Translating and Adapting the Life Wish Cards for Turkish-Origin Patients in Belgium: Supporting Advance Care Planning in General Practice

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Abstract

Introduction: Advance care planning (ACP) supports individuals to make informed decisions about their emotional, social and spiritual needs and future healthcare based on their own values and preferences. However, ACP participation remains limited among ethnic minority groups in Belgium, particularly among those of Turkish origin. Barriers such as language differences, cultural taboos regarding death and limited health literacy often make ACP discussions difficult.

Objective: This study aimed to translate and culturally adapt the Flemish version of the "Go Wish" cards into Turkish and to investigate how these adapted cards support ACP discussions between general practitioners (GPs) and patients of Turkish origin in Belgium.

Methods: A three-stage qualitative design was used. First, the cards were translated into Turkish. In the second stage, they were culturally adapted with a reference group of Turkish-speaking community members and professionals. In the third stage, six Turkish-speaking GPs tested the cards in clinical practice with patients of Turkish origin and participated in semi-structured interviews about their experiences. The interviews were transcribed, translated, and analysed using reflexive thematic analysis in NVivo 14.

Results: The adapted cards enabled GPs to initiate sensitive end-of-life discussions in a structured and culturally appropriate manner. Patients responded positively and generally welcomed the opportunity to express their values and discuss their preferences. Patients often linked their wishes to family concerns, and the cards helped to reduce communication barriers, and strengthen the doctor-patient relationship. However, GPs noted challenges such as limited time during consultations, emotional difficulty in raising the issue and the need for more training on ACP. Recommendations included reducing the number of cards, involving other professionals such as social workers and integrating the cards into routine care.

Conclusion: This study demonstrates that culturally adapted Life Wish cards can effectively support ACP discussions between Turkish patients and GPs. Despite the persistence of cultural and structural barriers, the findings highlight the potential of such tailored tools to further promote ACP in a variety of clinical settings.

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Abbreviations

ACP	Advance care planning
PSDA	Patient Self-Determination Act
GP	General practitioner
EOL	End-of-life
NGOs	Non-governmental organizations
GSK	GlaxoSmithKline
UCL	Université Catholique de Louvain

Introduction

Advance care planning (ACP) is a process that enables individuals to make thoughtful decisions about their values and goals in physical, psychological, social and spiritual areas and what type of healthcare they would like in the future (1). The meaning of advance care planning has expanded over time, shifting to a process that includes not only legal forms but also conversations between patients, families, and healthcare providers (2). It encourages open communication between patients, their families, and their healthcare providers, ensuring that medical decisions are consistent with the patient's values and personal preferences (1). The idea was first proposed in 1969 by Luis Kutner with the concept of "Will to Live," a concept that aimed to give patients greater control over their healthcare decisions while also legally protecting healthcare providers (3). In the United States, ACP was formally recognized with the enactment of the Patient Self-Determination Act (PSDA) in 1991. Belgium granted individuals the legal right to refuse treatment and to appoint a healthcare representative with the Patient Rights Act of 2002 (4).

Although the importance of ACP is increasingly recognized, participation remains relatively low in many Western countries (5). In the United States, only 18% to 36% of adults have completed ACP, and in Belgium and the Netherlands, only 34% of non-sudden deaths included ACP discussions with a general practitioner (GP), and only 8% of these discussions resulted in formal written plans (4). Given Belgium's cultural diversity, it is also important to include minority groups in the process of ACP (11,23). Individuals of Turkish and Moroccan origin, most of whom are Muslim, represent significant communities within the country. Approximately 2.1% of the Belgian population is of Turkish origin (22). However, studies have shown that end-of-life (EOL) discussions are relatively rare among patients of Turkish origin (23). This highlights the importance of promoting ACP to better serve these communities. They tend to rely on their faith and family to make end-of-life decisions, but some understand its importance when informed or facing serious illness (24). Promoting ACP in these communities may help individuals make more informed decisions, ease the emotional burden on their families and ensure that their care aligns with their personal wishes (12,13). Low use of ACP in these groups, as in general, is affected by four main barriers: lack of awareness, psychological resistance, cultural and religious beliefs, and inadequate social support (6). Patients often find ACP documents overwhelming because of complex language and lack of clear instructions (7). Similarly, many healthcare providers are hesitant to bring up ACP for fear that it may upset patients, destroy their hope, or make them uncomfortable talking about death (8,14).

Cultural and Language Barriers in ACP Discussions

Cultural and religious values play an important role in how people view ACP, especially within ethnic minority communities (25,26). These communities often have different views on illness, death, and medical care than mainstream Western perspectives (9). Why people from minority backgrounds are less likely to participate in ACP is often attributed to challenges like language barriers, limited health literacy, mistrust of the healthcare system, and cultural expectations around family involvement in medical decision-making (10,11).

Studies from Belgium have shown that patients of Turkish and Moroccan origin are unfamiliar with the concept of ACP and have lower rates of participation in discussions about EOL (11–13). This limited participation may be due to a number of barriers as well as a general unfamiliarity with the healthcare system and the role of ACP within it. Limited awareness of ACP, language difficulties, and religious factors contribute to their reluctance (11,24). Although some research suggests that many older Turkish patients see the benefits of ACP and are open to discussing it, the best ways to introduce ACP into primary care for this population remain unclear (11,12).

Go Wish cards as a communication tool for ACP in general practice

Family physicians are ideally positioned to lead ACP discussions because of their long-term relationships with patients and their understanding of their cultural context, GPs can effectively guide conversations about future care. Additionally, as they coordinate care for patients with chronic conditions or those approaching the end of life, GPs are naturally the first point of contact to discuss care preferences (14,15).

A variety of tools, including checklists, conversation guides, and card games, have been created to help initiate ACP conversations in different settings (16, 17, 27). The Go Wish card game, originally developed in the United States, is one such tool that has been successful in encouraging patients to reflect on and express their EOL care preferences (17). Studies on the Go Wish cards in palliative care, oncology, and medical education have shown that they aid in facilitating both structured and open-ended discussions. Patients find it easier to articulate their values and priorities (19,20). However, for these tools to be effective across various populations, they must be culturally and linguistically adapted to meet the specific needs of the communities using them (18). The Go Wish cards have since been adapted for use in a number of countries, including Sweden, Switzerland, Belgium, France, Italy, China, Vietnam, and several Pacific Islands (18). These adaptations demonstrate how flexible and culturally adaptable the cards can be when used to talk about death and dying. Although a culturally adapted version of the Go Wish card game has been developed for use in Flanders (Belgium), referred to locally as *Levenswensen* cards —including immigrant communities such as those of Turkish and Moroccan origin— (18), this version does not address the specific linguistic and cultural needs of Turkish-origin communities, despite the significant presence of this population.

Given how important cultural sensitivity is in ACP, this study seeks to fill an existing gap by translating and adapting the Flemish *Levenswensen kaarten* (translated to English: Life Wishes cards) for Turkish-speaking patients, and by assessing how effective these cards are in supporting ACP conversations in general practice, from the perspective of GPs.

Research Aim, Questions

Research Aim

The aim of this study was to translate and culturally adapt the Life Wish cards into Turkish and investigate their impact on initiating or facilitating ACP conversations between Turkish-origin patients and GPs in Belgium.

Research Questions

- What are GPs' experiences of using the Life Wish cards in ACP discussions with patients of Turkish origin?
- How do patients of Turkish origin experience and view ACP discussions using the cards, according to the GPs?
- What are the barriers and facilitators to ACP, including cultural and religious factors, observed in discussions using the Life Wish cards?
- What suggestions do GPs have to improve the cards?

METHODS

Study design

This qualitative study was conducted in Flanders and Brussels (Belgium) to investigate whether translated and culturally adapted Go Wish cards, locally called Life Wish cards, could effectively facilitate ACP discussions with patients of Turkish origin. The research focused on the perspectives of GPs experienced in caring for patients with Turkish origin.
The study consisted of two main components:
1. A multi-step translation and cultural adaptation process of the Life Wish cards (Phase 1 and 2).
2. A qualitative phase involving semi-structured interviews with Turkish-speaking GPs to assess the usability and perceived impact of the Life Wish cards in ACP discussions (Phase 3).

Phase 1 and 2: Translation and cultural adaptation of the Life Wish cards

This study used the Dutch version of the Go Wish card game, locally known as Life Wish cards. The Dutch version consists of 39 cards: 37 with pre-written statements and two blank “joker” cards.

Phase 1: Forward Translation

The bilingual researcher (DP and HD) translated the original Life Wish cards into Turkish and after the translation the two bilingual researchers discussed the entire translation card by card until consensus was reached for all cards.

Phase 2: Negotiated Consensus

Since the aim was to develop a card game accessible to all Turkish adults in Belgium—regardless of whether they were facing a life-threatening illness—it was essential to include a wide range of perspectives during the adaptation process. A reference group was formed (n=8), composed of individuals from diverse backgrounds, including researchers, religious scholars, physicians, and professionals working in non-governmental organizations (NGOs) (Table 1). Members were recruited through the researchers’ professional networks, based on the following criteria: age 18 or older, fluency in Turkish, good understanding of Dutch, and demonstrated interest in ACP. This inclusive approach ensured that both cultural and community values were integrated into the adaptation of the Life Wish cards.

The original Dutch and Turkish translations were shared with a reference group via email, along with suggestions for linguistic accuracy, a suitable Turkish name for the card game, and suggestions for appropriate cultural adjustments for patients with Turkish origin. During a face-to-face consensus meeting, all cards that received feedback (especially those with translation concerns or culturally sensitive content) were discussed in depth until full agreement was reached. Thirteen out of 37 cards were accepted as is without any changes. The wild cards were left as 2, as in the original version. The other 24 cards were discussed one by one to reach a consensus on the translation and expression style, and adaptations were suggested by the Turkish origin stakeholders, taking into account the sociocultural structure here. Corrections were generally made for cultural reasons and to better adapt to the Turkish language structure.

Table 1. Composition of the reference group

Participant Role	Affiliation / Workplace	Sector
English Teacher	Flemish Secondary School	Education
Islamic Religion Teacher	Flemish Secondary School	Education / Religion
Clinical Science Lead	GSK (GlaxoSmithKline)	Pharmaceutical Industry
Specialist in Physical Medicine and Rehabilitation	Group Practice	Healthcare
Project Officer	Non-Governmental Organization (NGO)	Civil Society / NGO
Manager and President	NGO	Civil Society / NGO
Director	Flemish Secondary School	Education
Postdoctoral Researcher	Université Catholique de Louvain (UCL)	Academia / Research

Phase 3: Pre-Testing

The Turkish version of the Life Wish cards was tested in the daily practice of GPs who work with Turkish-origin patients. We explored how practical the cards were to use, how well they fit the cultural context, and whether they helped start meaningful conversations about what matters most to patients in future care planning through semi-structured interviews.

Participants and recruitment

Inclusion Criteria
General practitioners were invited to participate if they met the following criteria:
• Currently practicing in Brussels or Flanders
• Experience working with patients of Turkish origin
• Fluent in both Turkish and Dutch
• Willing to take part in an interview

All participants were recruited by email and received comprehensive information about the study in advance.

Study procedure

The study procedure involved the implementation of the final Turkish version of the Wish for Life cards in daily general practice among GPs of Turkish origin. The cards were distributed after a

translation and cultural adaptation process. Participating GPs were asked to use the cards in ACP discussions with their patients and then share their experiences through interviews. GPs introduced the cards to patients and asked them to take the set home and select the ten statements they found most important. During the following appointment, they discussed the cards the patients had chosen. For patients with particular needs, such as those who were illiterate, some GPs adapted their approach by reading the cards aloud and discussing the options together, rather than providing the cards for independent selection. Following the patient consultations, interviews were conducted with the GPs.

Using the cards in real-life consultations allowed the researchers to explore how practical the cards were to use, how well they fit into the cultural context, and whether they helped initiate meaningful conversations about what was most important to patients in planning their future care.

Setting

Every interview took place one-on-one in the GP's own practice—just the researcher and the participant. We deliberately held these sessions in the GPs' workplaces because familiar settings tend to put people at ease. When you're comfortable, you're more likely to speak openly, and that's exactly what we needed for honest, meaningful conversations.

Data collection

Each interview was conducted one-on-one, face-to-face. Interviews were conducted in the GPs' own medical offices to provide a familiar and comfortable environment to encourage open and honest discussions. A semi-structured interview format was used to elicit more in-depth, open-ended responses, allowing the researcher to explore participants' perspectives, experiences, and thoughts on culturally sensitive aspects of ACP. Interviews were conducted in Turkish to ensure clear communication and eliminate potential language barriers. Participants were informed about the purpose of the interview, reassured that there were no right or wrong answers, and encouraged to share their thoughts freely. Written and verbal permissions were obtained in Turkish, including permission to audio record.
They were explicitly assured that their responses carried no judgment and were encouraged to speak freely about their professional experiences. Informed consent was obtained verbally and in writing (in Turkish), with explicit agreement to audio recording.
Interview durations ranged from 20 to 40 minutes (average: 25 minutes). Discussions focused on four main areas:

1) GPs' own experiences of EOL discussions with patients of Turkish origin,

2) GPs were asked how patients responded to the Life Wish cards. Whether they find them helpful or challenging to initiate conversations,

3) the difficulties and conveniences in patients' participation in ACP discussions with cards and the effects of Turkish cultural values and religious beliefs on this and

4) GPs' contributions and adaptations to the cards based on interviews with Turkish-origin patients

Data analysis

All interviews were transcribed verbatim and checked for accuracy against the audio recordings to preserve contextual meaning. The interview transcripts were translated into English using a

forward–backward translation method to ensure accuracy and preserve the integrity of participants' responses.
To maintain confidentiality, interview transcripts were not shared publicly and were only made available to the research team. Audio recordings were securely stored for reference only throughout the analysis process. Data protection was maintained anonymously throughout the research process. NVivo 14 software supported the management, coding, and organization of the data.
Two researchers (DP and HD) independently familiarized themselves with the data by reading transcripts multiple times and highlighting initial impressions. Using open coding, meaningful quotes were inductively coded. New codes were added as needed during the coding process. Following initial coding, codes were grouped into structured categories and a preliminary coding tree was developed. As analysis continued, these codes were continually reviewed, refined and organized into more fundamental themes. Similar themes were brought together to ensure consistency of the analysis, and more complex themes were divided into subthemes to better reflect the layers of meaning in the data. The researchers (DP and HD) made reflective and collaborative evaluations throughout the process, ensuring that the resulting themes represented the data in a clear, comprehensive and meaningful way. The researchers discussed the results among themselves until they reached a consensus, and the entire research team held also online discussions to enhance triangulation, limit bias and in order to accurately reflect the process and interpret it in the most reliable way.

Ethical considerations

Participants were informed of the voluntary nature of the study and their right to withdraw at any time. Confidentiality and anonymity were strictly maintained, and no identifying information is included in the final report.
Ethical approval for this study was granted by the Medical Ethics Committee (Commissie Medische Ethiek) under B.U.N. 1432020000317. The study, titled "The translation and cultural adaptation of the Go Wish cards for the Belgian context: a card game to discuss advance care planning and end-of-life preferences," received a favorable opinion on 22 December 2023. The committee reviewed and approved the following documents regarding the adaptation of the cards for people with a Turkish background (cf. Appendix 4)

RESULTS

Phase 2: Cultural Adaptations

Following the initial translation of the Life Wish cards in phase 1, we worked with a reference group to adapt specific cards. These changes were intended to make the cards more meaningful and culturally appropriate for patients of Turkish origin.

Some cards have been slightly adapted to reflect culturally specific values, beliefs, and preferences that differ from those in the original set. For example, Card 7, originally stated as “Dying at home,” has been adapted as “Dying in my own bed.” Although a subtle change, this change reflects a cultural emphasis on one’s private personal space, particularly the familiarity and comfort of one’s own bed, rather than the broader and sometimes abstract concept of “home.” Similarly, Card 27, “Be at peace with God,” has been reworded as “To be content with Allah.” Although the change is subtle, the adapted version more closely reflects the way Muslims express spiritual acceptance; specifically, the idea of being at peace with the divine will can also be interpreted as “being at peace with God’s will.”

In another example, the original card 36 “Being able to choose when and how I die” was adapted as “Knowing where I will die or be buried”. Although the original phrase was not explicitly related to euthanasia, in Turkish and Islamic cultural contexts, choosing the time and manner of death is something that only God knows, and can easily be associated with practices such as euthanasia; and it is not accepted. In fact, the phrase can be interpreted more broadly, such as wanting to die peacefully or with dignity. However, for many Muslims, life and death are seen as being in the hands of God, and the idea of actively choosing the moment or manner of death can be disturbing or even inappropriate. This cultural and religious sensitivity can lead people to misunderstand or reject the original phrase.

Linguistic/Nuance Adjustments. Some of the translated cards have been adjusted slightly to better reflect how certain ideas are expressed naturally or emotionally in Turkish, even though the core meaning remains the same. These are not major changes in content, but rather subtle changes that make the expression more familiar to Turkish speakers or more reflective of their emotional mood. For example, Card 1, which was originally stated as “Not being in pain”, was translated as “Not having pain or suffering”,”. Although the difference may seem minor, the addition of the word “suffering” introduces a stronger emotional nuance that better reflects the way suffering is commonly defined and experienced in Turkish culture. Another example is Card 13, “Keeping my sense of humour”, which was adapted as “Being able to keep my joy for life”. In this case, “sense of humor” has been interpreted more broadly, because Turkish expressions often associate well-being with “joy of life”, making the translation more culturally meaningful.

Structural or Contextual Reframing. These adaptations are not completely different from the original cards, but they have been tweaked slightly to reflect how emotions and relationships are expressed among Turks, especially in the context of health or family. One example is Card 31. The original version read, “Having someone to speak up for what I think is important” This was adapted to “Having someone take care of the things that are important to me” This may seem like a small change, but the adapted version is a stronger, more emotional way of saying it. It reflects how people in Turkish families often show care — not just by talking, but by taking responsibility for things that are important to their loved ones.

After this discussion, a preliminary version of the Turkish Wishes for Life card deck was finalized, printed, and prepared for distribution to participating GPs. (Table 2)

Table2: Overview of adaptation cards

No	Ordinal Life Wish cards	Adaptation and final version
1	Not being in pain	Not having pain or suffering
2	Not being short of breath	Not experiencing shortness of breath
3	Being neat and tidy	Being clean and well-groomed
4	Not being afraid	Being free from fear and anxiety
5	Having physical contact	Having human touch/contact
6	That my family is prepared for my death	That my family is prepared for my death
7	Dying at home	Dying in my own bed
8	Being able to say goodbye to my loved ones	Being able to say goodbye to my loved ones
9	Being able to share my memories and accomplishments with others	Being able to share my memories and accomplishments with others
10	Being able to take care of unfinished business with family and friends	Being able to talk about unfinished business with family and friends
11	Being treated the way I wish to be treated	Being treated the way I wish
12	Keeping my dignity	Maintaining my dignity
13	Keeping my sense of humour	Being able to keep my joy for life
14	Being surrounded by good friends	Having my friends around me
15	Having someone who listens to me	Having someone who listens to me
16	Not being a burden to my family	Not being a burden to my family
17	Being able to do something for someone else	Being helpful to others
18	Being able to talk about what scares me	Being able to talk about my fears
19	Being surrounded by my family	Having my family around me
20	Feeling that my life is complete	Feeling that my life has come full circle
21	That the doctor sees me as a whole person	Having a doctor who knows me well
22	Not dying alone	Not dying alone

23	Being clear-headed	Being mentally clear
24	Being able to pray	Being able to pray and worship
25	Having a spiritual counselor as support	Having someone who can offer spiritual support
26	Being able to talk about death	Being able to talk about death
27	Be at peace with God	To be content with Allah
28	Getting my financial affairs in order	Having taken care of my financial matters
29	Knowing how my body and mind will change	Knowing how my body and mind will change
30	Avoid discussions by ensuring my family knows what I want	Avoiding conflict by making sure my family knows my wishes
31	Having someone to speak up for what I think is important	Having someone take care of the things that are important to me
32	Being able to trust my doctor	Being able to trust my doctor
33	Having a healthcare professional I feel comfortable with	Having healthcare staff I feel comfortable with
34	Arrange my funeral in advance	Having my funeral arrangements prepared in advance
35	Not being dependent on machines to keep me alive	Not being kept alive by machines
36	Being able to choose when and how I die	Knowing where I will die or be buried
37	Being able to record my choices	Being able to define my own wishes
38	Joker	Joker
39	Joker	Joker

Phase 3: Pre-testing

Seven general practitioners met the study's inclusion criteria. Of these, six agreed to participate. One GP declined due to a lack of eligible patients and limited time. After the consultations with patients, we interviewed the participating GPs to learn about their experiences with using the adapted cards. Below, we describe the main themes that emerged from these conversations.

1-Experiences of GPs

Patients were surprisingly open to EOL conversations. Before the interviews, some physicians thought that patients of Turkish origin might be closed to discussing end-of-life issues. However, after the interviews, they stated that they saw the opposite. One GP noted, *"According to my culture, even as a doctor, asking a patient what they think about death can feel like suggesting they are on that path — as if you're causing them pain. That's what I thought, but I realized that's not the case. People are actually open, open to questions; they just expect us to show some interest"* (GP, U). Another GP explained, *"I hadn't really given much thought to having these kinds of conversations or discussing such topics. Initially, I was concerned about how patients might react, but once I explained the situation, they responded very positively"* (GP, H).

Most GPs found that patients responded to the cards with surprising openness and positivity. The process went more smoothly than expected. One GP shared, *“I didn’t face any difficulties. The process went quite well, and my patients didn’t find it strange at all... They accepted it and they gave their answers”* (GP, I). Another added, *“It wasn’t difficult at all. In fact, patients were eager... They really enjoyed it”* (GP, M).

The cards made difficult conversations easier.The cards made difficult conversations easier. GPs emphasized that the cards helped them to talk about these issues and include helpful tips. One said, *"The cards made my job much easier. They provided clues about what could be thought about in particular. I think using cards is a great approach because they give us hints"* (GP, S). Another remarked, *"Normally, during a conversation, you don’t ask certain questions. But thanks to these cards, you can ask them"* (GP, M). They also stated that the cards helped conversations flow more smoothly and naturally: "*Thanks to these cards, I can approach such patients more easily. Instead of asking direct questions, it’s a softer format*" (GP, U).

The cards gave structure to the conversation. The Life Wish cards helped doctors bring more structure to their conversations. The cards made it easier to talk about end-of-life care in a clear and meaningful way. One GP reflected, *"I never asked any of these EOL questions before. But now, thanks to these cards, I have at least formed a structure in my mind. I now think more clearly about how to approach a patient"* (GP, U). Some doctors said the cards also helped patients think more clearly about their future. *"Of course, you can also ask these EOL questions during a normal consultation, but these cards address different kinds of topics. In this way, they made concrete plans about the future in their minds"* (GP, HE).

Closer doctor-patient relationship. Conversations with the cards not only helped to gain information but also improved the patient-doctor relationship. One GP noted, *"This conversation also strengthened the relationship between my patients and me. They told me very special things, we experienced very emotional moments together, our eyes filled with tears"* (GP, S).

The cards helped GPs recognize communication gaps between them and their patients. *"For instance, I realized that I had never asked him these questions when he was ill. But that's terrible because he felt very lonely"* (GP, U). Another GP said, *"To tell the truth about her, the subject was never brought up. Until she used these cards, of course. Never before" (GP, HE).*

Own confrontation. This process also made GPs reflect on themselves. One said, *"Reflecting on my own thoughts, I realized I have a lot of fear as well... I started wondering, will my children come and visit my grave there? After all, soil is everywhere... But in our society, there's a certain mindset about this — like it's different because this isn't a Muslim country"* (GP, U).

2- Patient reactions and emotional responses to the Life Wish cards

The cards led to emotional reactions from patients. Some patients became visibly emotional when discussing their preferences for end-of-life care, particularly on sensitive topics such as nursing home placement. One GP shared, *"When they say, 'When I become bedridden, just put me in a nursing home,' it gets a bit emotional"* (GP, HE). Another added, *"One of them cried quite a lot because of the questions due to the cards. The first one I did—should I say he was deeply saddened?"* (GP, M).

Some patients already engaged in end-of-life discussions with their families. GPs reported that several patients had already talked about these topics with loved ones, indicating that such conversations may be more common than expected. *"The three patients I spoke to were already discussing these topics normally... So, they were already talking about it among themselves... 'We've already talked about this with our family; everyone knows what to do if I become ill or pass away'" (GP, I).*

Also, some patients stated that that these conversations should take place regularly, as preferences and needs can change over time. *"They said these cards could be discussed repeatedly every five years... because a person's perspective can change" (GP, S).*

Family concerns shaped patients' EOL wishes. According to GPs, some patients stated that they did not want to be a burden to their families and preferred nursing homes to avoid burdening their relatives with responsibilities." *They said that they would rather continue their lives in a place like this (nursing home) than be left alone or dependent on the care of their families"* (GP, HA)

Cards helped patients think about and share their EOL preferences. The cards were indeed effective in identifying and prompting patients' EOL preferences, such as where they would like to die and how they would be cared for during that time. *"For example, they said things like: 'Where would I want to die? Would I prefer to die in a hospital? How should my doctor approach me during that period?' They expressed that they would want these preferences to be known."* (GP, S) This highlights the importance of early discussions about EOL care and allows patients to clearly express their wishes.

As one GP noted, the cards opened up questions they had not yet considered. *"It was an opportunity to talk about certain topics. I also noticed that for the patients, it helped them think about things they hadn't considered before or questions about the future that hadn't crossed their minds yet. At least, they started to think about them."* (GP, HA)

Family bonds. GPs noted that the process helped some patients to start conversations about such issues with their children. One GP said,*"…In fact, the patient said, 'I actually need to tell you about these things (nursing home admission,) in advance, I need to explain them, right?' he said to me later. He said I need to tell my children, too. These are actually important things, he said."* (GP, HE)

In some cases, the cards helped to strengthen the bond between families. *"But on the other hand, being with their children and hearing directly from their mother or father's own words can be*

important. For them, perhaps the children — for example, I hesitated to talk to my father about that topic. Maybe they would hesitate too. But since we opened the topic together, it also opened a door for them. They can now talk to their mother or father about it." (GP, M)

Writing this information down can also help them communicate better with families during difficult times, as one GP noted, *"When I write this in her file, if something bad happens, I will also inform her children. This means the process will proceed more smoothly when discussed together."* (GP, U)

Family ties always came to the fore in discussions. Many patients emphasised their ties to their families and the emotional difficulty of parting with them. *"I think the hardest thing for them was breaking away from their families. For example, they all said that of course I want to be with my family."* (GP, I)

Patients and GPs agreed that planning ahead would benefit both patients and their families. *"They said they would definitely want these things to be documented."* (GP, S)

"They thought it was very important to plan things in advance. In fact, they even said, 'Make a note of it in the file.'" (GP, HE)

3- Barriers and supporting factors in ACP conversations

Supporting factors

Cards made discussing EOL care easier. Life Wish cards served as a valuable tool for GPs, facilitating the initiation and guidance of ACP discussions. GPs stated that the cards helped patients focus on their values and preferences, enabling more effective and meaningful conversations about EOL care. *"With these cards, you can have a discussion based on the cards. For example, it is guiding. That's why I think it's good. Also, the patient chooses the 10 most important things, that's good in my opinion. You know, they are focused on that subject, and you can ask them. I think it was good in that way. For example, they say this is important, then they try to talk about it."* (GP, HE)

Another noted that the cards gave GPs as well as patients tips, *"I think it's very good to have these cards. Because the cards give us clues. It's also very good to have jokers. Patients may think about things we don't think about. The cards make my job easier, too."* (GP, S)

Facilitating conversations about death in Turkish patients. The Wish for Life cards helped reduce anxiety and fear associated with cultural taboos such as death among Turkish patients. *"Of course, since discussing these kinds of topics with Turkish patients is a big taboo, talking about death was initially very difficult. Culturally, even as a doctor, I realized that I had never directly talked to a patient about death. Yet this is a part of life — you live, and then you die. In fact, it's a big part of life; many people end their lives with this fear. Thanks to these cards, I understood that if we had these conversations, this anxiety and fear would actually diminish — because everything becomes easier when shared." (*GP, U)

Facilitating end-of-life discussions for elderly and chronically ill patients. Some participants stated that the cards could be more meaningful, especially for the elderly, those living alone, or individuals with chronic diseases, *"But with elderly people, I think it's as if death feels closer, and illnesses have increased. I felt that bringing up this topic might be a bit difficult, but thanks to the cards, it might be easier to open the conversation."* (GP, M). They also stated that for these groups, it was more important to put their preferences in writing, *"Maybe this topic is more relevant for certain groups. It could be more important for people who live alone, those without family support, or socially isolated individuals. For them, having a documented plan could be significant."* (GP, I).

Barriers

Time constraints and workload. ACP consultations can be a time-consuming process. GPs noted the difficulty of allocating enough time for such consultations:

"Of course, there's also the time factor. Right now, it's very busy and crowded, so it takes some time as well." (GP, HE)

Emotional Barriers. Some GPs stated that asking questions about death caused them to worry about upsetting the patient. They also mentioned that personal emotional barriers made it difficult to bring up these topics:

"I was going to do it with my father first. At the last moment, I changed my mind. Because seeing those questions reminds you of death. And I was afraid it would remind my father of death and upset him, so I didn't do it." (GP, M)

Another GP stated that asking questions about death caused them a fear of causing pain:

"Even though I am a doctor, when you ask, 'What do you think about death?' it feels as if the patient is already on that path, as if you are causing them pain." (GP, U)

Lack of Training. Lack of training in the ACP process can prevent GPs from effectively conducting such conversations. Some GPs mentioned that seminars and training programs would be useful to learn more about ACP:

"But I think it would be more useful to inform family doctors a bit more about this. Because this is not a topic we are used to. We are not accustomed to constantly talking about it, nor are we used to thinking about such things. I believe there could be seminars or informational sessions organized by Riziv for family doctors. This could help ensure they don't forget about this topic, that they address it, and engage in conversations with patients." (GP, HA)

Patients' Fear of Confronting Death. Some patients noted that confronting the topic of death can be particularly challenging for the elderly. This was particularly evident in a context where death is often taboo in Turkish culture:

"There was something — they all immediately thought about death. For example, they talked about being close to death. Because when topics like shortness of breath, graves, and similar things came up, it directly reminded them of the end of life... The questions were good, but they constantly reminded them of death…I think talking about death is harder for the elderly. Because it feels as if their time is running out." (GP, M)

Similarly, according to GPs, death and end-of-life care were reported to be difficult topics to discuss among Turkish patients at first, *"Of course, talking about such topics with Turkish patients is a big taboo, so talking about death at first is very difficult."* (GP, U)

Religious and cultural barriers. For a small number of patients, cultural and religious beliefs could also be an obstacle. Some patients stated that they felt that they were culturally obliged to care for their families and therefore did not leave their care plans to their families: *"We are Muslims. In Islam, there's an obligation to care for parents — we are required to do so. Regarding these matters,*

some people feel that because they are Muslim, they are obligated to care for their parents or their in-laws, and they say, 'I will take care of them because I have to...." (GP, M)

4-Recommendations for Improving the Levenswensen Cards

Reducing the Number of Cards. Many GPs noted that certain Life Wish cards contained overlapping content, and it was suggested that similar cards be simplified or combined, *"Ah yes, some questions were very similar to each other, and some of the cards were also quite similar. For example, 'not being afraid' and 'being able to talk about what scares me', or 'arranging my funeral in advance' and 'being able to choose when and how I die.' I even grouped them a bit. For example, when patients choose, say, ten cards, there were often many that were quite similar to each other."* (GP, HE)

"The disadvantage of the cards is that some topics are sometimes quite similar. I wouldn't necessarily present this as a disadvantage, but maybe we could reduce them or combine two cards. For example, things like being with my friends, being with my family, or not to die alone — they generally want all of these together. Maybe we could simplify it." (GP, S)

Involving Social Workers or Psychologists in the Process. Involving social workers or psychologists in the process can be helpful because the conversations take up so much time. GPs stated that, "As a family doctor, doing this solely within a consultation is difficult for me. I'm speaking for myself, of course. Because we are already just barely managing to keep up with consultations. But I actually thought more about involving a social assistant or a psychologist for this." (GP, I)

Integrating ACP into Routine Practice. Some participants stated that it would be more effective if the cards were applied systematically and regularly, rather than only in certain situations, *"Out of necessity, when a palliative care file is started, arranging such a consultation and opening a file for that patient, making a note of something, if it were mandatory in some way—wouldn't that actually be better?"* (GP, HE).

In this context, it was suggested that the cards be kept as a tool that could be pulled out of the drawer when necessary or linked to the palliative care files. She said, *"With these cards, as I mentioned, I actually keep them in my drawer and occasionally take one out. It's not something that happens in every consultation, but sometimes it can happen"* (GP, M).

GP stated that it would be difficult to conduct comprehensive interviews with cards in a single session and suggested that the cards be introduced gradually. It was stated that it would be more feasible to talk about only one or two cards in each interview, *"But I think ten cards are too many for a consultation. The important thing is to choose one or two each time. Or maybe just one, because usually, the patient doesn't come solely for this; they come for something else as well. For example, you can say, 'If you'd like to talk, we can go through one or two cards,' but during a consultation, a maximum of one card can realistically be discussed."* (GP, M)

Addition of New Cards Addressing Specific Topics. A GP said that adding more specific cards, especially on topics that are misunderstood among Muslims, such as morphine use, could support patient information, *"There are many misconceptions about morphine. People often think it's only given at the moment of death and believe it can hasten death, but that's not true. It can be started earlier, for example, to provide comfort. One of the cards mentioned pain relief, but that was more*

about general pain. Perhaps a more specific card addressing pain management towards the end of life or during palliative sedation could be added." (GP, HE).

DISCUSSION

Main study findings

This study examined the translation, cultural adaptation, and implementation of the Wish for Life cards by GPs among Turkish-origin patients in Belgium. Interviews with GPs revealed that this card game served as an effective, empathic, and practical communication tool for initiating ACP discussions. The tool encouraged EOL conversations, reflected patients' religious and cultural values, strengthened the doctor-patient relationship, and supported family-inclusive dialogues, while at the same time strongly suggesting the centrality of the family in the decision-making process according to GPs. However, the findings also revealed several systemic, cultural, and personal barriers for GPs to use this card game and to ACP discussions in general. In this section, we discuss these key findings in the context of existing literature and offer implications for practice, policy, and future research.

Comparison with existing literature

Our findings suggest that the adapted Go Wish cards are effective in initiating ACP discussions with patients of Turkish origin in general practice. GPs reported that having a structured set of cards with preformulated wishes facilitated a culturally sensitive conversation about EOL care that might otherwise be difficult to discuss. This is consistent with previous studies showing that such structured card games can facilitate the initiation of EOL discussions by focusing on personal values in a non-confrontational manner (28,18). Ribeiro Paiva et al. (19) report that the Go Wish card game is a valuable tool for facilitating EOL conversations by improving dialogue between patients and families. Our GPs found that the use of the cards helped normalize the ACP conversation and allowed for an open discussion based on patients' wishes rather than continuing to view death as taboo and avoid the conversation. This approach also appears to reduce patients' initial hesitations and create a safer space for expression in a culturally relevant sense. A recent adaptation of Go Wish cards in the Flemish Region of Belgium (18) reports that participants stated that these cards facilitated conversations about EOL choices and that stakeholders were enthusiastically engaged in the process and that the resulting set of cards was seen as a useful public health tool for thinking about and discussing these issues. According to the GPs in our study, the cards enabled patients to discuss their care preferences and GPs to implement ACP in a way that was also compatible with cultural norms. These results highlight how culturally adapted communication tools can overcome conversational barriers and enable more person-centred, culturally sensitive ACP dialogue.

The importance of cultural resonance in the content of the adapted set of cards was a key finding. GPs observed that the Turkish translation and modifications to the original Life Wish cards significantly improved patient engagement. According to them, patients could see their own values and beliefs reflected in the statements. In a first phase of this study, several stakeholders were encouraged to rephrase or localise certain concepts on the cards to suit Turkish cultural and religious contexts. This is consistent with the literature emphasising that literal translation is not sufficient; content needs to be culturally validated to ensure relevance (29). In our study, adapting references to spiritual care and family roles made the cards feel 'recognisable' to patients. For example, a statement about meeting with a clergy member was adjusted to refer to a spiritual advisor, which patients found much more meaningful. This is reflected in the Flemish adaptation, where the phrase "seeing a clergyman or priest" was changed to "having a spiritual advisor as support" to broaden the wording in the cultural context (18). Similarly, an Italian team that performed a rigorous translation of the Go Wish cards reported the need for less explicit end-of-life terms and a greater emphasis on the role of healthcare providers in discussions, reflecting Italian cultural nuances (29). Our findings

confirm that incorporating social values such as faith, humility and family duty into the content of the

ACP tool may generate greater engagement. GPs reported that patients responded positively to cards that were compatible with Islamic beliefs (e.g. the importance of accepting God's will) or Turkish traditions (e.g. the request to be buried in the place of birth). In contrast, any culturally incompatible elements could have caused confusion. For example, Schouten et al. (30) stated that ignoring cultural characteristics can lead to patients being misunderstood and receiving poor care. Furthermore, a study by Coolen (31) highlights that cultural beliefs strongly shape how patients and their families approach advanced care planning. In many societies, there is a preference for making decisions together with the family, relying on verbal statements, and sometimes avoiding direct conversations about death. This shows the importance of using culturally adapted tools such as Life Wish cards, which offer a gentle and sensitive approach to initiating conversations about patients' future care. Therefore, ensuring cultural adaptation is critical: it not only confirms patients' worldviews, but also encourages more honest communication. As suggested by Dupont et al. (18), involving community members in the adaptation process was crucial to creating a card deck that "felt right" to the target audience. In summary, culturally adapted cards successfully tapped into patients' values and life experiences, demonstrating how cultural adaptation can make ACP tools more effective across different populations.

Family-centered values and shared decision-making structures were prominent themes in our study. The emphasis on family-centered decision-making, as in our study, is supported by previous studies in Muslim and collectivist cultures. For example, research with Turkish Moroccan populations in Belgium (32,13) highlights how family members play an important role in ACP decisions. They are not only involved in decision making, but they are also trusted to speak on behalf of the patient. The importance of family involvement and its role in shaping discussions among Muslim Americans has been confirmed in other studies (33).

ACP conversations via the Life Wish cards also had a positive impact on the doctor-patient relationship. Many GPs reported that these conversations with their patients of Turkish origin strengthened mutual understanding and trust. Patients appeared to appreciate their GPs' efforts to communicate about EOL care in the context of their own culture and in their preferred language. This process extended the interaction beyond routine clinical conversation, allowing GPs to learn about patients' deeply felt wishes and fears. Research also suggests that high-quality communication about end-of-life preferences can increase trust in the physician (34). A study in the Netherlands showed that older patients who had an ACP conversation with their GP were significantly more likely to maintain or increase their level of trust in their GP over time compared to those who did not have such a conversation (34). Our findings are consistent with this: GPs observed that patients became more open with them after the EOL discussion with the cards, seeing the GP not only as a medical advisor but also as an ally who respected their personal values. In addition, being able to discuss sensitive topics in Turkish contributed to patients feeling "heard" and understood, further strengthening the relationship. Perspectives from other studies reinforce the importance of the physician's role in these discussions; for example, family members of Moroccan and Turkish patients stated that they felt it was the GP's responsibility to gently initiate ACP discussions and guide the family, given his position as a trusted link between the GP and the patient (32). By using a tool adapted to their language and culture, such as the Life Wish Cards, our GPs can fulfill this role in a more culturally compatible way. Together, these findings suggest that culturally sensitive ACP interventions can create greater trust between immigrant patients and their physicians, improve

communication, and strengthen the therapeutic alliance. Such trust-building is particularly valuable for increasing trust in healthcare or in a population that may be uncomfortable with ACP.

Study strengths and weaknesses

This qualitative study has several limitations. First, the sample consisted of X native Turkish-speaking GPs working in Belgium who deal with ACP, which may limit generalizability. The perspectives may not be representative of the perspectives of all primary care practitioners (for example, non-native Turkish-speaking GPs who care for patients of Turkish origin may face different challenges). In addition, we only collected the views of the physicians but not directly from the patients or their family members. GPs provided indirect information about the reactions of patients and families, but it would have been useful to conduct direct interviews with patients and their relatives to verify and deepen this information. Therefore, future research should include the views of Turkish-origin patients and their families who use the Life Wish cards and examine how this tool affects their knowledge, attitudes, and decisions.

Another limitation is that our study explored the impact of the Life Wish card game on ACP interviews with Turkish-origin patients, but did not examine the long-term outcomes of these interviews. It is not yet clear whether the use of the cards results in tangible outcomes—for example, improved patient completion of ACP documents, decision-making in line with care preferences, or improved quality of end-of-life care. Therefore, it is important for future research to evaluate the long-term impact of culturally adapted ACP tools. Additionally, a comparative evaluation of this card-based approach to traditional ACP interviews may also be valuable.

In addition, the cultural adaptation we assessed in our study focused specifically on the values of the Turkish-Muslim community in Belgium. However, even within this community (depending on factors such as level of religiosity, generation gap or level of education), we may not have been able to fully reflect every nuance. Comparative studies with other immigrant groups with similar religious beliefs but different cultural backgrounds could shed light on which adaptation strategies should be universal, and which ones should be culture specific. In this respect, recent ACP studies conducted with communities of Moroccan origin in Belgium (32,13) provide valuable comparative opportunities on how cultural adaptations can vary among different Muslim groups. Such studies will contribute to the evaluation of cross-cultural approaches on a larger scale.

Finally, in the future, it would be useful to investigate whether these cards can be used not only in individual interviews but also in wider settings such as group work or workshops organized within the community. It is also necessary to seek answers to questions such as how this tool can be integrated into the healthcare system, what kind of support doctors and other healthcare professionals need in this process, and how this process can be sustained over time. This study provides initial observations of how these cards are received in practice and experienced by doctors. The next step will be to develop this approach further and understand how it can be used effectively in a wider range of clinical settings with different audiences.

Implications for Practice and Research

Based on these findings, some practical recommendations can be made for the effective use of culturally adapted Life Wish cards:

Family physicians should be provided with short and applicable training on communicating with patients of Turkish origin with cultural sensitivity.

The cards should be introduced at earlier stages, not only in advanced disease periods; if necessary, family members should be encouraged to participate in the process.

In addition, Turkish information materials explaining the ACP process should be developed together with the cards to increase the understanding of patients and families, and implementation should be facilitated with short user guides for physicians.

The implementation of these recommendations supports the use of ACP tools in a culturally meaningful and sustainable manner, not only in theory but also in practice. The aim is to address EOL issues in a manner that is appropriate to each individual's cultural values, in an environment that is uncompromising and supportive. In this way, minority communities such as Muslims and immigrants can be equally included in ACP processes without being excluded.

Conclusion

This study has shown that Life Wish cards can support meaningful and sensitive ACP discussions between Turkish patients and GPs in Belgium as a culturally adapted communication tool. The cards facilitated patients' expression of their values, encouraged family involvement and strengthened the doctor-patient relationship. However, cultural, structural and practical barriers that limit this process remain significant. Recognizing these barriers and implementing suggested improvements can pave the way for more inclusive and effective ACP practices among immigrant and minority communities. Our findings contribute to the literature on culturally adapted approaches to care and provide a concrete example of how these approaches can be implemented in different clinical settings.

References

1. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 2017;18(9): e543–51.
2. Nicholson B. Advanced care planning: The concept over time. Nurs Forum. 2021;56(4):1024–1028.
3. Knight K. 50 Years of advance care planning: what do we call success? Monash Bioeth Rev. 2021;39(1):28–50.
4. Meeussen K, Van den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V, et al. Advance care planning in Belgium and The Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. J Pain Symptom Manage. 2011;42(4):565–77.
5. Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. Palliat Med. 2014;28(8):1000–25.
6. Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding Advance Care Planning as a Process of Health Behavior Change. J Am Geriatr Soc. 2009;57(9):1547–55.
7. Poveda-Moral S, Falcó-Pegueroles A, Ballesteros-Silva MP, Bosch-Alcaraz A. Barriers to Advance Care Planning Implementation in Healthcare: An Umbrella Review with Implications for Evidence-Based Practice. Worldviews Evid Based Nurs. 2021;18(5):254–263.
8. Lewis E, Cardona-Morrell M, Ong KY, Trankle SA, Hillman K. Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review. Palliat Med. 2016;30(9):807–24.
9. De Graaff FM, Mistiaen P, Devillé WLJM, Francke AL. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: A systematic literature review. BMC Palliat Care. 2012;11: Article 17.
10. Detering K, Sutton E, Fraser S, Wallis K, Silvester W, et al. Feasibility and acceptability of advance care planning in elderly Italian and Greek-speaking patients as compared to English-speaking patients: an Australian cross-sectional study. BMJ Open. 2015;5: e007485.
11. Demirkapu H, Van den Block L, Maesschalck SD, et al. Advance Care Planning Among Older Adults of Turkish Origin in Belgium: Exploratory Interview Study. J Pain Symptom Manage. 2021;62(2):252–259.
12. Demirkapu H, Van den Block L, et al. Advance care planning among older adults with a Turkish background and palliative care needs: a qualitative interview study. Br J Gen Pract. 2023;73(737): e78–e87.
13. Demirkapu H, Hajji R, Chater B, et al. Advance care planning among older adults of Moroccan origin: An interview-based study. Patient Educ Couns. 2023; 113:107794.
14. Lautrette, A., & Poupon, C. (2018). Advance care planning in general practice: Promoting patient autonomy and shared decision-making. Journal of General Internal Medicine, 33(12), 2079–2084.
15. Hsu, L. L., Chang, H. H., & Liao, Y. C. (2021). General practitioners' views of advance care planning: A questionnaire-based study. BMC Family Practice, 22(1), 18.
16. McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: What do we know and where do we go? A scoping review. J Am Geriatr Soc. 2021; 69:234–244.
17. Menkin ES. Go Wish: A tool for end-of-life care conversations. J Palliat Med. 2007;10(2):297–303.

18. Dupont C, Smets T, Monnet F, et al. The cultural adaptation of the Go Wish card game for use in Flanders, Belgium: A public health tool to identify and discuss end-of-life preferences. BMC Public Health. 2022; 22:2110.
19. Paiva BSR, Mingardi M, Fiacadori de Almeida L, et al. Go Wish card game—exploring end-of-life wishes of patients in oncology palliative care: a qualitative study. Ann Palliat Med. 2024;13(1):31–41.
20. Eneslätt M, Helgesson G, Tishelman C. Dissemination, use, and impact of a community-based, conversational advance care planning intervention: Ripple effects of the Swedish DöBra cards. Palliat Care Soc Pract. 2021; 15:26323524211032983
21. Fisher CM, Sangadji R, Njoki Mwangi D. Using bottom-up evaluation to build community practice-based evidence and strengthen community-engaged research. J Community Pract. 2023;31(3):1–19.
22. Noppe, J., Vanweddingen, M., Doyen, G., Stuyck, K., Feys, Y., & Buysschaert, P. (2018). Vlaamse Migratie- en Integratiemonitor 2018. Agentschap Binnenlands Bestuur.
23. Dupont, C., De Vleminck, A., Deliens, L., & Gilissen, J. (2023). Advance care planning in Belgium. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 180, 121–126.
24. Demirkapu, H. (2024). Advance care planning perspectives of older adults and their family members with Turkish and Moroccan backgrounds in Belgium [Doctoral dissertation, Vrije Universiteit Brussel].
25. Selman, L., Robinson, V., Klass, L., Khan, S., Wright, M., & Byrne, A. (2023). Barriers to and facilitators for advance care planning among ethnic minorities in palliative care: A systematic review and thematic synthesis. Palliative Medicine, 37(1), 4–20.
26. Mayland CR, Powell RA, Brown J, Millington-Sanders C, Barclay S. Advance care planning: A multi-centre observational study of prevalence in UK palliative care services. BMC Palliat Care. 2023;22: Article 51.
27. National Institute on Aging. Advance care planning: A conversation guide. Washington, DC: U.S. Department of Health and Human Services; n.d. Available from: https://www.nia.nih.gov/health/advance-care-planning
28. Ribeiro Paiva BS, Trevizan FB, de Oliveira LC, et al. Go Wish Card Game for meaningful conversations in the oncology healthcare context: A narrative review. Cancers. 2023;17(4):560.
29. Perin M, Tanzi S, Botrugno C, Craddock C, Menkin E, Peruselli C, et al. Translation and cultural adaptation of the Go Wish game: Thinking about personal values to promote advance care planning. J Palliat Med. 2022;25(10):1540–1550.
30. Schouten BC, Meijer L, Eijkholt M, van den Muijsenbergh METC. Cultural diversity in end-of-life care: A scoping review of available tools. PLOS ONE. 2021;16(12): e0260112.
31. Coolen PR. Cultural relevance in end-of-life care ethics: An illustration from the Netherlands. Pittsburgh: Center for Ethics & Policy, University of Pittsburgh; 2012.
32. Demirkapu H, Edally W, De Vleminck A, et al. Views on advance care planning of family members of older adults with Turkish and Moroccan backgrounds: An exploratory interview study. Palliat Med. 2024;38(9):1000–1009.
33. Bani Melhem GA, Wallace DC, Adams JA, Ross R, Sudha S. Predictors of advance care planning engagement among Muslim Americans. J Hosp Palliat Nurs. 2023;25(4):204–214.
34. Van der Plas AGM, Schellekens JEAP, Glaudemans JJ, Onwuteaka-Philipsen BD. The patient's relationship with the general practitioner before and after advance care planning: A pre/post-implementation study. BMC Geriatr. 2022;22(1):558.

Appendices

Appendix 1 – Overview of adapted Life Wish cards with short explanations

Overview of the adapted Life Wish cards used in this study. Adaptations were made to enhance cultural, emotional, or linguistic appropriateness for Turkish-speaking patients. A short explanation is provided for each change.

No	Original Life Wish Card	Adaptation and Final Version	Short Explanation
1	Not being in pain	Not having pain or suffering	Adds emotional emphasis; suffering is often mentioned alongside pain in Turkish.
2	Not being short of breath	Not experiencing shortness of breath	More natural and commonly used phrasing in Turkish.
3	Being neat and tidy	Being clean and well-groomed	Reflects stronger cultural importance of cleanliness and appearance.
4	Not being afraid	Being free from fear and anxiety	Expands to include “anxiety,” a more complete emotional expression.
5	Having physical contact	Having human touch/contact	“Human touch” carries a warmer emotional connotation.
6	That my family is prepared for my death	That my family is prepared for my death	No adaptation needed.
7	Dying at home	Dying in my own bed	Emphasizes personal space and emotional comfort.
8	Being able to say goodbye to my loved ones	Being able to say goodbye to my loved ones	No adaptation needed.
9	Being able to share my memories and accomplishments with others	Being able to share my memories and accomplishments with others	No adaptation needed.

10	Being able to take care of unfinished business with family and friends	Being able to talk about unfinished business with family and friends	Shift to conversational expression, more natural in Turkish.
11	Being treated the way I wish to be treated	Being treated the way I wish	Simplified for fluency; meaning preserved.
12	Keeping my dignity	Maintaining my dignity	Minor wording change; meaning remains the same.
13	Keeping my sense of humour	Being able to keep my joy for life	Broader concept more aligned with cultural expressions.
14	Being surrounded by good friends	Having my friends around me	More natural Turkish phrasing.
15	Having someone who listens to me	Having someone who listens to me	No adaptation needed.
16	Not being a burden to my family	Not being a burden to my family	No adaptation needed.
17	Being able to do something for someone else	Being helpful to others	Simpler, more direct way to express the same idea.
18	Being able to talk about what scares me	Being able to talk about my fears	Common Turkish phrasing; simpler and familiar.
19	Being surrounded by my family	Having my family around me	More natural Turkish phrasing.
20	Feeling that my life is complete	Feeling that my life has come full circle	A poetic phrase that aligns better with cultural language.
21	That the doctor sees me as a whole person	Having a doctor who knows me well	Reflects relational continuity rather than abstraction.
22	Not dying alone	Not dying alone	No adaptation needed.
23	Being clear-headed	Being mentally clear	More common phrasing for cognitive clarity.
24	Being able to pray	Being able to pray and worship	Expanded to include broader spiritual practices.

25	Having a spiritual counselor as support	Having someone who can offer spiritual support	Inclusive of both formal and informal spiritual support.
26	Being able to talk about death	Being able to talk about death	No adaptation needed.
27	Be at peace with God	To be content with Allah	Reflects Muslim phrasing and theological nuance.
28	Getting my financial affairs in order	Having taken care of my financial matters	Natural Turkish structure for completed tasks.
29	Knowing how my body and mind will change	Knowing how my body and mind will change	No adaptation needed.
30	Avoid discussions by ensuring my family knows what I want	Avoiding conflict by making sure my family knows my wishes	Reframed to emphasize harmony and peace.
31	Having someone to speak up for what I think is important	Having someone take care of the things that are important to me	More emotional and relationship-oriented phrasing.
32	Being able to trust my doctor	Being able to trust my doctor	No adaptation needed.
33	Having a healthcare professional, I feel comfortable with	Having healthcare staff I feel comfortable with	Broadened to include more than just doctors.
34	Arrange my funeral in advance	Having my funeral arrangements prepared in advance	Passive voice sounds more natural in Turkish.
35	Not being dependent on machines to keep me alive	Not being kept alive by machines	More direct and clear phrasing.
36	Being able to choose when and how I die	Knowing where I will die or be buried	Avoids associations with euthanasia; aligns with spiritual concerns.
37	Being able to record my choices	Being able to define my own wishes	“Define” is clearer and more culturally intuitive.
38	Joker	Joker	No adaptation needed.

39	Joker	Joker	No adaptation needed.

Appendix 2- Information letter GPs

Information letter GPs

Geachte Dr. .....,

U bent uitgenodigd om plaats te nemen in een onderzoek. Voordat u hiermee akkoord gaat, willen wij u eerst van extra informatie voorzien zodat u een goede overwogen beslissing kunt nemen over uw mogelijke deelname. Mogen wij u vragen om deze informatiebrief aandachtig te lezen? Als u vragen hebt, neem gerust contact met ons op.

Waarom dit onderzoek? Voor onze studie vanuit de Vrije Universiteit Brussel zouden we u willen vragen of u wil deel nemen aan de pre-testing groep met de huisartsen die we opzetten binnen deze studie. Het doel van deze studie is om de Belgische Levenswenskaarten te vertalen en cultureel aan te passen in het Turks, en om te onderzoeken welke impact deze hebben op het initiëren of faciliteren van vroegtijdigezorgplanningsgesprekken tussen patiënten van Turkse afkomst en huisartsen in België. Voor de culturele adaptatie gebruiken we meerdere stappen: [1] vertaling, [2] consensus met referentiegroep, en [4] testen met huisarten.

Wat vragen wij van u?

Nadat we de originele Levenswenskaarten in het Turks hebben vertaald, zullen de voorlopige Turkse vertaling, de taalkundige gelijkwaardigheid en de noodzakelijke culturele aanpassingen worden besproken met een referentiegroep. Na consensus met de referentiegroep zullen we naar schatting 5 à 10 eerstelijnszorgverleners (Turkssprekende huisartsen) vragen om de vertaalde en cultureel aangepaste Turkse Levenswenskaarten te gebruiken tijdens 2 à 3 patienten per arts. Na de consultaties zullen we semi-gestructureerde interviews afnemen met de huisartsen om feedback te verkrijgen over het gebruik van de vertaalde kaarten en om bredere ervaringen met het kaartspel te verzamelen.

Extra informatie over uw bescherming en rechten als deelnemer aan deze studie.

Deze studie is goedgekeurd door de Ethische Commissie van het UZ Brussel

Deze studie kreeg de goedkeuring van de Ethische Commissie van de Vrije Universiteit Brussel en het UZ Brussel. De Ethische Commissie oordeelt of studies beantwoorden aan de wettelijke en ethische criteria en of het dus verantwoord is het onderzoek uit te voeren.

U bent geheel vrij om al of niet mee te doen.

De deelname aan deze studie is geheel vrijwillig. U kan weigeren om deel te nemen aan de studie, u bent volledig vrij om op vragen al dan niet te antwoorden en u kunt zich op elk ogenblik terugtrekken uit de studie. Hier hoeft u geen enkele reden voor op te geven.

Vertrouwelijkheid van uw gegevens

De gegevens die in het kader van uw deelname worden verzameld zijn vertrouwelijk. Als u akkoord gaat om plaats te nemen in de referentieroep, dan zullen de gegevens die tijdens deze studie over u worden verzameld worden geanonimiseerd. Dit betekent dat uw naam en andere persoonlijke

gegevens nergens worden vernoemd en uw gegevens niet terug te herleiden zijn naar uw antwoorden. Gegevens worden enkel gerapporteerd (bijvoorbeeld in wetenschappelijk artikel) op anoniem en geaggregeerd niveau. U hebt het recht om deze gegevens in te kijken en om verbeteringen te laten aanbrengen indien ze foutief zouden zijn . De bijeenkomsten worden opgenomen (audio) zodat de onderzoeker deze letterlijk kan uitschrijven en analyseren. Uw deelname aan de studie betekent dat u ermee akkoord gaat dat de bijeenkomsten worden opgenomen.

De onderzoekers verbinden zich ertoe om de verzamelde gegevens enkel in het kader van dit onderzoek te gebruiken. De gegevens zullen veilig bewaard worden voor een periode van 3 jaar, om daarna vernietigd te worden. Uw gegevens, de opnames en de uitgeschreven opnames zijn enkel toegankelijk voor de onderzoekers.

U heeft het recht om een klacht in te dienen over hoe uw informatie wordt behandeld, bij de Belgische toezichthoudende instantie die verantwoordelijk is voor het handhaven van de wetgeving inzake gegevensbescherming (Gegevensbeschermingsautoriteit (GBA), Drukpersstraat 35,1000 Brussel,

Tel. +32 2 274 48 00, e-mail: contact@apd-gba.be

Verzekering

Voor deze werd tevens een verzekering afgesloten met foutloze aansprakelijkheid voor deze studie in navolging van de wet van 7 mei 2004 betreffende experimenten op de menselijke persoon.

Appendix 3-Informed consent representatives and GP

Geïnformeerde toestemming om deel te nemen aan de studie: De culturele adaptatie van een kaartspel om waarden en voorkeuren rondom voorafgaande zorgplanning en het levenseinde te bespreken naar de Turkse context

De deelname aan deze studie is geheel vrijwillig . U kan weigeren om deel te nemen aan de studie, u bent volledig vrij om op vragen al dan niet te antwoorden en u kunt zich op elk ogenblik terugtrekken uit de studie. Hier hoeft u geen enkele reden voor op te geven. Voor meer informatie kunt u contact opnemen met ons via de contactgegevens onderaan deze pagina, of met de dienst gegevensbescherming van de Vrije Universiteit Brussel via dpo@vub.be.

Om deel te kunnen nemen aan de studie, dient u ons eerst nadrukkelijk toestemming te geven. Dit kunt u doen door de twee (onderstaande) hokjes aan te vinken. Wanneer u dit doet, gaat u akkoord met de voorwaarden zoals beschreven in de informatiebrief en geeft u aan dat u vrijwillig wil deelnemen aan de online enquête.

Vink het aan wat voor u van toepassing is*:

o Ik heb de informatie in de informatiebrief gelezen. Ik heb bovendien de mogelijkheid gehad daarover vragen te stellen en alle vragen die ik gesteld heb, zijn voldoende beantwoord. Ik stem hierbij vrijwillig toe deel te nemen aan deze studie.

o Ik stem in met de verwerking van mijn persoonlijke gegevens zoals beschreven in de informatiebrief. Ik geef ook toestemming voor het opnemen van de bijeenkomst.

Appendix 4 - Ethics Approval

Universitair Ziekenhuis Brussel

VRIJE UNIVERSITEIT BRUSSEL

COMMISSIE MEDISCHE ETHIEK (O.G. 016)
Reflectiegroep Biomedische Ethiek
Laarbeeklaan 101
1090 BRUSSEL

Tel + 32 2 477 55 84
Fax + 32 2 477 55 94
commissie.ethiek@uzbrussel.be

PROF. DR. LIEVE VAN DEN BLOCK
END-OF-LIFE CARE
VUB

Brussel, 22-12-2023

Ons Kenmerk: **2020/460**

ADVIES VAN DE COMMISSIE MEDISCHE ETHIEK

Betreft:
The translation and cultural adaptation of the Go Wish cards for the Belgian context: a card game to discuss advance care planning and end of life and preferences
B.U.N. 1432020000317

De Commissie Medische Ethiek nam kennis van, en verleent een gunstig advies aan volgende documenten betreffende bovenvermelde studie:

- E-mail dd 01-Dec-2023 van Mevr. C. Dupont betreffende een aanpassing van de kaarten om te gebruiken bij mensen met een Turkse achtergrond
- Protocol versie 4.0 dd 01-Dec-2023 in het Engels (met track changes)
- Handleiding levenswensen en overzicht van de kaarten in het Nederlands

Ter uwer informatie :
Tijdens haar vergadering van 30/03/2022 besliste onze Ethische Commissie het volgende :
"De voorzitter (en in zijn afwezigheid de ondervoorzitter) mag, zonder de Commissie te raadplegen, beslissingen nemen i.v.m. aanvullende gegevens of ongewenste effecten die voor sommige dossiers later dan de oorspronkelijke aanvraag zouden ingestuurd worden . Mocht een punt van majeur belang blijken te zijn dan moet hij dit op de dagorde van de eerstvolgende commissievergadering plaatsen."
Dit betekent dat de documenten enkel aan de voorzitter werden voorgelegd.

Met de meeste hoogachting,

Prof. Dr. F. Cools, voorzitter

FAGG, Departement R&D