



Attitudes Towards Deprescribing Among Older Adults with Limited Life Expectancy and Their Relatives: A Systematic Review

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Abstract

Background Deprescribing is of particular importance in older adults with limited life expectancy since this population group is highly susceptible to the potential harms of inappropriate medications.

Objective This systematic review aimed to explore attitudes towards deprescribing among older adults with limited life expectancy and their relatives.

Methods A systematic literature review was conducted in the MEDLINE and EMBASE databases from inception to October 2019. Inclusion criteria were studies specifically describing attitudes towards deprescribing among older adults (≥ 65 years) with limited life expectancy and/or their relatives regardless of study type. Results were analyzed, inspired by the Joanna Briggs Institute's method for synthesis of qualitative data.

Results A total of 842 studies were identified and screened; 84 were full-text assessed for eligibility and 7 were ultimately included. Two studies investigated the attitudes of older adults with limited life expectancy and their relatives towards deprescribing of statins and donepezil, respectively, while the five remaining studies related to attitudes towards deprescribing in general. Four main themes were identified: (1) the well-being of older adults with limited life expectancy; (2) involvement of older adults and their relatives in deprescribing; (3) the role of health care professionals in deprescribing; and (4) medication-related factors affecting deprescribing. Within each of these themes, several subthemes were identified.

Conclusions Attitudes towards deprescribing among older adults with limited life expectancy and their relatives vary and highlight several barriers and enablers to the deprescribing process. Several of these factors must be addressed to successfully implement deprescribing initiatives in this patient group.

Key Points

The perceived risks and benefits of taking specific medications change when older adults reach the end of life.

Older adults with limited life expectancy want a discussion regarding the reasons and risks and benefits of deprescribing before making a decision.

Inadequate communication and cooperation between the different specialist health care providers can be a barrier to deprescribing.

Older adults and their relatives have unquestionable trust in their GP and their medication management.

1 Introduction

Older patients often receive potentially inappropriate medication, defined as medications where the potential risks associated with their use outweigh the potential benefits [1]. Furthermore, older adults have a significantly higher risk of developing adverse drug events [2] due to, for example, physiological changes, multiple comorbidities, age-related changes in pharmacodynamics and pharmacokinetics, and an increase in frailty [3]. Observational studies have found that adverse drug events occur in at least 15% of older patients [4], contributing to ill health [5], hospitalization [6], and increased mortality [7].

Deprescribing, defined as the planned process of dose reduction or discontinuation of a medication, supervised by a health care professional, with the goal of managing polypharmacy and improving outcomes [9], has been proposed as an approach to target inappropriate medication use [8].

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There is increasing interest in the discontinuation of unnecessary and inappropriate medications in people with limited life expectancy [1, 10], as treatment in this population should ultimately focus on improving functional level and quality of life [11]. A review on the attitudes of health care professionals about deprescribing showed that health care professionals find several factors important when considering deprescribing in this patient group, e.g. the importance of teamwork and the involvement of patients and their relatives [12]. Consequently, it is important to consider attitudes regarding medication use and deprescribing of older adults with limited life expectancy and their relatives, as the risk-to-benefit ratio of medications can change when the goal of the patient's care shifts from a curative to a palliative focus [13].

Reviews on the attitudes of adults in general, older adults, and relatives towards deprescribing have reported on attitudes towards the process of deprescribing [1, 13–16]. However, these reviews do not specifically consider the attitudes of older adults with limited life expectancy, i.e. approximately 1–2 years, and their relatives; it is important to explore the attitudes of this population group and their relatives in order to facilitate meaningful and successful deprescribing initiatives in clinical practice. Thus, in this review, we aimed to summarize existing literature on attitudes towards deprescribing among older adults with limited life expectancy and their relatives.

2 Methods

We performed a systematic review guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [14]. First, we conducted a broad search for this review and two other reviews [12, 15] in December 2017. Based on the central studies we found in that search, we conducted a more specific search for this review. The new search was conducted in the MEDLINE (via Ovid SP) and EMBASE (via Ovid SP) databases from inception to October 2019. The searches were conducted combining keywords for intervention (deprescribing) and population (older people with limited life expectancy). Additionally, three reviews were reviewed for relevant studies [1, 16, 17]. The search strategy is provided in full in Appendix 1.

2.1 Inclusion and Exclusion Criteria

The inclusion criteria for studies were (1) original research; (2) studies published in English; and (3) research on attitudes towards deprescribing among older adults with limited life expectancy and their relatives. As there is no clear definition of when an older adult is considered to be in their last years

of life, it was initially decided to include studies regarding older adults who resided in any kind of aged care facility, e.g. residential care or nursing home, or had a clinical status from which they could be expected to have a limited life expectancy. The exclusion criteria for studies were (1) studies including a majority of participants aged < 65 years; and (2) studies with participants not considered to have a limited life expectancy of 1–2 years.

2.2 Selection, Extraction, and Analysis

All titles and abstracts for potentially eligible studies were independently screened by two authors (CL, TG) using Covidence as the screening tool [18]. Disagreements were resolved through consensus. Hereafter, the two authors procured full-text articles for all studies that appeared to be eligible, or where eligibility could not be adequately judged based on title and abstract. The two authors then independently performed a screening of all full-text articles for eligibility, and disagreements were again resolved through consensus. Finally, all authors went through all studies that the initial assessors found eligible to decide on ultimate inclusion or exclusion.

Two authors (AB, TG) independently extracted the following information from the included studies: study details, aims, participants, methods, and main study findings (i.e. older adults' and their relatives' attitudes towards deprescribing). Disagreements on content were resolved through consensus. Results of all studies, regardless of the data collection method, were analyzed, with inspiration from the Joanna Briggs Institute's method for synthesis of qualitative data in systematic reviews [19]. Main findings from the studies were summarized and then divided into different categories, using the NVivo 11 software program [20]. These categories and their content were subsequently synthesized into themes. Attitudes towards deprescribing among older adults with limited life expectancy and their relatives were extracted from all studies, regardless of the data collection method. The extracted and analyzed data from the questionnaire and nominal group technique studies included the qualitatively derived themes about the attitudes of older adults with limited life expectancy and their relatives.

2.3 Reporting Assessment

Two authors (AB, TG) assessed the reporting of the included studies using the Standards for Reporting Qualitative Research (SRQR), a 21-item list of recommendations for reporting of qualitative studies, including questionnaires [21]. All included studies, both qualitative and quantitative, were assessed using SRQR. This assessment was not used to exclude studies, but rather it was used to transparently highlight how the findings were reported by the authors.

3 Results

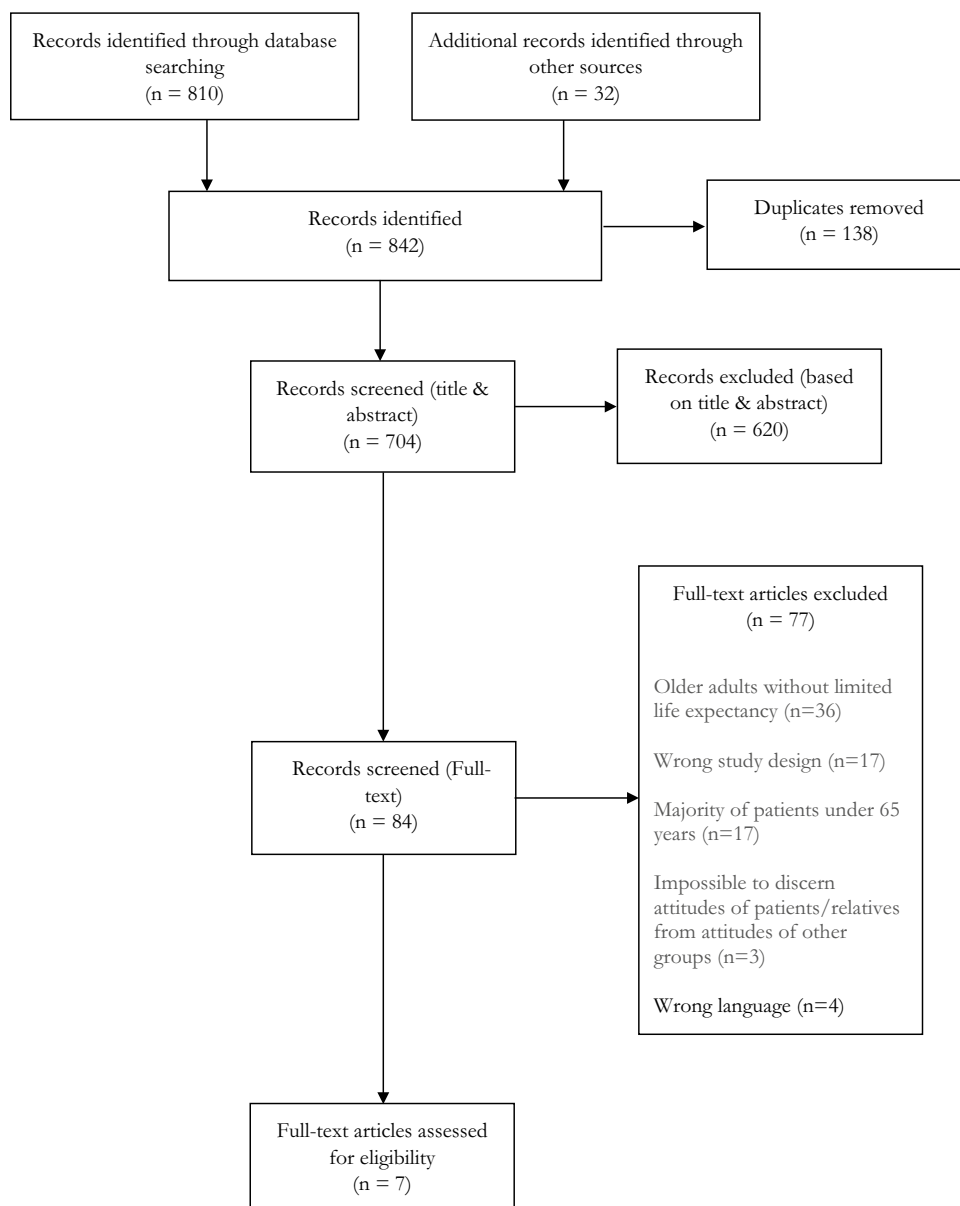
The flow of the study selection is presented in Fig. 1. The literature search yielded 842 references, ultimately leaving 7 studies for inclusion [13, 22–27].

Attitudes towards deprescribing among older adults with limited life expectancy and their relatives were explored via questionnaires [13, 22], focus group interviews [23, 25, 26], in-depth interviews [27], and the nominal group technique [24]. Four studies related to older adults residing in some type of aged care facility, i.e. residential aged care facilities [13, 23] and long-term care facilities [24, 25], while three studies did not specify the type of residence the participants lived in [22, 26, 27]. Two of the studies focused on the use

of specific drug groups, namely statins [22] and donepezil [26], while the remaining five studies explored the use of multiple medications.

Characteristics and main findings of the studies are presented in Table 1. A full account of our findings is presented in Appendix 2. The majority of the studies reported most of the criteria in the SRQR; however, three studies did not mention their rationale for choosing the data collection method, while three other studies did not mention the dates of the data collection period. None of the included studies reported researcher characteristics and reflexivity. Furthermore, five items in the SRQR were not applicable for two of the included studies [13, 22]. The assessment of reporting is presented in Table 2.

Fig. 1 Flow chart of study selection process



3.1 Attitudes of Older Adults with Limited Life Expectancy and Their Relatives

Four main themes regarding the attitudes of older adults and their relatives towards deprescribing emerged in the analysis: (1) the well-being of older adults with limited life expectancy; (2) involvement of older adults and their relatives in deprescribing; (3) the role of health care professionals in deprescribing; and (4) medication factors regarding deprescribing. The factors that made up these themes are illustrated in Fig. 2.

3.1.1 The Well-Being of Older Adults with Limited Life Expectancy

3.1.1.1 Medication Burden Administration of medication was mentioned as part of the daily routine by older adults with limited life expectancy and their relatives [27]. Many older adults with limited life expectancy felt they took a large number of medications [13, 25], however many reported being comfortable with the number of medications they took, and that they would accept taking more medications for their health conditions [13]. Older adults and their relatives found medication administration to be inconvenient [23], and many older adults perceived medication as burdensome. This could act as an enabler for deprescribing [24, 27]. The burden of administering medication included swallowing large tablets, the taste of crushed medications, and use of devices such as inhalers, injections, and eye drops [24].

3.1.1.2 Quality of Life Many older adults did not think that discontinuation of their medication would result in a better quality of life [22], and they, along with their representatives, ranked ‘well-being of the resident’ as the most important factor regarding deprescribing, including the right to continue medications that made them feel well [24].

3.1.1.3 Hope and Fear for the Future Hope for [26] and fear of missing out on [23] future benefits of the medication made some older adults and their relatives reluctant to discontinue medications despite the lack of effect [26]. Some older adults were not concerned with the future adverse effects of their medication because they thought there was not much future to consider [23]. Furthermore, the perceived risks and benefits of taking specific medications changed when the older adult accepted a life-limiting condition; some medications were more important than others [27]. These values and beliefs varied between types of medication.

3.1.2 Involvement of Older Adults and Their Relatives in Deprescribing

3.1.2.1 Desire and Willingness to Deprescribe Some older adults with limited life expectancy reported a desire to reduce their number of medications, and a larger number were willing to cease one or more of their medications if their doctor told them it was possible [13]. It seemed to increase the willingness to undergo deprescribing among older adults with limited life expectancy to start weaning off medications, one medication at a time [23]. Caregivers welcomed deprescribing initiatives if the benefits and risks were clearly explained [27].

3.1.2.2 Discussing Deprescribing with Health Care Professionals Patients expressed a desire to have a discussion about the reasons and effects of deprescribing before making a decision on reducing their number of medications [23]. The patients wanted an explanation of the reason for medication cessation, what the benefits of medication cessation were, and what effects this decision would have afterwards. Older adults with limited life expectancy and their relatives ranked the factor ‘well-being of resident’ as the most important factor regarding deprescribing [24]. This included the right to question the general practitioner (GP) about medications. Additionally, older adults with limited life expectancy expected the GP to inform them on monitoring and follow-up after deprescribing of medication [23]. Finally, older adults with limited life expectancy also mentioned that unfamiliar nursing staff who do not know their medical, social, and medication history could lead to their voices not being heard, which they considered a barrier for deprescribing [24].

3.1.2.3 Making Decisions for Others A relatives-only theme that emerged [23, 26] was ‘making decisions for others’. Relatives of older adults with limited life expectancy found it to be an important factor when considering deprescribing. Furthermore, they thought it was important that all family members were in agreement with medication withdrawal in end-of-life care [23]. Relatives experienced making decisions for older adults with limited life expectancy being a source of frustration for wanting to help, or a source of guilt if something went wrong after making the decision [26].

Furthermore, the relatives made decisions regarding continuation and discontinuation of medication without involving the doctor, despite their wish to have a dialog with the doctor. There were difficulties in communicating with the doctor, as the contact usually took place through the nurse [26].

Table 1 Characteristics for the included seven studies as presented in the individual papers

Study details (first author, publication year; country)	Aim	Methods	Setting	Participants	Main findings
Kalogianis, 2016; Australia [13]	To investigate residents' willingness to have their medications deprescribed	Cross-sectional study Participants completed the 10-item PATD questionnaire	Residential Aged Care Facilities	232 residents (mean age 87 years) completed the questionnaire 163 of the 232 residents (70.3%) took nine or more regular medications (polyp-harmacy) The mean number of medications taken (regular and as required) was 14.6 ± 5.3	A majority of older adults with limited life expectancy felt they were comfortable with the number of medications they were taking. Half of the older adults with limited life expectancy who took nine or more regular medications felt they took a large number of medications; however, about half of the older adults with limited life expectancy would accept taking more medications for their health conditions Many older adults with limited life expectancy believed all their medications were necessary; however, some felt they might be taking one or more medications they no longer needed Many older adults with limited life expectancy reported they had a good understanding of the indications for their medications and expressed a desire to reduce the number of their medications. A majority reported willingness to cease one or more of their medications if their doctor said that it was possible Older adults with limited life expectancy taking nine or more medications were more likely to feel they were taking a large number of medications compared with participants taking fewer than nine medications. Additionally, participants taking nine or more medications were more likely to believe they experienced adverse effects from their medications
Tjia, 2017; USA [22]	To describe the perceived risk, benefits, and concerns with statin discontinuation among patients with life-limiting illness	Participants answered a questionnaire that included nine questions regarding their perceptions about discontinuing statins	Ten academic medical centers and five community-based hospice/palliative care organizations	297 participants with a life-limiting illness and a life expectancy of 1–12 months. Mean age was 72 years and the mean number of medications was 11.5	Most older adults with limited life expectancy were not told they were to take their medications for the rest of their life. Furthermore, a majority of older adults with limited life expectancy did not think that discontinuing their statin meant that previous efforts were wasted or that they would experience additional problems if they stopped using statins Many older adults did not think that discontinuing statin treatment would result in fewer symptoms and in a better quality of life A vast majority of participants disagreed with the statement that discontinuation of statin treatment meant their doctor had given up on them, and that their doctor thought they were about to die

Table 1 (continued)

Study details (first author, publication year; country)	Aim	Methods	Setting	Participants	Main findings
Palagyi, 2016; Australia [25]	To explore perceptions of medication use and the concept of deprescribing in Long-term Care Facilities (LTCFs)	Ten focus group interviews were conducted with residents ($n = 25$), relatives ($n = 16$), and health care professionals ($n = 27$) from three LTCFs. Semi-structured interviews were conducted with four pharmacists. Thematic analysis was conducted on the transcripts from the audiotaped interviews	LTCFs	25 participating residents from three different LTCFs had a mean age of 89, 84, and 90 years, respectively (range 75–100). The average number of daily medications for participants was 8, 9, and 5, respectively (range 2–20)	Older adults with limited life expectancy have continued taking medications for conditions that have subsided. Most older adults and their relatives knew the number of medications they took daily, but rarely had knowledge about their medication, e.g. indications Older adults with limited life expectancy and their relatives displayed complete trust in the decisions made by their GP Older adults with limited life expectancy frequently complained about the large number of daily medications; however, a number expressed fear at the idea of reducing or ceasing some of their medications Relatives of older adults with limited life expectancy were concerned by the shortage of resources, e.g. registered nurses, which could result in fewer opportunities for medication reviews
Turner, 2016; Australia [24]	To rank factors GPs, nurses, pharmacists, and residents perceive as most important when deciding whether to deprescribe	Groups of residents/representatives, GPs, nurses, and pharmacists were convened and, using the nominal group technique, they ranked factors perceived to be most important when deprescribing. The prioritized factors from each group were then discussed and prioritized by a multidisciplinary metropolitan and regional group of resident representatives, GPs, nurses, and pharmacists	LTCFs	11 residents (median age 70–79 years) and their representatives	Top 7 ranking of important factors to deprescribing according to older adults with limited life expectancy and their representatives (1) Well-being of the resident (2) Continuity of nursing staff (3) Feeling of wellness due to medication (4) Burden of medication administration (5) Residents have the right to question their GP (6) Voice of the resident is not heard (7) Respect the GP and do as I'm told

Table 1 (continued)

Study details (first author, publication year; country)	Aim	Methods	Setting	Participants	Main findings
Reeve, 2016; Australia [23]	To explore the views, beliefs, and attitudes of older adults and carers on deprescribing	Qualitative focus group study The results were analyzed using a previously developed framework (directed content analysis) with additional conventional content analysis	Residential aged care facilities and retirement village	3 older adults [mean age 79.0 years (SD ± 1.0), mean number of medications 5.3 (SD ± 4.0)] and 6 carers [mean age of the care recipient 85.2 years (SD ± 5.7), mean number of medications of self or care recipient 3.4 (SD ± 1.5)]	Enablers and barriers to the deprescribing process were identified within six themes: (1) Appropriateness of deprescribing (2) Process (3) Influences on willingness to have medications deprescribed (4) Fear as a barrier to having medications deprescribed (5) Dislike of medications (6) Making decisions for others
Post, 2001; USA [26]	To gain qualitative insights into therapeutic goals and efficacy of cognition-enhancing medications in AD, and into hypothesized disparities between consumer and professional viewpoints	Focus group interviews	The Cleveland Area Chapter of the Alzheimer's Association	Three focus groups were conducted: 1) Mild AD: 3 patients + 4 caregivers 2) Moderate AD: 5 caregivers 3) Moderate and advanced AD : 5 caregivers A group of 20 professionals participated in all three focus group interviews	Caregivers of older adults with limited life expectancy reported different experiences regarding the effect of donepezil. Some caregivers took their relatives off donepezil, with or without the involvement of the doctor, because of adverse effects, futility, costs, or giving the patients confidence to do things they are not capable of doing safely Some caregivers did not want to discontinue donepezil despite seeing no effect of the medication, as long as the older adult did not experience adverse effects Caregivers made decisions regarding continuation and discontinuation of the medications without involving the doctor. Sometimes caregivers wanted to have a dialog with the doctor about the medication but refrained from that because the contact with the doctor usually takes place through the nurse

Table 1 (continued)

Study details (first author, publication year; country)	Aim	Methods	Setting	Participants	Main findings
Todd, 2016; UK [27]	To explore the lived experience of patients, carers, and health care professionals in the context of medication use in life-limiting illness	In-depth interviews using a transcendental phenomenological approach were used to explore the 'lived experiences' of medication use	Day care center at a specialist palliative care unit	12 patients with a life-limiting illness attending a day care center at a specialist palliative care unit. The average life expectancy was 18 months. Carers (family members of the patients)	<p>The majority of older adults with limited life expectancy and their relatives often referred to organizing and taking medication as part of the daily routine; however, the majority of these adults lacked knowledge of their medications, while the relatives had a good understanding of the medications</p> <p>The majority of patients described experiencing adverse events from taking their medications</p> <p>Older adults with limited life expectancy felt that the perceived risk and benefit of taking specific medications changed over time depending on the course of the disease and the types of medication</p> <p>Older adults with limited life expectancy were not concerned with the type of medications they took as much as being overwhelmed by the volume of it</p> <p>Carers welcomed deprescribing approaches if the risks and benefits were clearly explained and that it was done for the benefit of the patient. All participants had experiences with deprescribing</p> <p>There was a mismatch of expectations between health care professional, patient and carer, when the prescriber doctor stated that this medication should be taken for the rest of their lives, while another doctor talked of deprescribing that same medication</p>

PATD Patients' Attitude Towards Deprescribing, *LTCFs* long-term care facilities, *GP* general practitioner, *SD* standard deviation, *AD* Alzheimer's disease

^aIn this review, we only present results from the focus groups of residents and relatives. Results from the focus groups of health care professionals are presented in a separate review by Lundby et al. [12]

Table 2 Assessment of the included studies according to Standards for Reporting Qualitative Research (SRQR) [19]

Topic	Number of studies meeting the criterion	Studies meeting the criterion	Criterion not applicable
S1: Title	4	[21, 23, 24, 25]	
S2: Abstract	7	[12, 20, 21, 22, 23, 24, 25]	
S3: Problem formulation	6	[12, 20, 21, 22, 23, 25]	
S4: Purpose or research question	7	[12, 20, 21, 22, 23, 24, 25]	
S5: Qualitative approach and research paradigm	3	[21, 23, 25]	[12, 20]
S6: Researcher characteristics and reflexivity	0		[12, 20]
S7: Context	4	[12, 21, 23, 25]	
S8: Sampling strategy	6	[20, 21, 22, 23, 24, 25]	
S9: Ethical issues pertaining to human subjects	6	[12, 20, 21]—minus consent, [22, 23, 25]	
S10: Data collection methods	7	[12]—minus rationale, [20]—minus rationale, [21]—minus dates, [22]—minus dates, [23, 24]—minus rationale, [25]—minus dates	
S11: Data collection instruments and technologies	7	[12, 20, 21, 22, 23, 24, 25]	
S12: Units of study	7	[12, 20, 21, 22, 23, 24, 25]	
S13: Data processing	4	[21, 23, 24, 25]	[12, 20]
S14: Data analysis	6	[12, 20]—minus rationale, [21, 23, 24]—minus rationale, [25]	
S15: Techniques to enhance trustworthiness	2	[22, 23]	[12, 20]
S16: Synthesis and interpretation	7	[12, 20, 21, 22, 23, 24, 25]	
S17: Links to empirical data	4	[21, 23, 24, 25]	[12, 20]
S18: Integration with prior work, implications, transferability, and contributions to the field	6	[12, 20, 21, 22, 23, 25]	
S19: Limitations	7	[12, 20, 21, 22, 23, 24, 25]	
S20: Conflicts of interest	6	[12, 20, 21, 22, 23, 25]	
S21: Funding	6	[12, 20, 21, 22, 23, 24]	

3.1.3 Role of Health Care Professionals in Deprescribing

3.1.3.1 Shortage of Resources Lack of resources, e.g. registered nurses, was a concern for relatives of older adults with limited life expectancy. This placed a high taskload on staff in long-term care facilities, which could result in a lack of time and opportunities to observe the need for changes in or reviews of the medication [25]. According to the older adults, lack of medication reviews after initiating pharmacological treatment for either an acute or circumstance-related condition, i.e. antibiotics, antihistamines, or antidepressants, had resulted in continued treatment for months after their condition had subsided [25]. Furthermore, one relative thought it unlikely for the GP to be the one to recommend deprescribing initiatives because they spend too little time with the patient in a residential aged care facility [23].

3.1.3.2 Health Care Professional Cooperation Inadequate communication and cooperation between the different specialist health care providers was thought to hinder deprescribing in older adults with limited life expectancy [23, 25]. The role of nurses and pharmacists was briefly men-

tioned by older adults and their relatives, which was limited to only giving recommendations to the GP [23].

3.1.4 Medication-Related Factors Affecting Deprescribing

3.1.4.1 Knowledge of Medication Some older adults reported to have a good understanding of the reasons for which they were taking their medications [13], while most appeared to have little to no knowledge of the indications of their medication and medication-related adverse events [25, 27]. Some relatives showed good understanding of the indications of the medication [27], while others did not [25]. Older adults with limited life expectancy and their relatives who had prior experience with medication-related incidents had more knowledge of adverse drug events [25].

3.1.4.2 Effect and Adverse Effects The experience of effect and adverse effects played a role in the attitudes towards deprescribing of older adults with limited life expectancy and their relatives. Some older adults experienced effects of their medication, while others did not [26]. The experience of effect from taking a medication seemed to act as a barrier

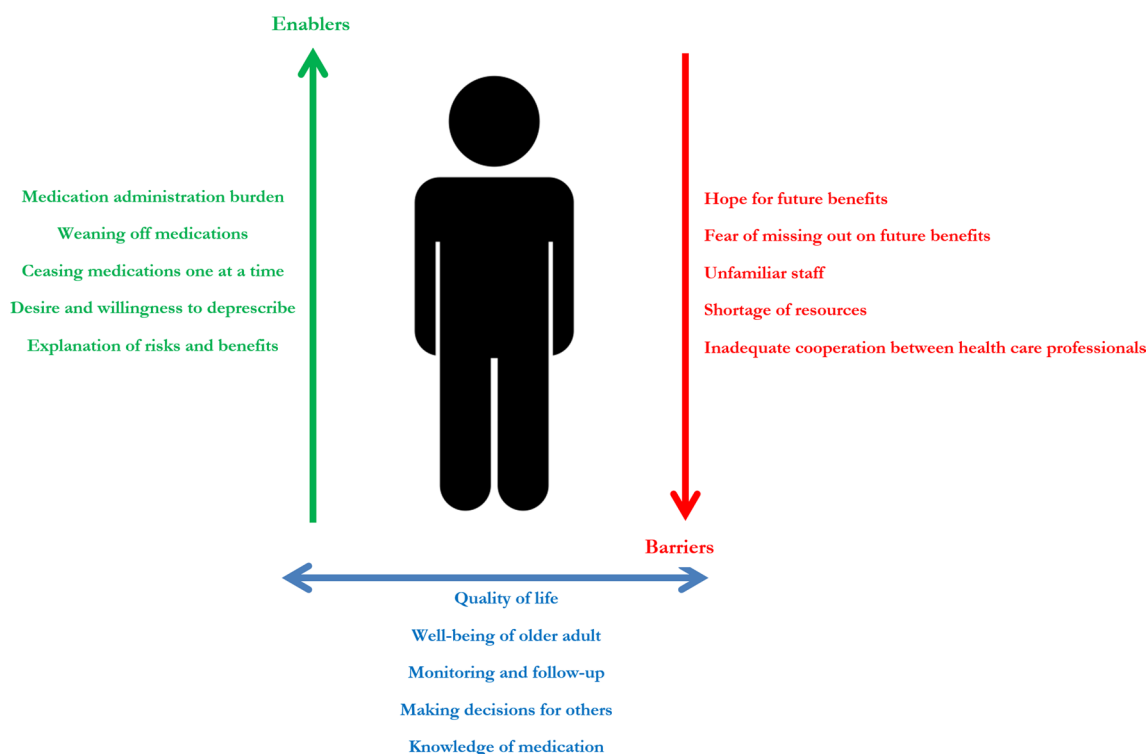


Fig. 2 Factors that act as enablers and barriers in deprescribing in older adults with limited life expectancy

to deprescribing, as the older adults and their relatives perceived that continuation with medications that made them feel well was part of the well-being of the older adult [24]. Some relatives who thought that the older adult experienced an effect of a medication, even temporarily, were reluctant to discontinue the medication despite the doctor stating a lack of effect [26].

Lack of effect of a medication could act as an enabler for deprescribing, as some older adults with limited life expectancy and their relatives felt that the treatment was futile and thus unnecessary [23, 26]. However, this was not always an enabler to deprescribing if relatives thought that taking the medication could not hurt [26]. Older adults with limited life expectancy did not think that discontinuing a medication would result in additional problems or that previous efforts were wasted [22].

Adverse effects were common among older adults with limited life expectancy, particularly in polypharmacy patients [13, 27]. Experiencing adverse effects, e.g. adverse effects and/or interactions, was found to act as an enabler for deprescribing [23, 26], whereas the absence of adverse events [23, 24, 26] and fear of withdrawal reactions [23] made older adults and their relatives reluctant to start deprescribing.

3.1.4.3 Indication Patients generally believed that all their medications were necessary and that they did not take medications they no longer needed [13]. However, if patients believed their medication was no longer necessary, that could act as an enabler to deprescribing [23]. Some patients experienced continuing medication they were prescribed for conditions that had subsided [25]. Many older adults with limited life expectancy reported they were not told they had to take their medication for the rest of their lives [22], while others were confused by suggestions of deprescribing of medications they were previously told were lifelong treatments [27].

3.1.4.4 Trust in Health Care Professionals Older adults and their relatives had complete trust in their GP and their decisions regarding medication management, and that their decisions were not to be questioned. This could result in a display of apathy from older adults and their relatives towards medication [25]. Many patients showed a lack of knowledge about the indications for which they were prescribed their medications, and the particular types of medications, because they had complete trust in health care professionals [27]. Some patients thought that respecting the GP and doing as they are told are important factors when it comes to deprescribing [24].

4 Discussion

In this systematic review, we identified four main themes relating to the attitudes of older adults with limited life expectancy and their relatives towards deprescribing: (1) the well-being of older adults with limited life expectancy; (2) involvement of older adults and their relatives in deprescribing; (3) the role of health care professionals in deprescribing; and (4) medication-related factors affecting deprescribing. Our findings suggest that the attitudes towards deprescribing among older adults with limited life expectancy and their relatives vary and are dependent on various factors that could act as either barriers or enablers to the deprescribing process.

4.1 Comparison with Existing Literature

Several studies have examined attitudes towards deprescribing among adults [1, 28], older adults [17, 29, 30], and people with a life-limiting disease [16]. However, as several factors might complicate the process of deprescribing in older adults, e.g. frailty, multimorbidity, and limited life expectancy, we chose to focus on the attitudes of older adults with limited life expectancy and their relatives towards deprescribing. To our knowledge, this is the first systematic review to explore this.

Similar to our findings, two studies [1, 28] reported the importance of several factors within three of the four themes identified in this review, e.g. hope for future benefits of the medication, fear of adverse effects, and the well-being of the older adult, and how deprescribing on a trial-only basis might increase willingness to deprescribing.

Two other studies [17, 29] reported findings similar to the findings in this review, and cited, apart from the subthemes that were also found in the abovementioned studies [1, 28], trust in health care professionals, health care professional cooperation, involvement in the deprescribing process, and medication burden as important factors when considering deprescribing.

Furthermore, a narrative review exploring barriers to optimizing deprescribing in older adults with dementia [30] argued that one of the patient-related barriers was the difficulties they experienced in prioritizing treatment options, and, in accordance with our findings, that treatment goals change over time. Furthermore, the study identified a handful of competing barriers and enablers, e.g. feeling that the medication is still necessary and the lack of effectiveness. These barriers and enablers are in agreement with our findings. The study also mentioned, in accordance with our findings, the subtheme ‘making decisions for others’, citing that carers face a significant burden in decision making regarding deprescribing, and feelings of responsibility and guilt related

to the impression of ‘giving up’ may result, which is also in accordance with our findings.

Finally, a systematic review exploring barriers and enablers to deprescribing in people with a life-limiting disease found, in concordance with our findings, that a shortage of staff in nursing homes was a barrier to the deprescribing process [16].

The findings of this review are, overall, in accordance with the abovementioned studies regarding deprescribing. The same themes apply to the attitudes towards deprescribing among older adults with limited life expectancy and their relatives. However, our findings suggest that deprescribing in older adults with limited life expectancy is further complicated by a shortage of resources in long-term care facilities. We found that relatives of older adults with limited life expectancy expressed worry because of a lack of resources, e.g. registered nurses, which is specific to older adults with limited life expectancy and people with life-limiting disease, many of whom reside in some type of care facility and depend on the resources of health care professionals at the facility.

4.2 Strengths and Limitations

The main strength of this review is that at least two authors conducted the screening of articles, data extraction, data analysis, and quality assessment, and that the final study selection was discussed among all authors. Furthermore, the analysis was performed systematically using an established method for synthesizing qualitative data in systematic reviews [19]. Finally, the completeness of reporting in all included studies was assessed according to the SRQR [21] to ensure a critical examination and general impression of the quality of each study.

This review has limitations that should be acknowledged. First, the inclusion of studies was restricted to studies in English, which may have excluded relevant literature. Second, the included studies did not all list deprescribing as their main objective, but, in all included studies, deprescribing figured as an element. Therefore, the findings of these studies may not be exhaustive on the attitudes of older adults with limited life expectancy and their relatives towards deprescribing. Third, the definition of older adults with limited life expectancy, which we used in this review, may be associated with some uncertainty, as there is no clear definition of the point where an older adult is at the end of life [31–33]. Therefore, each included study was assessed individually by every author in the author group. Finally, we decided to include all study types as there were not many qualitative studies on the subject, and analyzed them with inspiration from a method for synthesis of qualitative data. However, the data extracted from studies using the nominal

group technique and questionnaires was not as rich as the data extracted from studies using interviews.

4.3 Implications for Practice

The findings of this review indicate that several factors could hinder deprescribing in older adults with limited life expectancy, which should thereby be addressed. First, older adults with limited life expectancy and their relatives must be supported in expressing their preferences when it comes to deprescribing, and be better informed about the option of deprescribing, so that they are better equipped to engage in shared decision making regarding deprescribing. Second, it is important to support relatives of older adults with limited life expectancy, specifically relatives of patients with cognitive impairment, in making decisions regarding deprescribing for their family members. Third, the shortage of resources in residential care facilities needs to be addressed when it comes to discovering the need for reviews in older adults' medications. Last, it is vital to engage in initiatives that aim at strengthening health care professional cooperation regarding deprescribing, as this would facilitate the provision of a more seamless health care for older adults with limited life expectancy.

5 Conclusions

The findings of this systematic review suggest that attitudes towards deprescribing among older adults with limited life expectancy and their relatives vary and cover barriers and enablers to deprescribing. Therefore, implementation of deprescribing initiatives within this patient group should take into consideration several of the identified issues in this review. Finally, research regarding deprescribing in older adults with limited life expectancy is scarce, which calls for more research on deprescribing in this specific patient group.

Author contributions The initial study idea was proposed by Anton Pottegård and the study was designed by all authors. Screening was performed by Carina Lundby and Alaa Burghle, and data extraction was performed by Alaa Burghle and Trine Graabæk. Final study selection was decided by all authors. Data analysis was performed by Alaa Burghle and Trine Graabæk. Alaa Burghle wrote the initial draft, and all authors participated in writing and revising the article, and read and approve the final version.

Compliance with Ethical Standards

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Conflict of interest Alaa Burghle, Carina Lundby, Jesper Ryg, Jens Søndergaard, Anton Pottegård, Dorthe Nielsen, and Trine Graabæk have no conflicts of interest to declare.

Appendix 1: Search Strategy

The electronic databases MEDLINE (via Ovid SP) and EMBASE (via Ovid SP) were searched from inception to October 2019. The searches were conducted combining keywords for population (older people with limited life expectancy) and intervention (deprescribing). The following search string was used:

(frail OR elderly OR old OR older OR end of life OR eol OR lifelimiting illness) AND (deprescribe OR deprescribing OR deprescription OR medication cessation OR medication withdrawal OR medication discontinuation OR inappropriate prescribing OR inappropriate prescribings OR inappropriate medication OR inappropriate medications OR unnecessary prescription OR unnecessary prescriptions OR unnecessary medication OR unnecessary medications) AND (attitudes OR perspectives OR perceptions OR enabler OR enablers OR barrier OR barriers OR belief OR beliefs). The searches were only restricted by filters for conference abstracts.

Appendix 2

Study details (first author, publication year, country, reference number)	All findings	Categories
Kalogianis, 2016, Australia [12]	<p>Half of the participants felt that they were taking a large number of medications</p> <p>A majority of participants answered that they were comfortable with the number of medications that they were taking</p> <p>Many of the participants believed that all their medications were necessary</p> <p>Many participants reported a desire to reduce the number of their medications, and even more reported willingness to cease one or more of their medications, if their doctor said that it was possible</p> <p>Some participants felt that they may be taking one or more medications that they no longer needed</p> <p>About half of the participants would accept taking more medications for their health conditions. Many reported that they had a good understanding of the reasons for which they were prescribed their medications</p> <p>Participants taking ≥ 9 medications were more likely to feel that they were taking a large number of medications compared to participants taking < 9 medications. Additionally, participants taking ≥ 9 medications were more likely to believe they experience side effects from their medications</p> <p>Some of the participants stated that having to pay less for their medication would play a role in their willingness to stop one or more of their medications</p>	<p>Effects and adverse effects</p> <p>Indication</p> <p>Knowledge of medication</p> <p>Medication burden</p> <p>Desire and willingness to reduce medication</p> <p>Cost</p>
Tjia, 2017, USA [31]	<p>Many participants disagreed with the statement that they have been previously told that they should never discontinue their medication</p> <p>Many participants did not agree with the statement that discontinuing their statin medications meant that their previous efforts were wasted</p> <p>Many participants in the study did not think that they would experience additional problems if they stopped using statins</p> <p>Many participants did not think that discontinuing statin treatment would result in fewer symptoms or in a better quality of life</p> <p>Many participants thought that they would spend less money if they discontinued their statin medications</p> <p>Some participants believed that they might be able to stop taking other medications if they discontinued their statin medications</p> <p>The majority of the participants disagreed with the statements that discontinuation of statin treatment meant that their doctor had given up on them, and that their doctor thought that they were about to die</p>	<p>Effect and adverse effects</p> <p>Indication</p> <p>Quality of life</p> <p>Cost</p>

Study details (first author, publication year, country, reference number)	All findings	Categories
Palagyi, 2016, Australia [23]	<p><i>The pitfalls of coordinated care:</i> Residents reported that they have continued taking medications after the condition for which they were prescribed had subsided</p> <p><i>Strain on resources:</i> Shortage of registered nurses was a concern for family members of LTCF residents as it placed a high task-load on carers, giving the LTCF staff less time to observe the need for changes in or reviews of the medication</p> <p><i>Medication knowledge among residents and relatives:</i> Most residents and relatives were aware of the number of medications they had to take every day, but had little to no knowledge of the indications for these medications, and there was minimal recognition of medication-related drug-events aside from the most common side effects, e.g. dry mouth and drowsiness. Those who had prior experience with medication-related incidents had wider knowledge of adverse drug events, including warfarin-related bleeding and dizziness</p> <p><i>Whatever the GP says goes:</i> The apathy towards medication use displayed by LTCF residents is caused by their complete trust in decisions made by the GP. An overwhelming number of LTCF residents and relatives believed that the GPs medication management is not to be questioned</p> <p><i>If it ain't broke don't fix it:</i> Although the big number of medications they have to take daily was a frequent complaint from residents, a number of residents expressed fear at the concept of reducing or ceasing some of their medications, believing that the medications are prolonging their life</p>	<ul style="list-style-type: none"> - Healthcare professional cooperation - Indication - Knowledge of medication - Medication burden - Shortage of resources - Trust in healthcare professionals
Turner, 2016, Australia [22]	<p>Residents Top 7 ranking:</p> <ol style="list-style-type: none"> (1) Well-being of resident (2) Continuity of nursing staff (3) Feeling of wellness due to medication (4) Burden of medication administration (5) Residents have the right to question their GP (6) Voice of the resident is not heard (7) Respect the GP and do as I'm told <p>Residents ranked "Well-being of resident" and "continuity of nursing staff" as the most important factors for deprescribing. "Well-being of resident" included the right to continue medications they believed made them feel well, and cease the medications they perceived contributed to 'burden of medication administration' or caused ADEs. Residents perceived good communication with health professionals as essential to achieve these factors</p> <p>Residents also commented that unfamiliar nurses were unlikely to know of their medical, social and medication history and preferences, which could potentially lead to the residents' voices not being heard which, in turn, is a barrier to deprescribing</p> <p>Residents also prioritized the factor "burden of medication administration", which included difficulties swallowing large tablets, taste of crushed medications, and use of devices such as inhalers, injections and eye drops. This was considered as a facilitator of deprescribing</p>	<ul style="list-style-type: none"> Effect and adverse effects Medication burden Discussing deprescribing with healthcare professionals Quality of life Trust in healthcare professionals

Study details (first author, publication year, country, reference number)	All findings	Categories
Reeve, 2016, Australia [21]	<p>Enablers and barriers to the deprescribing process were identified within 6 themes</p> <p>(1) Appropriateness of deprescribing</p> <p>Enablers:</p> <p>Why: Knowing why the medication was to be stopped and what benefits would come of it seemed to be an enabler for deprescribing. There seemed to be a need for understanding the reason for cessation of the medication</p> <p>Lack of benefit or necessity: Believing that the medication was no longer beneficial nor necessary to end of life care was an enabler for deprescribing</p> <p>Available alternative: Finding a better medication or lifestyle choice that would render the medication unnecessary was an enabler for deprescribing. However, participants acknowledged that was not always possible</p> <p>Drug interactions: Concerns on whether a certain medication caused interactions may cause older adults to favour discontinuation of that medication</p> <p>Barriers:</p> <p>Long-term use: This was considered a barrier to deprescribing. There seemed to be a belief in the older adults and carers that taking medications for a long time meant that it was still appropriate</p> <p>Lack of current harm: Older adults and carers were happy to continue the medication because of the lack of adverse effects and they seemed to have little concern for future harm, some citing the fact that there is not much future to consider, in the light of limited life expectancy</p> <p>(2) Process</p> <p>Discussing why the medication should be discontinued with healthcare professionals was an important factor when making a decision about deprescribing, according to the participants</p> <p>Participants expected the GP to inform them what monitoring and follow-up initiatives were required after deprescribing</p> <p>Knowing that withdrawal of medications was on trial-only basis seemed to increase participants' willingness to medication cessation</p> <p>Participants mentioned that medications should be weaned before cessation, that medications should be withdrawn one at a time and that a lack of cooperation between healthcare professionals is an issue that may hinder deprescribing</p> <p>(3) Influences on willingness to have medications deprescribed</p> <p>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. The role of nurses and pharmacists was only mentioned briefly by participants and was limited only to giving recommendations to the GP</p> <p>There were mixed opinions on whether or not family members and friends should be an influence in the decision on deprescribing or not. It was mentioned that it was important for all family members to be in agreement with medication withdrawal at end of life</p> <p>(4) Fear as a barrier to having medications deprescribed</p> <p>Participants mentioned factors like general and non-specific fear, fear of return of condition, concern about return of symptoms, missing future benefits and fear of adverse drug withdrawal reactions</p> <p>(5) Dislike of medications</p> <p>The inconvenience of administering the medication to carer and care recipient was reported as an enabler for deprescribing. This was mentioned in the context of the overall conditions and goals of care</p> <p>(6) Making decisions for others</p> <p>An additional carer-only theme emerged in the analysis, 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 when the care recipient still had some remaining cognitive function, their level of involvement in making decisions with the doctors, and the difficulty in making decisions for others</p>	<p>Effect and adverse effects</p> <p>Healthcare professional cooperation</p> <p>Hope and future</p> <p>Indication</p> <p>Making decisions for others</p> <p>Medication burden</p> <p>Discussing deprescribing with healthcare professionals</p> <p>Desire and willingness to reduce medications</p>

Study details (first author, publication year, country, reference number)	All findings	Categories
Post, 2000, USA [24]	<p>Caregivers of individuals with moderate and advanced AD:</p> <p>Some caregivers experienced that donepezil enhanced the patient's cognitive and physical abilities, maintaining a normal lifestyle, whereas others stated it did not calm the agitations</p> <p>One caregiver was frustrated that the doctor refused to continue medication, because of no effect within advanced cognitive decline</p> <p>Some caregivers took the patients off donepezil, with or without the involvement of the doctor, because of side effects, futility, costs, or giving the patients confidence to do things they are not capable of to do safely</p> <p>Despite seeing no improvement when the patients were taking donepezil or no change in the patients after medication cessation, some caregivers did not want to take the patients off the medication, if they did not experience any side effects</p> <p>One patient died of a heart attack shortly after medication cessation and the caregiver felt guilty for stopping the treatment</p> <p>One caregiver felt bad about not being able to help the patient, and a friend advised her to start the patient on the medication again, even though the doctor said it had no effect, because it could not hurt</p> <p>Perception of or hope for improvement as well as seeing their relatives happy, telling jokes and laugh made caregivers want to keep the medication even without any effect</p> <p>Caregivers made decisions regarding continuation and discontinuation of the medications without involving the doctor. Sometimes caregivers wanted to have a dialogue with the doctor about the medication, but refrained from that because the contact with the doctor usually took place through the nurse</p>	<p>Effect and adverse effects</p> <p>Hope and future</p> <p>Making decisions for others</p> <p>Discussing deprescribing with healthcare professionals</p> <p>Cost</p>
Todd, 2016, UK [25]	<p>Medication forms part of daily routine</p> <p>The majority of patients and carers specifically referred to medication when asked to describe what a normal day was like for them. Patients described organizing and taking medications and carers often referred to organizing and following-up on medication-related changes with the GP</p> <p>The majority of patients lacked knowledge of the indications of their medication and what particular medication they took, as they placed complete trust in the healthcare professionals. The carers had a good understanding of the patients' medication</p> <p>Risk of medication</p> <p>The majority of patients described experiencing adverse events from taking their medications, which appeared to be a significant part of the overall experience of using medications</p> <p>Patients felt that the perceived risk and benefit of taking specific medications changed over time; at first patients find themselves in a state of anxiety until a specific point was reached. The patients described this point after having been diagnosed with life-limiting illness and appeared to occur after the patient was accepting of their disease. After this point, patients described some medications are perceived as more important to take than others. These values and beliefs were not consistent and varied between types of medication</p> <p>Willingness to change medication</p> <p>When it comes to willingness to change medication, many patients perceived medications as burdensome. Patients were not concerned with the type of medications they took, as much as being overwhelmed by the volume of it. This made patients and carers willing to discontinue medications</p> <p>The carers welcomed deprescribing approaches if the risks and benefits were clearly explained and that it was done for the benefit of the patient. All of the participants had experiences with deprescribing</p> <p>Patients described experiencing a mismatch of expectations between healthcare professional, patient and carer, when the prescribing doctor stated that this medication will be taken for the rest of their lives, and another doctor talked of deprescribing that same medication</p>	<p>Effect and adverse effects</p> <p>Hope and future</p> <p>Indication</p> <p>Knowledge of medication</p> <p>Medication burden</p> <p>Discussing deprescribing with healthcare professionals</p> <p>Trust in healthcare professionals</p> <p>Desire and willingness to reduce medications</p>

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