Cooper JA, Boland F, et al. Beliefs about prescribed medication among older patients with polypharmacy: a mixed methods study in primary care. *Br J Gen Pract.* 2017;67(660):e507-e518.
22. Linsky A, Simon SR, Bokhour B. Patient perceptions of proactive medication discontinuation. *Patient Educ Couns.* 2015;98(2):220-225.
23. Burghle A, Lundby C, Ryg J, et al. Attitudes towards deprescribing among older adults with limited life expectancy and their relatives: a systematic review. *Drugs Aging.* 2020;37(7):503-520.
24. Dees MK, Geijteman ECT, Dekkers WJM, et al. Perspectives of patients, close relatives, nurses, and physicians on end-of-life medication management. *Palliat Support Care.* 2018;16(5):580-589.
25. Palagyi A, Keay L, Harper J, Potter J, Lindley RI. Barricades and brickwalls – a qualitative study exploring perceptions of medication use and deprescribing in long-term care. *BMC Geriatr.* 2016;16(1):15.
26. Post SG, Stuckey JC, Whitehouse PJ, et al. A focus group on cognition-enhancing medications in Alzheimer disease: disparities between professionals and consumers. *Alzheimer Dis Assoc Disord.* 2001;15(2):80-88.
27. Reeve E, Low L-F, Hilmer SN. 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-e560.
28. Todd A, Holmes H, Pearson S, et al. “I don't think I'd be frightened if the statins went”: a phenomenological qualitative study exploring medicines use in palliative care patients, carers and healthcare professionals. *BMC Palliat Care.* 2016;15:13.
29. Kvale S, Brinkmann S. *InterViews: learning the craft of qualitative research interviewing*, 3rd edn. Los Angeles: Sage Publications; 2015:405.
30. Brinkmann S, Tanggaard L. *[Kvalitative metoder: en grundbog]* In Danish. Kbh.: Hans Reitzel; 2015.
31. Malterud K. Theory and interpretation in qualitative studies from general practice: Why and how? *Scand J Public Health.* 2016;44(2):120-129.
32. Lavery SM. Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *Int J Qual Methods.* 2003;2(3):21-35.
33. Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health.* 2012;40(8):795-805.
34. Giorgi A. The phenomenological movement and research in the human sciences. *Nurs Sci Q.* 2005;18(1):75-82.
35. Turner JP, Edwards S, Stanners M, Shakib S, Bell JS. What factors are important for deprescribing in Australian long-term care facilities? Perspectives of residents and health professionals. *BMJ Open.* 2016;6(3):e009781.
36. Kuntz J, Kouch L, Christian D, Peterson PL, Gruss I. Barriers and facilitators to the deprescribing of nonbenzodiazepine sedative medications among older adults. *Perm J.* 2018;22:17-157.
37. Hughes CM, Goldie R. “I just take what I am given”: adherence and resident involvement in decision making on medicines in nursing homes for older people: a qualitative survey. *Drugs Aging.* 2009;26(6):505-517.
38. Thompson W, Jacobsen IT, Jarbøl DE, Haastrup P, Nielsen JB, Lundby C. Nursing home residents' thoughts on discussing deprescribing of preventive medications. *Drugs Aging.* 2020;37(3):187-192.
39. Lundby C, Graabæk T, Ryg J, Søndergaard J, Pottegård A, Nielsen DS. Health care professionals' attitudes towards deprescribing in older patients with limited life expectancy: a systematic review. *Br J Clin Pharmacol.* 2019;85(5):868-892.

**How to cite this article:** Graabæk T, Lundby C, Ryg J, Søndergaard J, Pottegård A, Nielsen DS. “I simply don't know, because I don't know which drugs I get”: Perspectives on deprescribing among older adults with limited life expectancy and their relatives. *Basic Clin Pharmacol Toxicol.* 2020;00:1–13. <https://doi.org/10.1111/bcpt.13476>

## APPENDIX 1

### Additional information on reporting according to the Consolidated Criteria for Reporting Qualitative Research (COREQ)

#### Domain 1: Research team and reflexivity

##### Personal characteristics

Interviewer/facilitator	Trine Graabæk
Credentials	PhD
Occupation	Pharmacist/Health Services Researcher
Gender	Female
Experience and training	Previously carried out ethnographic research including semi-structured interviews and focus group interviews in both hospital and community settings. Training and feedback on the interviews by DSN, who is an experienced qualitative researcher.

##### Relationship with participants

Relationship established	Initially, TG or DSN contacted the nursing homes by telephone or e-mail to explain about the study. The staff at the nursing homes helped with identification of older adults willing and able to participate in an interview. Relatives were selected by the older adults in the end of the interview. Contact details for the relatives were given from either the resident or the staff after acceptance from the resident. No relationship with the participants existed before the interviews. All participants were informed by TG that participation in the study was voluntary. If a participant had signed the consent form beforehand but did not want to participate on the day of the interview, the participants were free to withdraw their consent. No payment was given for participation.
Participant knowledge of interviewer	The interviewer was presented as a researcher interested in use of medication in older adults and their relatives.
Interviewer characteristics	The interviewer had the presumption that some medications could be inappropriate in older adults and that deprescribing could be a solution to the problem. The interviewer was aware to try not to cause worry among the older adults or their relatives about their medication use, hereby never stating what was wrong and what was right.

#### Domain 2: Study design

##### Theoretical framework

Methodological orientation and theory	We used a hermeneutic-phenomenological approach inspired by Gadamer, where the phenomenology openly seeks experiences of the phenomenon from the perspectives of the participants and the hermeneutic uses the preunderstandings of the researchers to interpret the explored experiences. The analysis was performed by systematic text condensation according to Malterud (see Methods section).
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##### Participant selection

Sampling	Convenience sampling (see Methods section).
Method of approach	Residents were asked for participation by nursing home staff. Relatives were asked for participation by TG either via telephone or in person.
Sample size	19 participants.
Non-participation	Six participants declined to participate, and seven participants dropped out of the study after consent was given (see Methods section).

##### Setting

Setting of data collection	Nursing homes, own homes and Odense University Hospital.
Presence of non-participants	None.
Description of sample	The residents had a median age of 87 y, and the relatives had a median age of 60 y. Of the 19 participants, 11 were female.

##### Data collection

Interview guide	The semi-structured interview guide was developed based on previous literature and consisted mostly of open-ended questions, see Methods section. The interview guide was not piloted.
Repeat interviews	No interviews were repeated.
Audio/visual recording	Interviews were audio-recorded. The transcription was carried out by two research assistants, and the transcripts were checked for accuracy according to the audio records by TG.

Field notes	TG made field notes during the interviews.
Duration	The interviews had a duration of 7-55 min (median 14 min).
Data saturation	Data saturation was not discussed. However, it is presumed that sufficient data were collected to reveal the themes in the analysis.
Transcripts returned	No transcripts were returned to participants for comments.
<b>Domain 3: Analysis and findings</b>	
<b>Data analysis</b>	
Number of data coders	One (TG).
Description of coding tree	Codes were grouped in code groups, which were organized in main themes (see Methods section and Table 1).
Derivation of themes	Themes were derived inductively from the collected data.
Software	NVivo 11 (QSR International, Melbourne, Australia)
Participant checking	Participants did not provide feedback on the findings.
<b>Reporting</b>	
Quotations presented	In order to illustrate the findings, quotations are presented in the paper together with the identification of the participant.
Data and findings consistent	There is consistency between the data presented in the paper and the findings.
Clarity of major themes	Major themes are clearly presented in the paper.
Clarity of minor themes	No minor themes are presented in the paper.

## APPENDIX 2

### Interview guides for older adults and their relatives

#### TOPIC 1: EVERYDAY LIFE

##### Older adults

- How is it to live here at the nursing home? How long have you lived here?
- How is your everyday life?
- Can I ask how old you are?

##### Relatives

- What is your relation to the resident?
- Do you live together with the resident?
- Can I ask how old you are?
- How is your everyday life as a relative? (visit, confidence, worry)
- Are you worried for the resident in general?

#### TOPIC 2: MEDICATION USE

##### Older adults

- How is it to take the medication?
- Who helps you with your medication?
- Do you control the dispensed pills? Do you take all your pills? (prioritizing)

- Who decides which medication you get? (yourself, physician, relative, staff, other)
- Do you get medication from more instances? (general practitioner, hospital, specialist, other)
- Do you think you are involved in decisions about your medication? Would you like to?

##### Relatives

- Are you involved in the resident's medication? (administration, dispensing, control, prescriptions)
- Do you experience problems with the resident's use of medication?
- Do you think the resident experiences problems or mistakes with the medication? (administration, prescriptions, other)
- Who decides which medication the resident gets? Who has the responsibility? Who takes it?
- Does the resident get medication from more instances? (general practitioner, hospital, specialist, other)
- Do you think you are involved in decisions about the resident's medication? Would you like to?

#### TOPIC 3: KNOWLEDGE OF MEDICATION

##### Older adults

- Can you tell me which medication you get?
- Do you know why you get your medication? Would you like to?

- Do you think your medication is effective? In which way?
- Do you think your medication has side effects? In which way?
- Who would you ask, if you get in doubt about your medication?
- How often do you see your physician/go to the hospital?

#### Relatives

- Can you tell me which medications the resident gets?
- Do you know why the resident gets medication? Would you like to?
- Do you think the resident's medication is effective? In which way?
- Do you think the resident experiences side effects? In which way?
- Who would you ask, if you get in doubt about the resident's medication? Do you seek out information?
- Do you have contact with the resident's physician/the hospital?

#### *TOPIC 4: ATTITUDES TOWARDS MEDICATION*

##### Older adults

- How do you look at taking medication? (burden, gift, necessity)
- Does it affect you to take medication in your everyday life? How?
- Do you think you get many pills? Too many?
- Are you satisfied with your medication? All or some?
- What do you have of wishes for your medication?
- Do you think your medication is important?
- Which type of medication do you find most important to take? Less important?
- Would you be willing to take more medication, if the physician recommended it?
- Do you find it expensive to take medication?

##### Relatives

- How do you think the resident looks at taking medication? (prioritizing, burden, gift, necessity)
- Does it affect you that the resident takes medication? How?

- Do you think the resident gets many pills? Too many?
- Are you satisfied with the resident's medication? All or some?
- What do you have of wishes for the resident's medication? (prolonging life, preventive, symptom relief)
- Which type of medication do you find most important for the resident to take? Less important?
- What would you think if the physician recommended the resident to take more medication?
- Do you find it expensive for the resident to take medication?

#### *TOPIC 5: PERSPECTIVES CONCERNING DEPRESCRIBING*

##### Older adults

- How do you feel if your medication is changed?
- Do you think some of your medication is unnecessary? No longer effective?
- Which thoughts would you have if the physician suggests stopping some medication? (giving up hope, confused by changes, afraid of losing effect)
- Would you be willing to try stopping some medication? As a trial? To reduce dose?
- What could make you willing to try?
- Have you ever tried that the physician has suggested reduction of your medication? How was that?

##### Relatives

- How do you feel about changes in the resident's medication?
- Do you feel competent to talk to the physician about use of medication? In which way?
- Do you think some of the resident's medication is unnecessary? No longer effective?
- Which thoughts would you have if the physician suggests stopping some of the resident's medication? (giving up hope, confused by changes, afraid of losing effect, secure)
- Would you support it, if the resident should try stopping some medication? As a trial? To reduce dose?
- What could make you support stopping some of the resident's medication? Which kind of medication?
- Have you ever tried that the physician has suggested reduction of the resident's medication? How was that?

## APPENDIX 3

### Characteristics of the participants

Participant	Age	Gender	Interviewer/ moderator	Duration of interview (minutes)	Place for interview	Time living in nursing home	Number of medications prescribed <sup>a</sup>	Number of tablets per day
Resident 1	96	Female	TG/CL	11	Nursing home	0-6 mo	4	5
Resident 2	88	Female	TG/CL	12	Nursing home	≥5 y	5	3
Resident 3	87	Female	TG/CL	11	Nursing home	0-6 mo	12	12
Resident 4	77	Male	TG/CL	10	Nursing home	1-2 y	9	16
Resident 5	72	Male	TG/none	28	Nursing home	1-2 y	9	20
Resident 6	89	Female	TG/none	17	Nursing home	1-2 y	10	17
Resident 7	86	Female	TG/none	20	Nursing home	1-2 y	15	25
Resident 8	87	Female	TG/none	13	Nursing home	1-2 y	12	13
Resident 9	74	Male	TG/none	12	Nursing home	≥5 y	11	31
Resident 10	83	Male	TG/none	12	Nursing home	0-6 mo	12	15

Participant	Age	Gender	Interviewer/ moderator	Duration of interview (min)	Place for interview	Relation to the resident
Relative 1	70	Female	TG/CL	7	Nursing home	Daughter of Resident 1
Relative 2a <sup>b</sup>	60	Male	TG/none	41	Hospital	Son of Resident 2
Relative 2b <sup>b</sup>	55	Female	TG/none	41	Hospital	Daughter in law of Resident 2
Relative 4	45	Female	TG/none	55	Own home	Daughter of Resident 4
Relative 5	45	Male	TG/none	28	Own home	Son of Resident 5
Relative 7	63	Female	TG/none	34	Hospital	Daughter of Resident 7
Relative 8	68	Male	TG/none	38	Own home	Son of Resident 8
Relative 9	45	Male	TG/none	15	Own home	Son of Resident 9
Relative 10	82	Female	TG/none	9	Nursing home	Wife to Resident 10

Mo, months; y, years.<sup>a</sup> Medications prescribed cover all medication forms of regular medication and as needed medication.

<sup>b</sup> Relative 2a and 2b were interviewed together.