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**Advance Care Planning Among Older Adults of Turkish Origin in Belgium: Exploratory Interview Study**

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## **Abstract**

**Context.** Although conversations about future medical treatment and end-of-life care are considered to be important, ethnic minorities are much less engaged in advance care planning (ACP).

**Objectives.** To explore ACP knowledge, experiences, views, facilitators, and barriers among older adults of Turkish origin in Belgium.

**Methods.** This qualitative study was based on constant comparative analysis of semi-structured interview content. Participants were 33 older adults (aged 65–84 years; mean, 71.7 years; median, 74.5 years) of Turkish origin living in Belgium.

**Results.** Despite unfamiliarity with the term ACP in this sample, several participants had engaged in some ACP behaviors. Respondents considered ACP to be useful and were ready to engage in conversations about it. The most commonly mentioned facilitator was the provision of tailored information about ACP. Other facilitators included concerns about future care needs, increasing awareness among respondents' children about the advantages of ACP, and respondents' desire to avoid "burdening" their children. The most commonly mentioned barrier was respondents' lack of knowledge about ACP. Other barriers were language issues, a lack of urgency about ACP discussion, reliance on familial support, and older adults' fear of triggering negative emotions in themselves and their children.

**Conclusions.** The provision of tailored information about ACP to older adults of Turkish origin in Belgium and the promotion of awareness about the importance of ACP among their children (when patients desire), as well as the use of professional interpreters, could facilitate ACP engagement in this population.

## **Key Words**

*Advance care planning, older adult, ethnicity, minority group, qualitative study*

## **Key Message**

## ACP VIEWS OF OLDER TURKISH ADULTS IN BELGIUM

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51 Older people of Turkish origin in Belgium who participated in this study were not familiar with the term  
52 “advance care planning,” indicating that this population requires tailored information about this practice.  
53 In this population, family relationships can facilitate or act as barriers to engagement in advance care  
54 planning.

## Introduction

Advance care planning (ACP) enables individuals to define, record, and review future care preferences, and to discuss them with family members and healthcare providers.(1) ACP benefits include the improvement of end-of-life care and patients' satisfaction with it, and the reduction of patients' and family members' stress, anxiety, and depression, leading to increased use of hospice and palliative care over hospitalization and life-sustaining treatment.(1,2)

ACP engagement is significantly lesser among older ethnic-minority than among ethnic-majority adults in various countries, due partly to healthcare providers' overlooking of cross-cultural ACP perspectives.(3–5) Providers should take a culturally sensitive approach to ACP because ACP awareness and attitudes may vary among ethnic-minority groups.(6)

Studies of ACP engagement among ethnic-minority older Turkish adults are lacking. People of Turkish origin form one of the largest non-western groups in Belgium and other European countries (e.g., Germany, France, the Netherlands, Austria).(7,8) About 2.1% of the Belgian population is of Turkish origin.(8) The first generation of Turkish-origin patients in Belgium is now aged > 65 years and requires care.(9,10) ACP is ideally initiated when patients are relatively well and able to make informed decisions, enabling more effective care planning.(11) However, a systematic literature review showed that diagnoses, prognoses, and end-of-life decisions are seldom discussed with incurably ill Turkish patients.(12) When end-of-life care conversations are postponed, patients may lack decision-making competence when they occur; family members must make decisions that may not reflect patients' preferences.(13,14) Furthermore, healthcare professionals and family members of ethnic-minority individuals in Belgium may have conflicting views on what constitutes "good care."(15)

Thus, an understanding of ACP perspectives, facilitators, and barriers among older adults of Turkish origin is important. ACP adapted to this group's needs might improve patients' and family-member caregivers' well-being. This study aimed to characterize ACP knowledge, experience, views, facilitators, and barriers among older adults of Turkish origin.

## **Methods**

### *Study Design*

This qualitative study was conducted with data from semi-structured face-to-face interviews, which allowed us to explore respondent-constructed meanings, experiences, processes, and assumptions, and to determine whether participants wished to engage in ACP. We followed the Consolidated Criteria for Reporting Qualitative Research and Consolidated Standards of Reporting Trials in describing the methods and findings.(16,17) The Medical Ethics Commission of Brussels University Hospital approved this study (B.U.N. 143201838280), which is registered at ClinicalTrials.gov (no. NCT03930823). All data were pseudonymized.

### *Participants and Recruitment*

We recruited respondents of Turkish origin aged > 65 years who lived in Belgium. We excluded patients of “palliative status,” according to the Palliative Care Indicator Tool (PICKT),(18) who had two or more frailty indicators and fulfilled one or more criteria for incurability of a potentially lethal condition. We also excluded those diagnosed with cognitive impairment or dementia by their general practitioners (GPs).

The principal researcher (HD) contacted GPs serving older Turkish adults in the Brussels region, explaining the study and PICKT use. Participating GPs explained to eligible patients that a GP of Turkish origin would like to explore their ACP perspectives, and asked them to participate and allow provision of their contact information to the researcher. The GPs completed the PICKT for patients wishing to participate. The researcher contacted eligible patients to obtain informed consent, answer questions, and ascertain their willingness to participate. After oral and written consent provision, the researcher interviewed participants at locations of their choice (often their homes). Participants were recruited until no new relevant knowledge was obtained from the last three participants (data saturation).

105

106 *Data Collection*

107 An interview topic guide was developed and translated from English to Turkish using forward–  
108 backward procedures (Fig. 1). Before study initiation, it was pilot tested to examine content clarity with  
109 six older adults from the target group. The researchers then revised the guide to ensure that it was  
110 understandable and elicited relevant information.

111 The interviewer (HD), who is trained in qualitative healthcare research, conducted one audio–  
112 recorded interview (mean duration, 45 min) in the participant's spoken language (Turkish) with each  
113 participant; a non–research team member transcribed the interviews verbatim. During interviews, the  
114 researcher described ACP to the participants (Fig. 1), paraphrased, and asked participants to provide  
115 comments and/or corrections. The researcher collected sociodemographic data and took field notes  
116 immediately after each interview.

117

118 *Data Analysis*

119 Two investigators (HD and FZC) independently reviewed and coded all transcripts using the constant  
120 comparative method for open-ended data and NVivo 12 software (QSR International, Melbourne,  
121 Australia), regularly discussing the coding structure. Initially, verbatim transcripts in Turkish were  
122 analyzed. Line-by-line review was conducted until codes were applied to transcript sections representing  
123 study-related concepts. Coding was iterative, with comparison within and across interviews until  
124 overarching themes were identified.(19) The researchers, fluent in Turkish and English, worked  
125 independently to develop research findings without loss of meaning, to enhance transparency during  
126 translation, and to manage data sensitively. They then translated the selected relevant parts of the  
127 transcripts into English, compared the Turkish and English transcripts, and repeated the analysis with the  
128 English transcripts. Bilingual data analysis permitted the consideration of cultural context and meaning–  
129 based interpretation and translation, reflecting participants' experiences as closely as possible.(20) The

entire research team held regular discussions to enhance triangulation, limit bias, and ensure the reliability of interpretations.

## **Results**

Thirty-three participants aged 65–84 (mean, 71.7; median, 74.5) years were interviewed. No respondent contacted by the researcher refused participation. All respondents identified as Muslim and were first-generation immigrants to Belgium who arrived as adults (aged > 18 years) for work, family reunification, or marriage. Few respondents had come to Belgium to join their emigrated children. Thirteen respondents (including 12 women) were illiterate (Table 1). Box 1 shows the themes and subthemes identified.

### *ACP Knowledge and Experience*

#### **Lack of ACP Knowledge and ACP Experience with a Healthcare Provider**

No respondent had heard of “advance care planning” previously. Respondents did not know what ACP entailed, confusing it with prevention, healthy lifestyle maintenance, or treatment adherence. No respondent had discussed ACP with a healthcare provider:

“Now, I have heard it [ACP] for the first time. I didn't know you could talk about it. I have been here for 57 years, I have seen many doctors, but nobody ever talked to me about it.” (Respondent 1, 78-year-old woman);

“I think it means if you look at yourself, if you follow the advice of doctors on time...Taking care of yourself. To listen to the doctor's advice, to take the pills on time.” (Respondent 2, 68-year-old man).

Despite not having heard of the term ACP, some respondents had discussed end-of-life preferences (e.g., about life-prolonging treatment, nursing home admission, burial location) with their partners or children:



“I say to my children: ‘if I can’t look after myself, then leave me in a nursing home. I don’t want to be a burden to you’...I want my grave to be next to my parents in Eskisehir...I made my testament orally to my children.” (Respondent 1, 78-year-old woman).

#### *ACP Views*

##### *ACP is Useful*

After ACP was explained to them, respondents of both genders viewed ACP engagement as advantageous and said that they were ready have ACP-related conversations. Respondents’ views suggest that they perceived ACP to be useful, helping them express their wishes while their mental health is good and allowing them to prepare for a more comfortable end-of-life period:

“I can’t see any disadvantage. I want to speak about my wishes, so when I get older, it would be more comfortable. It’s better to talk now when you have a clear mind...So we will not depend on the machine [ventilator] and do not suffer.” (Respondent 29, 66-year-old woman).

##### *ACP is Not “Against Religion”*

Most respondents considered ACP to be compatible with their religious beliefs and practices:

“It is not against religion because I am not committing suicide by doing ACP.” (Respondent 4, 65-year-old man).

Three respondents did not want to engage in ACP because they believed it was against their religion. They considered proactive decision making to be a sin:

“It is difficult because only God knows in advance what will happen, nobody else. If you decide beforehand, you are against Allah. It’s a sin...Only Allah can decide, not you” (Respondent 32, 74-year-old woman).

#### *ACP Facilitators*

##### *Concerns About Future Care Needs*

Respondents concerned about their future care needs wanted to talk about ACP with healthcare providers. They had reflected on their possible future situations after witnessing seriously ill or dying older adults in their social networks. They had concerns about whether they could rely on their children when they needed care:

“Of course we think we can't take care of ourselves when we become bedridden. I took care of my father for six months, so I wonder whether I will be in his situation one day. We wonder whether the children will take care of us or we should go to the nursing home. It is advantageous to talk in advance because we do not know what will happen to us.” (Respondent 23, 69-year-old man).

Some respondents expressed less trust in their sons and daughters-in-law than in their daughters regarding their potential future care needs:

“Who will take care of me if I get sick?...My sister had daughters, they looked after her, but I don't...I'm thinking who will look after me. When I talk to my children [sons], they say: ‘Mum, we will take care of you!’, but I know my daughters-in-law won't take care of me. It would be helpful to talk beforehand. So doctors will do what children don't do.” (Respondent 26, 73-year-old woman).

#### Obtaining Comprehensible ACP Information

After receiving comprehensible ACP information in their native language, respondents stated that access to more ACP knowledge would facilitate their engagement. They mentioned that doctors should explain ACP to their patients, as they would respond to doctors' questions about their future care preferences:

“We did not know about this [ACP]. First, it must be known and announced...It would be nice if every doctor could talk to his patient about this. They [patients] will appreciate it. They will say: ‘Look, my doctor is taking care of me’.” (Respondent 2, 68-year-old man).

### Raising Children's Awareness About ACP Advantages

Some respondents mentioned that their children are not concerned about ACP and do not take it seriously. They stated that their children's awareness of ACP advantages would facilitate ACP-related conversations. They would prefer that doctors provide ACP information to their children, as well as themselves:

"The doctors should speak about these topics to the children because children aren't concerned about these topics. Even if it comes to their mind, they will have difficulty talking, the doctor should open these issues to them also. The children need to be conscious about these issues." (Respondent 6, 78-year-old woman).

### The Desire to Not Be a Burden

After learning about ACP, respondents stated that they would prefer to engage in it because they did not want to burden loved ones. They felt that ACP would prepare their family members for their potential future poor health, and that knowledge of their preferences could relieve the emotional burden on family members. They did not want their children to be saddened by having to make end-of-life decisions for them:

"I think it would be one million percent useful and I recommend that this information [about ACP] spreads to the Turks living in Belgium. If you tell in advance, the relatives of the older people will feel comfortable honoring their [ACP] wishes." (Respondent 3, 69-year-old man);

"If I say what to do, they act accordingly and don't regret it afterwards." (Respondent 17, 70-year-old man).

### *ACP Barriers*

#### Lack of ACP Knowledge

Respondents' lack of ACP knowledge was the most common barrier to ACP engagement. They had not discussed ACP with their healthcare providers because they did not know about it:

“It is not difficult to talk about this [ACP], but when you do not know about it, you cannot have discussions about it.” (Respondent 22, 76-year-old woman).

#### Language Issues

Some respondents stated that language was a barrier to ACP discussions with Belgian GPs. They said that they could not speak properly about these topics with doctors who don’t speak Turkish:

“It’s hard to talk about these topics with the Belgians. There is silence when you don’t speak the language. You can’t follow when you don’t know the language.” (Respondent 14, 69-year-old woman).

#### Lack of Urgency

Some respondents felt that ACP was premature because their current health situations did not necessitate action. As their wishes could change over time, they did not want to engage in ACP at the moment:

“The disadvantage is that we may not want the decision that we made in the past, because when time passes, the wishes and ideas of the human being may change. Talking before about it [ACP] doesn’t mean anything...It is useful to talk about such issues when you become sick.” (Respondent 19, 65-year-old man).

#### Reliance on Familial Support

Some respondents’ reluctance to engage in ACP was related to the high quality of relationships with their children. They trusted their children to take responsibility for their care and for decision making:

“If I end up in a bad situation, my children will take care of me...I cannot make that decision or say anything about connecting to the machine [ventilator] or not. I leave the decision to my children.” (Respondent 11, 74-year-old woman).

## 259 Fear of Triggering Negative Emotions

260 Some respondents stated that discussing difficult issues during ACP conversations would damage  
261 their morale. They were reluctant to have such conversations, which bring up negative emotions. Such  
262 reactions were related mainly to the fear of death:

263 “I don’t want to think about it because I’m scared. I can’t talk because I’m getting stressed. I  
264 don’t want to remember that bad script [about end-of-life suffering].” (Respondent 7, 67-year-old  
265 woman);

266 “The time of death is certain for all of us, you don’t need to bring it forward. I don’t want to do it  
267 because it will damage my mood.” (Respondent 11, 74-year-old woman).

268

## 269 Fear of Upsetting One’s Children

270 Some respondents feared that their children would be saddened by talks about the ends of their lives,  
271 and that they would make incorrect assumptions, such as that their parents distrusted them. They  
272 preferred to not talk about ACP because of the fear of upsetting their children:

273 “The reason I didn’t talk to anyone about my preferences is to not upset the children. If I say ‘put  
274 me in a nursing home,’ they will get stressed and say ‘you do not trust us!’” (Respondent 25, 69-  
275 year-old woman);

276 “It [ACP] is a difficult subject. It’s actually a very nice thing, but our children will not be happy to  
277 talk about it... We don’t talk so that the children are not upset.” (Respondent 19, 65-year-old man).

278

## 279 **Discussion**

### 280 *Main Findings*

281 This study revealed that some older adults of Turkish origin in Belgium have had ACP discussions  
282 with family members, despite overall unfamiliarity with the term ACP in this population. Informed  
283 individuals tended to consider ACP to be useful and were ready to engage with it. The most commonly

mentioned facilitator was the provision of comprehensible ACP information. Other facilitators were concerns about future care needs, increased ACP awareness among respondents' children, and respondents' wish to avoid burdening their children. The most commonly mentioned ACP barrier was respondents' lack of ACP knowledge. Other barriers were language issues with Belgian-origin GPs, a lack of urgency, reliance on familial support, fear of triggering negative emotions, and fear of upsetting their children.

### *Study Strengths and Limitations*

Study strengths include the researcher's Turkish origin and use of Turkish in interviews, which enabled patients to express opinions freely, facilitating in-depth exploration and reliable information acquisition. Additionally, respondents' sociodemographic heterogeneity allowed us to capture various perspectives, and their sociodemographic characteristics aligned with those of the general population of older Turkish adults in Belgium [from rural areas, with many children,(21) little education,(10) and poor subjective health(22)].

Study limitations include the presence of respondents' children in nearly half of cases in which respondents expressed trust in their children to make future care decisions, which may have introduced bias. Additionally, most respondents had no severe illness, which potentially affected their views about ACP urgency. Finally, the interviewer was a male medical doctor/researcher of Turkish origin committed to improving end-of-life care planning for ethnic minorities, and thus an authority figure, which could have affected interviewees' responses.

### *Interpretations*

The observed lack of ACP knowledge and experience is consistent with findings for ethnic minorities in the US and Canada,(4,23) and with evidence that older adults of Turkish origin lack familiarity with the Belgian healthcare system and do not receive appropriate care relative to native Belgians.(9,24) The competence to access, understand, appraise, and apply health information requires adequate health

literacy,(25) which is less common among less-educated older adults and non-western migrants.(22) The low education levels(10) and illiteracy(9) of many older Turkish adults might contribute to general ACP unawareness. Conversely, the main facilitator in this study was ACP information provision. Knowledge enhancement has been shown to increase ACP prevalence and utilization.(26)

Our respondents' willingness to engage in ACP contrasts with the lack of ACP interest among ethnic-minority older adults in other countries.(6) Several factors may have contributed to our respondents' interest. First, the interviewer provided understandable information, examples, and scenarios involving incurable illness in Turkish; native language use has been confirmed to increase ACP acceptance,(26) and language issues hamper the discussion of sensitive end-of-life issues with healthcare providers.(9,24) Second, our respondents' perspectives align with older Turkish immigrants' awareness of a decline in family caregiving identified in other studies, due mainly to adaptation to western values and norms (e.g., fewer multigenerational households, men's and women's employment outside the home), prompting uncertainty about future care.(9,27) Third, our respondents largely considered ACP to be compatible with their religious beliefs and practices, in line with a previous report of religious leaders' ACP acceptance.(28) The preparatory nature of ACP was expressed as a means of considering death while capable, which instilled a sense of control when respondents became dependent on others. In another study, however, more religious participants were less likely to engage in ACP due to beliefs about God's control of life length and values dictating the use of all available treatments.(29)

Our respondents' perspectives regarding their children were ambiguous. Identified ACP barriers included reliance on family support and the fear of upsetting children with ACP discussions. Such reliance may be explained by two factors. First, in more collectivistic cultures (e.g., that in Turkey), families and immediate social networks assume responsibility for older adults' care,(10) sometimes considered to be a religious duty.(30) Second, older adults could have difficulty making appropriate decisions due to low education levels and health literacy. As in our sample, older Turkish adults in the Netherlands participating in another study identified fear of upsetting their children with end-of-life conversations as a barrier; they had difficulty openly discussing their late-life care desires and needs with

family members.(27) Conversely, respondents' desire to avoid burdening their children and lack of trust in their children concerning future care needs were identified as ACP facilitators in this study. The fear of burdening one's children with later care needs has been documented among first-generation Muslim immigrants in the US.(31) The reduced trust in children is related to the decline in family caregiving in this immigrant population.(9,27) Another identified facilitator was children's increased awareness of ACP advantages. A previous study confirmed that healthcare providers must understand that decision making seldom involves one-on-one communication with patients of Turkish origin; family members often function as care management groups with "equal" say.(32) Family members' presence also increases the likelihood that patients complete advance directives.(2) Thus, ACP knowledge could help Turkish patients and family members make informed choices and facilitate effective communication about future care.

Other barriers identified in this study, such as the lack of urgency and fear of triggering negative emotions, are well known and not specific to this population.(4,33)

#### *Practice and Research Implications*

The responses provided by respondents in this study suggest that older adults of Turkish origin in Belgium need to be more informed and aware of ACP. Thus, we recommend that healthcare providers use understandable, translated information with relatable examples, adapted to the lower reading and health literacy levels of this group.

As ACP views differ among patients of Turkish origin, ACP discussions should be consistent with individual patients' values, needs, and desires.(34) A deeper understanding of ACP barriers may help healthcare providers to prioritize and address them.(33) When patients' family members play important roles in decision making, healthcare providers should inform Turkish patients and their children about ACP advantages to facilitate conversations. When a language barrier exists, professional interpreters should be used, especially for emotionally difficult and complex conversations (i.e., those about ACP), to increase the likelihood of effective communication.(26,35)



Additional research is needed to clarify how patients' children's ACP perspectives can be leveraged to enhance healthcare provider–patient–family member communication and shared decision making. Research on ACP for patients of Turkish origin with palliative care needs would reveal whether patients' views change in this context. Finally, research conducted with older adults from other ethnic minority groups in Belgium would broaden our knowledge of diverse ACP perspectives, enhancing the ability to provide culturally adapted and sensitive ACP information to specific populations.

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Table 1

**Sociodemographic Characteristics of the Sample ( $n = 33$ )**

Characteristic	<i>n</i>
Age (years)	
65-74	25
75-84	8
Sex (male)	16
Educational level	
Illiterate/no degree	15
Primary	15
Bachelor's/master's degree	3
Childhood residence (rural)	27
Profession before retirement	
Housewife	8
Laborer	22
Employee/tradesperson	3
Marital status	
Married	23
Widowed/divorced	10
Living arrangement	
Alone	6
With spouse	17
With children or spouse and children	10
Residence in Belgium (years)	
10-29	7

## ACP VIEWS OF OLDER TURKISH ADULTS IN BELGIUM

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40-59	25
60-69	1
Number of children	
1-2	5
3-4	20
5-7	8
Self-identified health status	
Good	13
Neutral/poor	20
General practitioner's background	
Turkish	16
Belgian	17



486 Fig. 1. Interview topic guide.

**The purpose of the research is to explore your views on advance care planning. There are no wrong answers.**

**On confidentiality: everything will be anonymized.**

### **Introductory questions**

How would you describe your state of health?

Do you have any questions regarding your concerns and worries about your healthcare in the latter part of your life?

Have you spoken to anyone about these matters? Why?

Have you done something about your concerns and worries?

Have you planned something for the future?

Can you explain more?

### **What knowledge does the interviewee have?**

What do you know about advance care planning?

If the interviewee knows nothing, explain:

“Advance care planning” is thinking ahead about the future. This is about discussing your future healthcare wishes with your relatives and your doctor. It is about voicing your wishes while you are still in good health, and are able to express your thoughts and wishes.

Older people do this planning to communicate their thoughts and wishes regarding their healthcare in the future, and even concerning end-of-life situations. Such planning is important for people to prepare for situations where, as a result of their future illnesses, they are unable to speak or make decisions. Thus, it enables others to take your wishes into account as much as possible.

Did you know that you could communicate your wishes in advance for situations such as this?

How do you feel about this?

**What experience does the interviewee have?**

Some older people might have already experienced instances when this “advance healthcare planning” would have been useful with some of their relatives.

For example, if a relative falls seriously ill or has an accident and loses consciousness, it is up to the family and the doctor to make decisions on their behalf because of the patient's incapacity to communicate their own wishes.

Have you come across something like this?

Have you yourself ever thought about your future healthcare?

Have you yourself ever looked up something about that?

Can you explain more?

**What are the interviewee's views?**

Before you become severely ill, do you wish to discuss your future wishes with someone in advance?

Why?

How do you feel about discussing illness and death?

**What are the barriers and facilitators?**

In your opinion, what makes it easier or what would make it easier to talk about these subjects?

In your opinion, what makes it harder to talk about these subjects?

**Final question**

Do you think what we have discussed would be helpful to the Turkish community in Belgium? Why?

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491 Box 1. Themes related to ACP among older Turkish adults in Belgium

Lack of ACP knowledge and ACP experience with a healthcare provider
<p>ACP Views</p> <p>ACP is useful</p> <p>ACP is not “against religion”</p>
<p>ACP facilitators</p> <p>Concerns about future care needs</p> <p>Obtaining comprehensible ACP information</p> <p>Raising children’s awareness about ACP advantages</p> <p>The desire to not be a burden</p>
<p>ACP barriers</p> <p>Lack of ACP knowledge</p> <p>Language issues</p> <p>Lack of urgency</p> <p>Reliance on familial support</p> <p>Fear of triggering negative emotions</p> <p>Fear of upsetting one’s children</p>

492 ACP, advance care planning.