Views on advance care planning of family members of older adults with Turkish and Moroccan backgrounds: An exploratory interview study

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Impact statement: We certify that this work is novel. We investigated advance care planning knowledge, experience, views, facilitators and barriers among family members of older adults with Turkish and Moroccan backgrounds in Belgium. The main study findings were that advance care planning is largely unknown in this population, and that these family members had varying views regarding their relatives' involvement in such planning. Self-identified barriers to advance care planning included personal and relational characteristics, the emotional difficulty of discussing end-of-life issues and a perceived lack of urgency. Facilitators included the distribution of advance care planning information in older adults' native languages, the cautious initiation of advance care planning discussions by general practitioners and the involvement of several family members in such planning. Care professionals should provide opportunities for the discussion of advance care planning in a culturally appropriate manner and recognise the diversity of perspectives on whether and how to engage in such planning.

Key statements

What is already known about the topic?

- Significantly fewer people with than without migration backgrounds participate in advance care planning.
- Cultural values and norms impact views on and attitudes toward advance care planning.

What this paper adds

- Family members have highly variable views on the usefulness, benefits, limits and possibilities of advance care planning.
- Older adults' personal characteristics, such as non-acceptance of ageing, and family dynamics, such as parental authority, may impede advance care planning discussions.

Implications for practice, theory or policy

- Care providers should acknowledge Turkish and Moroccan family members' significance in advance care planning for their relatives, addressing their concerns and emotions.
- Family caregivers need to be given opportunities to discuss advance care planning in a culturally appropriate manner, and the diversity of perspectives on whether and how to engage in such planning needs to be recognised.
- General practitioners should facilitate communication about advance care planning between older adults and their family members by initiating discussions and involving all key relatives.

Abstract

Background: Advance care planning among migrants, including large Turkish and Moroccan communities, in Europe is underexplored.

Aim: To explore advance care planning knowledge, experience, views, facilitators and barriers among relatives of older Turkish and Moroccan adults in Belgium.

Design: We conducted 22 semi-structured interviews and deductive/inductive thematic data analysis.

Setting/participants: Relatives of older Turkish and Moroccan adults in Brussels, Mechelen and Antwerp, recruited via general practitioners.

Results: Participants had limited advance care planning knowledge and had not discussed such planning with healthcare professionals. Some had discussed their relatives' end-of-life preferences and considered such discussions beneficial, alleviating their emotional/psychological burden and facilitating their honouring of their relatives' end-of-life preferences. Others opposed the discussion of specific advance care planning topics (e.g. nursing home admission, life-prolonging treatment cessation, official document preparation) or felt that such discussions were unnecessary due to their commitment to and confidence regarding their relatives' care. Advance care planning barriers were personal and relational characteristics (non-acceptance of ageing, parental authority), emotional difficulty of end-of-life conversations and perceived lack of urgency. Facilitators were the distribution of relevant information in older adults' native languages, general practitioners' cautious initiation of discussions and the involvement of several family members.

Conclusions: Relatives of older people with Turkish and Moroccan backgrounds are unfamiliar with advance care planning and have highly variable views on it. People should be given opportunities to discuss advance care planning in a culturally appropriate manner, and the diversity of perspectives regarding whether and how to engage in such planning should be recognised.

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Key words: Advance care planning, end-of-life care, family member, migrant, qualitative study

Introduction

Advance care planning enables individuals to identify values, goals and preferences regarding future medical care, discuss them with family members and healthcare professionals, and record and review preferences for reference when individuals lose decisional capacity.[1] Results regarding its effectiveness and optimal implementation are mixed. Advance care planning may help patients feel in control and have trusting relationships with their loved ones, but – especially when conceptualised only as advance directive establishment – may not improve subsequent care.[2,3] A recent scoping review of randomised controlled trials revealed inconsistent effects on care quality, health outcomes and healthcare utilisation.[4] Another review of qualitative and quantitative evidence showed that advance care planning can be effective if implemented well.[5]

The views of people with diverse ethnocultural backgrounds in Europe on advanced care planning remain under-studied. Uptake has been found to be lesser among migrants than natives in New Zealand, the United States, Australia and the United Kingdom.[6–8] Cultural factors such as patients' religiosity, comfort with the discussion of death, and attitudes toward decision making affect the acceptability of advance care planning.[9] Turks and Moroccans are among the largest visible and ageing non-Western minority groups in Belgium, France, Germany and the Netherlands,[10–12] and our research has revealed family members' significant roles in facilitating or hindering advance care planning conversations in these groups in Belgium.[13–15] Some older adults recommended that healthcare providers increase awareness of the advantages of advance care planning among their children, involving them in conversations to avoid 'burdening' them with end-of-life decisions and to reduce dependence on them.[13–15] Others preferred not to involve their children to avoid triggering negative emotions or because they trusted their children to make the right decisions.[13–15]

Research on the advance care planning views of family members of older adults with Turkish and Moroccan backgrounds is lacking, despite recognition of the importance of involving family members, including surrogate decision makers, in future planning.[16–18] Individuals' effective communication with family members reduces the surrogate decision-making burden and is crucial for goal-oriented care.[19] This study explored advance care planning knowledge, experiences, views, facilitators and barriers among family members of older adults with Turkish and Moroccan backgrounds in Belgium.

Method

Design

For this qualitative study, we conducted face-to-face semi-structured interviews to collect in-depth, contextualised information.[20] The interviewees provided written informed consent, including for the publication of pseudonymised findings. The study was approved by the Medical Ethics Commission of Brussels University Hospital (B.U.N. 1432021000571, 2 February 2022) and registered at ClinicalTrials.gov (no. NCT05241301, protocol ID ACP2021M&T). We followed the consolidated criteria for reporting qualitative research.[21]

Participants

Participants were primary family caregivers of older adults (age ≥ 65 years) of Turkish and Moroccan origins in Brussels, Mechelen and Antwerp, Belgium, aged ≥ 18 years and fluent in Dutch or French. They were identified by older-adult participants in our previous studies[13,14] and recruited via these individuals' general practitioners. Two researchers (HD and WE) contacted all willing participants by telephone to provide further study information and schedule interviews. Participants were recruited until no new relevant information, theme or code emerged from the last three participants' data, signifying saturation.

Data collection

One male researcher (WE), a general-practitioner-in-training with qualitative interview training, interviewed the participants (mean, 50 minutes) between April 2022 and January 2023 at their homes or preferred locations (mostly general practitioners' offices). The interviews were conducted in Dutch or French (at interviewees' preference) with no other individual present and audio recorded. The authors developed an interview guide (Textbox 1), ensuring that it was understandable and elicited relevant information about participants' perspectives on advance care planning for their relatives. Socio-demographic information (age, gender, educational level, background, work time, informal care duration, birthplace, relation to older adult, living situation, number of children) was collected and field notes were made at the interviews' conclusions.

The interviewer asked about participants' advance care planning knowledge without explaining the concept, then introduced it as 'a means of communicating in advance with family members and/or healthcare professionals about the care and/or treatment a person would or would not like to receive in the case that he/she was no longer able to communicate such preferences'. He provided more details during the interviews, focusing on aspects such as life-prolonging treatment, care location (e.g. nursing home) and power of attorney, presenting a case example (Supplementary Textbox 1) and simply worded comprehensive information about advance care planning use (Supplementary Textbox 2).

Textbox 1. Interview topic guide summary.

Introductory questions
Relationship to, health status of cared-for relative
Effects of relative's health on interviewee, experience of caregiving, concerns about late-life care
Extent of involvement in decisions about relative's healthcare
Advance care planning knowledge
Pre-interview awareness/knowledge of advance care planning, advanced written communication of wishes to family members/doctors
[Definition of advance care planning]
Knowledge of ability to refuse future treatment, designate power of attorney, record care location preferences [with explanations]
Experience related to advance planning of relatives' care
Pre-interview conversation with relative about future care needs, wishes, priorities
  If yes: conversation topic, participants, occasion; interviewee's experience, triggers; concrete plans made
Possession of knowledge needed to make decisions for relative
Advance care planning experience [with examples]
  If yes: describe/contextualise further
Views on advance planning of relatives' care
Opinion on advance care planning
Importance/advantages/disadvantages of relative's communication of wishes
[Presentation of example case (Supplementary Textbox 1)]
Opinion on example case, including wish communication while healthy
Post–example case importance of relative's communication of wishes, factors influencing view
[Provision of comprehensive advance care planning information (Supplementary Textbox 2)]
Thoughts on/emotions about future wish communication of relative without serious illness
Effect of relationship with relative on thoughts/emotions, difference from other family member(s)
Effect of culture/religion (if applicable) on views on advanced planning of relative's care
Perceived openness of relative to end-of-life conversations/advance care planning
  If yes: who should be involved, interviewee's preferred role
Openness of interviewee upon relative's desire to have advanced care planning conversation
Respect of relative's advance care planning choices, dealing with disagreement with those choices
Possession of knowledge needed to make decisions for relative
Barriers to and facilitators of advance planning of relatives' care
Open conversation with relative about advance care planning
Factors making conversation harder/easier
Timing of conversation
Final questions
Feeling about interview
Helpfulness of discussion to Turkish/Moroccan community in Belgium?
Most important topic discussed, why

Data processing and analysis

One researcher (WE) transcribed all interviews verbatim. Two researchers fluent in Dutch and French (HD and WE) independently conducted combined deductive/inductive coding-reliability thematic analysis of all transcripts to identify and richly describe patterns (themes) in the data.[22,23] Through line-by-line reading and structured coding, they assigned the data to five a priori–defined categories based on the interview guide (advance care planning knowledge, experience, views, barriers and

facilitators; deductive component), then assigned the category data to subcategories (inductive component), which were grouped into themes. Coding objectivity, reliability and accuracy were ensured by pre-defined category use and the assessment of inter-coder agreement.[23] The process followed a six-phase thematic analysis guide, with constant movement between the entire dataset and coded extracts and ongoing (concurrent) analysis.[22] Code recording and analysis were performed using NVivo12 (QSR International, Melbourne, Australia). The researchers discussed the results monthly until reaching consensus. The results were also discussed with the research team during 6-weekly meetings to reflect on the process and explore initial insights, enhancing triangulation, limiting bias and ensuring interpretation reliability. The final results were forward-backward translated into English.

Results

Participant characteristics

Of 26 eligible participants, 22 [10 men, 12 women; age, 25–64 (mean, 44.5; median, 44.5) years; 14 Turkish, 8 Moroccan origin] provided consent and were interviewed. Most were adult children (10 daughters, 9 sons), had provided informal care for >5 years and had high educational levels (Table 1).

Table 1. Participants' socio-demographic characteristics (*n* = 22).

Characteristic	**Category**	***n***
Age (years)	25–45	12
	46–64	10
Gender	Man	10
	Woman	12
Educational level	Primary school	3
	High school	10
	College/university (bachelor's degree)	6
	Graduate school (master's degree/PhD)	3
Origin	Turkish	14
	Moroccan	8
Work time	Full time	12
	Part time	3
	Unemployed	5
	Incapacitated	2
Informal care duration	>5 years	21

Birthplace	Belgium	16
	Turkey	4
	Morocco	2
Relation to older adult	Daughter	10
	Son	9
	Grandchild	2
	Spouse	1
Living situation	With parents	4
	With spouse/children	18
Number of children	0, 1	7
	2	5
	3	8
	4, 5	2

Advance care planning themes

The themes and subthemes identified are shown in Textbox 2. As perspectives did not differ between participants with Turkish and Moroccan backgrounds, we report them together.

Textbox 2. Advance care planning themes and subthemes.

1. Limited advance care planning knowledge
2. Lack of advance care planning experience with healthcare providers, but some end-of-life care discussions with family
3. Varying views on relatives' engagement in advance care planning
    - Honouring relatives' preferences and avoiding emotional/psychological burden
    - Opposition to certain advanced care planning discussions/actions
    - Lack of need due to commitment to care and trust
4. Advance care planning barriers
    - Personal and relational characteristics
    - Emotional nature of discussing end-of-life issues
    - Lack of urgency
5. Advance care planning facilitators
    - Distribution of advance care planning information in relatives' native language
    - Initiation of advance care planning discussions by general practitioners
    - Involvement of several family members in advance care planning discussions

Limited advance care planning knowledge and experience. The participants, excepting two who were general practitioners, had no advance care planning knowledge. Some struggled to grasp the concept during the interviews, requiring multiple definitions and explanations. Some participants knew that

people could refuse certain future treatments and express care location preferences to their doctors and family members in advance.

> *I do know that in Belgium a lot of people sell their houses to go to a nursing home. They say in advance that when they are not healthy enough to stay at home, that they want to go to a nursing home.* (Respondent 3, 41-year-old son, Turkish origin)

None of the participants had discussed advance care planning with healthcare providers or helped relatives prepare official documents such as advance directives. Some interviewees' relatives had initiated family discussions and expressed their wishes regarding care and burial locations, life-prolonging treatment, organ donation and/or surrogate decision makers, usually following acquaintances' nursing-home admission or death or the viewing of a television programme on organ donation.

> *We talked about the nursing home because there was a person who had put his father in a nursing home, so my father said 'Those people who put their parents in a rest home have understood nothing about life".* (Respondent 20, 37-year-old son, Moroccan origin)

Some adult children had discussed topics such as life-prolonging treatment with their siblings, without informing or involving their parents, whom they believed would leave such decisions to them.

> *In relation to life-prolonging treatments, we discussed among ourselves* [siblings] *that we do not want intubation and resuscitation... Since my father's death, she* [mother] *no longer takes any decisions. She lets everything wash over her.* (Respondent 6, 55-year-old daughter, Turkish origin)

Varying views on relatives' advance care planning engagement. Honouring relatives' preferences and avoiding emotional and psychological burdens. Some interviewees felt that advance care planning should be discussed openly and that they should know their relatives' preferences, given their concerns about future care needs and the psychological burden of uninformed decision making. They did not know whether they could make the right decisions and wanted to respect their relatives' choices; thus, they would feel relieved to have such discussions.

> *For me, it's important to discuss things so that we don't find ourselves in situations afterwards where our minds might be clouded by emotions and we won't be able to make the right decisions. So it's better to discuss things beforehand.* (Respondent 18, 48-year-old son, Moroccan origin)
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> *He* [father] *has to choose and all we can do is respect his choice. Even if it's difficult, even if it can lead to conflicts, it's his choice. And I think we should always respect*

parents' choices because they know best. (Respondent 14, 32-year-old daughter, Turkish origin)

Some of these participants said that the interviews raised many questions and prompted them to initiate discussions with their relatives. They realised that they wanted to have advance care planning discussions while their relatives were in good health and could make and convey their own decisions. Others indicated that they would try to elicit their relatives' preferences indirectly, i.e. by using examples of other people's end-of-life situations, to avoid hurting their feelings.

I think it's important that the discussion happen before she gets very sick because otherwise she might not be able to decide for herself then. (Respondent 8, 40-year-old granddaughter, Turkish origin)

We can start the conversation via his brother who died not long ago. For example, by saying 'you say he had this and that...and what do you think? I'd rather help you more.' You see, you have to get into a conversation like that. I don't have to be direct, I have to be indirect, so he'll not get hurt. (Respondent 5, 39-year-old son, Turkish origin)

Opposition to certain advanced care planning topics. Some interviewees were reluctant to discuss topics such as nursing homes and the stopping of life-prolonging treatment, but were open to discussing their relatives' preferences regarding, e.g. home care, burial location, organ donation and legal representative designation. Interviewees who completely opposed advance care planning discussions also specifically mentioned nursing homes and life-prolonging treatment. Interviewees in both groups were unsure that they could respect and fulfil their relatives' preferences due to possible conflict with their own views. For example, some participants opposed life-prolonging treatment cessation (due to religious beliefs) and nursing home admission (due to cultural norms regarding care duties), and felt that this obviated the need for discussion even if contradictory to their relatives' wishes.

Even if he wants to go to a nursing home, I don't want that…Also I don't want to stop [life-prolonging] *treatment. We know that in religion* [Islam] *you have to leave it in God's hands. But as I said, it's destiny in fact...it's Allah who decides when it's over.* (Respondent 16, 64-year-old wife, Moroccan origin)

Talking makes them feel better...They don't want to donate their organs. We have discussed this and they told me 'I want to keep everything inside me'…We can't talk about nursing homes. I'd never put my parents in a nursing home. That's not up for discussion with us. My parents have helped me grow up. I'm helping them until they die...Power of attorney, I think it's useful…It could be a good option. My parents have

already said to my sisters and brothers 'He's the eldest, he's going to make all the decisions'. (Respondent 15, 51-year-old son, Turkish origin)

Some participants, including some of those who were open to advance care planning discussions, opposed official advance care planning document preparation. They considered verbal agreements to be easier, avoiding extra administrative tasks, and trusted such agreements within families. Moreover, some feared that their relatives' preferences would change and that the adaptation of registered documents would be impossible.

For families like ours, where everyone communicates with everyone else, I think it's pointless to do it on paper, to record it, because it's a lot of extra administration. And the situation can change and evolve. So if you take the decision at 60, maybe you've thought of something else at 80. (Respondent 19, 39-year-old son, Moroccan origin)

Lack of need due to care commitment and trust. Some interviewees felt that anticipatory end-of-life conversations were useless, as caring and decision making for ill parents was their duty and a recognition of the parental care that they had received, in line with their cultural and religious norms, values and practices.

We don't discuss it [end of life] *because we don't think about it. We don't think ahead, we don't think like that in our culture and in our religion. Culture always says to take care of your parents and do everything for them and to always look after them.* (Respondent 5, 39-year-old son, Turkish origin)

Other interviewees presumed that they knew their relatives' wishes without discussing them. They felt that their relatives would not be interested in end-of-life discussions because they trusted family members and their ability to make all future decisions.

No, we haven't discussed end-of-life care because I think it's also natural that if anything happens to her, we'll take care of her…The thing is, it's logical for them [parents]*. We already know what to do…it's the default. Basically they're saying 'but you know what we want'.* (Respondent 7, 33-year-old daughter, Turkish origin)

Advance care planning barriers. Personal and relational characteristics. Some interviewees who were open to advance care planning discussions indicated that such discussions with their relatives would be impossible, based on relatives' clear indications or interviewees' assumptions. Reasons for this (assumed) refusal included relatives' stubbornness, non-acceptance of ageing or reduced independence, lack of concern about their future care, and the difficulty or taboo nature of discussing end-of-life aspects. These interviewees felt that end-of-life discussions would be painful, causing fear and sadness (and thus interviewees' guilt) and making their relatives feel that the end of

life was approaching. They feared that their relatives would react poorly and think that they (largely children) did not want to provide care.

> *I want to talk, but my mother refuses it. It's her character. She doesn't like to think or talk about death. She's a very stubborn and difficult person. So it's very difficult to know what's going on in her head because she doesn't even want to talk about it. Moreover, she's afraid of being looked after by her children, of being dependent on her children. She says 'Allah is great'. We're not there* [end of life]*. I don't want to think about all that.'* (Respondent 13, 50-year-old daughter, Turkish origin)

> *I think a discussion is very good because sometimes it allows the other person to open their eyes, to have better ideas. I'm open to having these discussions… But for our parents, we're not going to start talking about morphine injections and machines. It'll scare them. I'm afraid of giving them the impression that their life is coming to an end… Talking about a nursing home will show in advance that we won't look after him* [father] *when he gets sick and bedridden.* (Respondent 11, 40-year-old daughter, Moroccan origin)

Some adult children mentioned their hierarchical (authority-based) relationships, especially with their fathers, as a barrier to end-of-life discussions. Some did not regularly speak in depth with their fathers on any topic.

> *There's no healthy relationship between the father and the children because the first-generation older adults were very hard on their children. Even today, children are afraid to talk about these kinds of things* [end-of-life issues] *with their parents.* (Respondent 15, 51-year-old son, Turkish origin)

Emotional nature of discussing end-of-life issues. Some interviewees (especially daughters of older adults) found end-of-life conversations to be very emotionally challenging and wanted to avoid them; some cried during the interviews because they were reminded of their relatives' impending death. Some reported they had interrupted or blocked their parents' conversations about end-of-life preferences, such as going to a nursing home, due to fear of the eventual outcome and their grief.

> *It's very difficult to talk about this* [end of life]*. It's very touchy. I never expected that one day she'd think about going to a nursing home… I said, 'Listen, Mum, you mustn't think about this anymore'… She wants to talk, but we* [children] *don't let her because we don't want to give her the idea that she can't stay in our house. I prefer not to think about it...sometimes when I think about it I feel really bad* [starts to cry]*. I know that one day she'll leave...but I don't know how that'll happen.* (Respondent 2, 53-year-old daughter, Turkish origin)

Lack of urgency. Some interviewees felt that the discussion of advance care planning, especially life-prolonging treatment, while their relatives were still in good health was premature. They felt that the right decisions would be made when the time came, and would depend on the degree of illness and family relations. They considered that advance care planning discussions should happen when their parents were seriously ill and when they had concerns.

> *We never talk about that* [end of life] *because there's no reason, he's still fine, he's never ill, we always see him as fine, strong, solid. If he's weak and ill, then we'll talk about it... But now, I don't see any reason.* (Respondent 16, 64-year-old wife, Moroccan origin)
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> *Difficult in the sense of you can hardly empathise now. I think when the moment comes, only then will you really experience it and you can actually make decisions. At the moment, she* [mother] *is stable. If she's bedridden in a year or two, unable to do anything, then you're in a totally different situation. You're also going to decide in a different way then. It's not correct to decide things in advance. You can talk about possibilities now, but you can't expect them to make decisions now. Depending on pathologies, family circumstances, decisions may change.* (Respondent 17, 48-year-old son, Moroccan origin)

Advance care planning facilitators. Distribution of advance care planning information in relatives' native language. Interviewees who were open to advance care planning discussions felt that their relatives' timely receipt of relevant information, to prepare them, would facilitate such discussions. They recommended the dissemination of tailored information in the older adults' native languages through advertising in waiting rooms, social media, television programmes and gathering places such as mosques.

> *I'd put money into a social worker who should spread information about advance care planning in doctors' waiting rooms, or maybe go and see the imams in the mosques to get them to talk about it during the speeches at Friday prayers.* (Respondent 18, 48-year-old son, Moroccan origin)

General practitioners' initiation of advance care planning discussions. Some interviewees felt that advance care planning discussions were most appropriately initiated by general practitioners, who knew and could influence/motivate their relatives and to whom their relatives liked to listen and speak openly about their concerns. They recommended that general practitioners communicate cautiously, using examples of other people, to avoid hurting their relatives.

The GP is important because he's the link between the medical world and the patient. So for me, I think that's their role. It should be a GP's role to discuss this subject with his patients. (Respondent 18, 48-year-old son, Moroccan origin)

I think the GP can discuss with examples like 'person A experienced that, what do you think about it yourself? That way I can form a bit of an opinion'. So afterwards we [children] *can ask 'how do you yourself feel about it if it happens to you like that?'* (Respondent 17, 48-year-old son, Moroccan origin)

Involvement of several family members in advance care planning discussions. Some interviewees expressed that the involvement of several family members would facilitate advance care planning discussions and future decision making, avoiding conflict among the children. Some felt that their exclusion from such conversations would constitute betrayal. Some interviewees also mentioned respect for the relational hierarchy, as cultural norms place the heavy responsibility for decision making with the eldest child.

I think I'll need help because it's complicated for me to do it on my own. It'll be in the presence of the older members of the family too. (Respondent 9, 25-year-old son, Turkish origin)

Listen, if one day my mother takes decisions with the doctor and I'm left out and I'm not aware of her wishes, it's true that would be difficult for me to accept afterwards. What kind of state of mind was my mother in at that time, confiding in a doctor and not confiding in me? (Respondent 2, 53-year-old daughter, Turkish origin)

Discussion

Main study findings

This study showed that the family members of older adults with Turkish and Moroccan backgrounds had limited advance care planning knowledge and had not discussed advance care planning for their relatives with healthcare professionals. Some participants had spoken with their relatives about end-of-life preferences outside of professional contexts. They tended to consider advance care planning discussions to be beneficial because they would alleviate their emotional and psychological burdens and help them to honour their relatives' preferences. Other family members were opposed to discussing specific advance care planning topics (e.g. nursing home admission, life-prolonging treatment cessation, official document preparation). Still others viewed end-of-life conversations as completely unnecessary due to their commitment to care for their parents and their relatives' perceived trust. Self-identified barriers to advance care planning were personal and relational characteristics (e.g. non-acceptance of ageing, parental authority), emotional difficulty and the

perceived lack of urgency. Facilitators mentioned by the participants included the distribution of information in their relatives' native languages, general practitioners' cautious initiation of advance care planning discussions and the involvement of several family members.

Study strengths and weaknesses

This study has several strengths. It offers in-depth insight into the advance care planning views of family members of older people with Turkish and Moroccan backgrounds, among the largest minority groups in several European countries, including Belgium. The interviewer's migration background and knowledge of the participants' religious and cultural backgrounds and languages enabled the participants to express their opinions freely and aided the acquisition of nuanced, reliable information.

This study also has limitations. The interviewer's position of authority as a male medical doctor may have influenced the respondents' assertiveness in their responses. Additionally, although the participants were more educated than their relatives, some had difficulty understanding advance care planning–related concepts, despite the interviewer's detailed explanations with a case example and comprehensive information. This factor may have impacted their responses.

Comparison with existing literature

Our participants expressed highly variable views on advance care planning, ranging from acceptance to dismissal. These results underline the importance of understanding personal preferences and coordinating care accordingly in advance care planning, as supported by other findings.[17] In a qualitative study, some family members of native-Belgian older adults emphasised that advance care planning discussions would reduce the emotional burden associated with the fear of making incorrect decisions,[24] similar to some of our participants but in contrast to others who saw little merit in such discussions due to their strong commitment to care and their relatives' trust in their decision making. The latter perspective reflects the deeply ingrained filial responsibility and reciprocal love underlying family care responsibilities in collective societies, and aligns with our previous findings from older adults with Turkish and Moroccan backgrounds.[13–15,25–27]Klik of tik om tekst in te voeren.

Some interviewees recommended family members' involvement in advance care planning to streamline future decision making and avoid conflict, in agreement with previous findings, including those from older adults of Turkish and Moroccan origins.[13–15,28] Family members of the latter often operate as care management groups with equal roles in communication and decision making.[29]

Some participants were reluctant to complete official advance care planning documents due to their trust and preference for verbal family agreements. Such trust aligns with our previous findings.[13–15] Some respondents also implied that such documents (e.g. advance directives) were

unchangeable, in agreement with previous findings and potentially reflecting perceived discrimination in the healthcare system[30] and advance directive use to reduce healthcare costs.[31]

Some participants felt confident making well-informed decisions for their relatives without discussion, believing that they understood their relatives' desires, which has been shown to often be inaccurate.[32] Others intended to override their relatives' plans, especially regarding life-sustaining treatment cessation, for religious reasons, which has been described among migrant in Belgium and groups in the United States and Australia.[17,33] In confirmation, some interviewees considered discussing such topics to be futile. Decision making about life-prolonging treatment is challenging for individuals with Muslim backgrounds due to beliefs about God's omnipotence and sovereignty over life and death.[34]

Some participants perceived their relatives' non-acceptance of ageing and discomfort discussing their dependence or mortality as potential barriers to advance care planning, consistent with the preference of older adults with Turkish and Moroccan backgrounds to 'live in the moment' and their difficulty discussing death.[13–15] The participants were concerned that end-of-life conversations would cause their relatives pain and fear, as also indicated by some native-Belgian relatives of older adults.[24] Some participants hesitated to engage in end-of-life conversations due to their fathers' authority, consistent with the traditional gender hierarchy in Turkish and Moroccan families.[35,36]

Implications for practice and research

Care providers should acknowledge Turkish and Moroccan family members' significance in advance care planning for their relatives, addressing their concerns and emotions to facilitate effective, ongoing planning and engagement, and initiate discussions to reduce the possible interference of older adults' personal characteristics.[37] Opposition to the preparation of official documents, including advance directives, should not hinder engagement in advance care planning conversations.

Research on advance care planning for relatives in this population requiring palliative care, and for those with other migration backgrounds, in Belgium would expand our understanding of existing perspectives, enhancing provider–patient–family communication. The exploration of methods for effective advance care planning communication involving several family members could facilitate future decision making and minimise conflict. The present results challenge the common assumption that advance care planning communication centres around single primary caregiver.

Conclusion

Relatives of older people with Turkish and Moroccan backgrounds were unfamiliar with advance care planning and had highly variable views on its usefulness. People need to be given opportunities to

discuss advance care planning in a culturally appropriate manner, and the diversity of perspectives on whether and how to engage in such planning needs to be recognised.

Authorship

HD is the grant holder and chief investigator; HD wrote the protocol with critical input from all authors. All authors drafted the protocol and HD submitted it for ethical approval. HD and WE coordinated data collection and analysed the data. All authors discussed the interpretation of the findings and take responsibility for the data integrity and analysis. HD and WE drafted the manuscript. All authors critically revised the manuscript for important intellectual content and approved the final version.

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Declaration of conflicting interests

The authors declare that they have no conflict of interest.

Research ethics and patient consent

The study design was approved by the Ethics Committee of Brussels University Hospital (B.U.N. 1432021000571, 2 February 2022) and registered with ClinicalTrials.gov (no. NCT05241301, protocol ID ACP2021M&T). The interviews were conducted after receiving written consent, including to the publication of anonymised findings, from the participants.

Data management and sharing

All requests for data access should be addressed to the Chief Investigator at hakki.demirkapu@vub.be and will be reviewed by all authors.

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Reflectieverslag Wael Eddaly

In het kader van mijn opleiding huisartsgeneeskunde aan de VUB heb ik meegedaan aan het opschrijven van deze masterproef over een periode van drie jaar (2021-2024) in nauwe samenwerking met Dr Hakki Demirkapu.

Drie jaar geleden heb ik het onderwerp “ Views on advanced care planning of family carers of older adults with Turkish and Moroccan background: An exploratory interview study” uit interesse gekozen. Enerzijds omdat ik veel interesse heb in de vroegtijdige zorgplanning en geloof dat iedereen voor zichzelf mag beslissen, anderzijds omdat ik zelf van buitenlandse herkomst ben en in mijn moederland zijn dergelijke onderwerpen, nog steeds, zeer moeilijk om ter sprake te brengen omwille

van religieuze en culturele redenen. Door middel van deze studie wou ik meer kennis bekomen over deze problematiek zodat ik het belang van VZP beter kan uitleggen/ verdedigen in mijn verdere carrière voornamelijk bij mensen met migratie achtergrond.

Ik was erg gemotiveerd om deze studie tot een goed einde te brengen. De studie was uitdagend omdat ik een minimum 20 mantelzorgers moest bevragen om de thesis te mogen schrijven. Ik moet toegeven dat het geen makkelijke opdracht was. Vele mantelzorgers vonden het een zeer gevoelig onderwerp en in eerste instantie hadden ze de neiging om het gesprek te weigeren. Sommige mantelzorgers heb ik zelf kunnen overtuigen voor het interview, anderen via Dr Hakki Demirkapu of via de desbetreffende huisarts.

Er waren ook moeilijke momenten voor mij. Eén mantelzorger was er aanvankelijk mee eens om zich te laten interviewen maar toen hij me zag heeft hij zich teruggetrokken : Hij begreep niet zo goed hoe een persoon met moslimachtergrond dergelijke studies kan uitvoeren (God beslist voor ons en wij mogen geen vragen stellen over het levenseinde als moslims).

Hoewel ik hierdoor af en toe wat frustratie ervaarde heb ik me niet laten ontmoedigen en gelukkig toonden de meeste mantelzorgers enthousiasme voor dat gesprek.

Uiteindelijk heb ik 22 mantelzorgers kunnen interviewen: 14 van Turkse en 8 van Marokkaanse origine. Verplaatsingen hoorden hier natuurlijk bij, ik ben een paar keer naar Antwerpen en Mechelen getrokken...en dat vond ik erg plezant.

Het interview was op zich erg uitdagend voor mij. Aan de ene kant omdat ik zowel Franstaligen als Nederlandstaligen moest interviewen. Aan de andere kant omdat je telkens iemand anders voor jou hebt met een verschillend opleidingsniveau, dus ik moest me vaak aanpassen om de juiste vraag te kunnen stellen in een duidelijke en begrijpelijke tala. Dit was niet zo evident voor iemand die anderstalig is zoals ik. Daarbovenop vond het gesprek plaats vaak in de thuissituatie en in het bijzijn van andere familieleden wat het verloop van het interview soms bemoeilijkte.

De transcriptie van de gesprekken was een van de belangrijkste stappen van dit onderzoek. Door al de interviews door te nemen verwerf je dieper inzicht in de gegeven antwoorden. Ook is het een goede oefening om de daaropvolgende gesprekken op een betere manier te voeren en de vragen op een doeltreffende manier te stellen.

Omdat ik zelf de transcriptie heb gedaan was de analyse een pak makkelijker geworden want zo kreeg ik al een idee over de belangrijkste thema's van mijn resultaten. De analyse van de interviews is gebeurd via het NVIVO programma. Door regel voor regel te lezen en gestructureerd te coderen, heb ik de data toegewezen aan vijf vooraf gedefinieerde categorieën op basis van de interviewgids (kennis over VZP, ervaring, meningen, barrières en facilitatoren; deductieve component). Vervolgens heb ik de

categoriedata toegewezen aan subcategorieën (inductieve component), die gegroepeerd werden in thema's

Om betere resultaten te bekomen ben ik maandelijks met Dr Hakki Demirkapu samengekomen om onze analyse te vergelijken/ bespreken. Ongeveer om de 2 maanden hebben we de resultaten ook gediscussieerd met andere auteurs van het artikel om een betere analyse te kunnen verkrijgen.Het was een fijne samenwerking en een verrijkende uitwisseling van ideeën waardoor wij accurate bevindingen hebben kunnen bekomen.

Ik ben van mening dat ons onderzoek een grote meerwaarde kan opleveren voornamelijk voor zorgverleners die werken met mensen van Turkse en Marrokaanse origine. In de bestaande literatuur zijn er tamelijk weinig onderzoeken die zich hebben toegespitst op het perspectief van de mantelzorger in het kader van vroegtijdige zorgplanning.

Het feit dat ik iemand met migratieachtergrond ben alsmede mijn kennis van de religieuze en culturele achtergronden en talen van de deelnemers stelde hen in staat om hun mening vrij te uiten en hielp bij het verzamelen van genuanceerde, betrouwbare informatie.

Dit onderzoek toont aan dat familieleden van oudere volwassenen met een Turkse en Marokkaanse achtergrond beperkte kennis hadden van VZP en ze het niet met zorgverleners besproken hadden. Sommige deelnemers hadden buiten de professionele context met hun familieleden gesproken over hun voorkeuren met betrekking tot het levenseinde.

Meestal beschouwden de deelnemers de gesprekken over planning van de palliatieve zorg als nuttig omdat het hun emotionele en psychologische last zou kunnen verlichten en hen zou helpen om de voorkeuren van hun familieleden te respecteren.

Andere familieleden waren terughoudend tegenover het bespreken van specifieke onderwerpen in verband met vroegtijdige zorgplanning (bv. opname in woonzorgcentrum, stopzetting van levensverlengende behandelingen, opstellen van officiële documenten...).

Nog anderen beschouwden gesprekken over het levenseinde als volledig overbodig vanwege hun toewijding aan de zorg voor hun ouders en het vertrouwen dat hun oudere familieleden in hen stelden.

Zelfbenoemde barrières voor VZP waren persoonlijke en relationele kenmerken (bv. niet-acceptatie van het ouder worden, ouderlijk gezag), emotionele moeilijkheden en een gebrek aan urgentie. Als faciliterende factoren noemden de deelnemers de verspreiding van informatie in de moedertaal van hun familieleden, het voorzichtige begin van gesprekken over planning van voorafgaande zorg door huisartsen en de betrokkenheid van verschillende familieleden.

Onze studie heeft verschillende sterke punten. Het biedt een diepgaand inzicht in de opvattingen over VZP van familieleden van ouderen met een Turkse en Marokkaanse achtergrond, die tot de grootste minderheidsgroepen in verschillende Europese landen, waaronder België, behoren. Deze studie toonde dat familieleden van ouderen met een Turkse en Marokkaanse achtergrond niet gewend waren met vroegtijdige zorgplanning en hadden zeer uiteenlopende meningen over het nut ervan. Deze populatie moet de kans krijgen om de verschillende perspectieven op een cultureel passende manier te mogen bespreken.

Hopelijk wordt dit onderzoek vervolgd door andere studies die het onderwerp verder belichten. Zo kunnen wij meer inzicht bekomen in de perspectieven van mantelzorgers van andere etnische minderheden naast die van Turkse en Marokkaanse origine met betrekking tot VZP. Op die manier kan de toegankelijkheid van dergelijke patiëntengroepen tot de zorg rond het levenseinde verbeterd worden.