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ADVANCE CARE PLANNING PERSPECTIVES OF OLDER ADULTS AND THEIR FAMILY MEMBERS WITH TURKISH AND MOROCCAN BACKGROUNDS IN BELGIUM

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CHAPTER 1

GENERAL INTRODUCTION

1. Background

1.1 Older adults with Turkish and Moroccan migration backgrounds in Belgium

Demographics

The population in Belgium is becoming increasingly ethno-culturally diverse. According to the Belgian statistical office Statbel and based on the registered first nationalities of individuals and their parents, 65.5% (n = 7,665,100) of the Belgian population was Belgian with a Belgian background, 21% (n = 2,459,184) was Belgian with foreign backgrounds and 13.4% (n = 1,573,273) was non-Belgian on 1 January 2023.[1] In other words, 34.5 % (n = 4,032,457) of Belgian citizens had foreign background in 2023. The percentage of residents with foreign backgrounds, with and without Belgian nationality, varies among regions; it is 26.8% of the population in Flanders, 35.4% in Wallonia and 76.6% in Brussels. [1] By 2060, an estimated one-half of the Belgian population will have foreign ethnic backgrounds.[2] Based on the criterion of nationality of origin, those from Moroccan and Turkish backgrounds form the largest groups of non-European migrants in Belgium.[3-5]Among all new arrivals to Belgium after 1945 and their descendants, including the grandchildren of those who became Belgian, 624,845 people with Moroccan backgrounds and 338,973 people with Turkish backgrounds (5.34% and 2.90 %, respectively, of the Belgian population) reside in Belgium in 2024.[6]

Major migration of people with Turkish and Moroccan backgrounds to Belgium began in the early 1960s, with men coming as guest workers based on bilateral agreements with their home countries and their wives joining them later through family reunification.[7,8] Today, Belgium faces challenges associated with the ageing of this population.[9–11] Statbel estimates that 14.1% of people in Belgium aged ≥ 65 years or their parents had foreign first-registered nationalities in 2023.[1] This percentage varies among regions; it is 8% in Flanders, 20% in Wallonia and 44% in Brussels. [1] In all Belgian regions, persons with Moroccan and Turkish backgrounds form the largest non-European groups of residents aged ≥ 65 years.[3,4]

Most of these labour migrants were illiterate and from rural areas, primarily recruited based on their physical ability; Lodewijckx reported in 2007 that 72% of Moroccan men, 82% of Moroccan women, 38% of Turkish men and 69% of Turkish women aged ≥ 65 years in Flanders had had no formal education.[9] The Belgian government and the labour migrants initially thought that they would work in the country temporarily and then return to their home countries, but many stayed in Belgium, initially to remain close to their children and maintain their social security benefits, and later to remain close to their grandchildren and due to the high-quality healthcare system. This situation created a ‘return dilemma’ challenging Turkish and Moroccan migrants’ assumption that they would age in their home countries.[10–12] Conflicting desires are represented in this population: the desire to return to one’s home country for reasons associated with family, the climate and nostalgia; and the desire to reside in Belgium for practical and emotional reasons, including the presence of (grand)children and social and financial security.[13] As a result, these older migrants often feel disoriented and alienated.[14] Moreover, older migrants of Turkish and Moroccan origins are considered to be socially vulnerable and to have a transnational sense of belonging to their countries of origin, which contributes to more loneliness than found among their native peers.[15]

Socio-economic status

Most older people with Turkish and Moroccan backgrounds in Belgium have low socio-economic status and have had similar socialisation experiences in the country.[8,16,17] During the 1970s, this largely Muslim population faced great insecurity and social vulnerability due to various combinations of difficult/poor work conditions, job insecurity, unemployment, business closures, poverty, discrimination and racism.[16,17] As a result of this low-skill work and/or incomplete career context, most of these migrants have very small pensions and their current financial situations of many are precarious.[18]

Health status

Older people with Turkish and Moroccan backgrounds in Belgium have less education and poorer health than do older people born in Belgium.[9] Generally, people with migration backgrounds are more prone than natives to develop illnesses, including chronic conditions such as diabetes, obesity and cardiovascular disease at earlier ages.[19] In Belgium, such disorders tend to develop in migrants around the age of 50 years and in natives around the age of 60 years; as a result, migrants have lower healthy life expectancies.[17] Similarly, in the Netherlands, older Turkish and Moroccan migrants also have lower overall life expectancies than do Dutch natives.[20] Older adults with migration backgrounds have more psychosomatic conditions than do those of Belgian descent, due in large part to their migration histories. [21]

For example, they may experience emotional problems due to homesickness, difficulties in adapting to the host culture, the feeling of powerlessness because they have insufficient command of the Dutch language and stress due to financial problems and/or problems with partners or adolescent children, all of which cause conditions such as chronic gastrointestinal disorders, migraine, diabetes and insomnia.[21] A health survey conducted in Belgium in 2018 confirmed that migrants were in poorer health than natives, with greater likelihoods of having anxiety disorders and a 'poor' subjective health rating.[22]

Healthcare use and access

Older adults form increasingly large proportions of ethnic-minority populations in Belgium.[1,23] The Belgian healthcare system provides a wide range of services that are, in theory, available to people in the country of all cultural and religious backgrounds and based on the principles of independent medical practice and free choices of care provider and institution.[24] Ageing Turkish and Moroccan immigrants in Belgium increasingly require formal care, but their health system access and receipt of appropriate end-of-life care can be hindered by a lack of knowledge about the system, the language barrier, low education level and health literacy, precarious financial situations, return and care dilemmas, and the perceived insensitivity of the system to their cultural and religious attitudes and values.[25] Ethnic minorities often have more difficulty than ethnic-majority groups with health system access and use and the receipt of quality care.[19] In the evaluation of the experiences of socio-economically disadvantaged populations, an intersectional approach is required.[26] According to this approach, the use of individual categories of social identity and position, such as in the examination of ethnic variation in healthcare access and utilisation, requires that the potential confounding impacts of factors such as deprivation and occupation be accounted for.[26] Individuals have multiple, intersecting social identities and positions reflecting ethnicity, gender and social class, which collectively shape their access to resources and contribute to health disparities.[26] Problems are complex and associated with multiple factors, such as cultural and linguistic barriers, socio-economic vulnerability and organisational barriers.[27–29] First-generation Turkish and Moroccan migrants play a pioneering role by ageing in the Belgian context, and often cannot navigate care services.[10,12] Moreover, professional care is not adapted to the wishes and needs of older migrants, resulting in less use of formal support services and greater reliance on family members.[25,28, 30-33]

Care provision by family members

In traditional collective societies, such as those of Turkey and Morocco, care responsibilities usually lie in the hands of families and/or social networks.[9] Caring for ill older family members, predominantly by women, is culturally and religiously mandated, driven by reciprocal love and filial responsibility.[30,33-38] As a result, exhaustion is more prevalent among family caregivers with than among those without migration backgrounds.[39]

Some second generation individuals with Turkish and Moroccan backgrounds are experiencing difficulties fulfilling this duty of care in balance with their work obligations, given the different socio-cultural context and availability of less time for care-related tasks. [40] This situation leads to the emergence of the 'care dilemma' among older adults with Turkish and Moroccan backgrounds.[10-12] Thus, researchers have argued that the assumption of migrants from collectivistic societies, and of care service providers, that a substantial portion of their care will be provided informally by family members is under pressure and needs to be revised.[10] The family solidarity that is central to the Turkish and Moroccan cultures is less present among members of the second and third generations, due to acculturation processes such as adaptation to Western norms and values, less multi-generational living situations and the working of men and women outside of the home. [12,36,40,41] Adult children are no longer guaranteed to take care of their parents, disrupting the traditional ideal of integral family care and potentially causing the children to feel shame due to the inability to meet their parents' expectations and the need to turn to professional care.[12,36,40,41] Many older adults understand the reality of the situation and opt for professional healthcare services, but still feel disappointment and have trouble talking about it, often repressing their feelings to the point that the subject becomes taboo.[11,25] This situation creates heavy care burdens for people responsible for providing or securing care for ill older family members.[30,34] Generally, family caregivers of older adults face the lack of accessible points of information, supportive professionals to guide them in informal care processes, favourable work leave policies and coherent financial support to make care provision feasible.[42,43] A health survey conducted in 2018 in Belgium showed that first-generation migrants with non-Western backgrounds receive little social support, including others' attention to and interest in what they are doing and neighbours' willingness to provide practical help if needed.[22]

Communication issues

Large proportions of older adults with non-Western backgrounds speak only their native languages and are illiterate.[17] Despite these factors, the use of professional interpreters in various healthcare settings in Belgium is not common; family interpreters are commonly used when language barriers are encountered.[44-46]

With increases in societies' ethno-cultural diversity, healthcare professionals must communicate increasingly often with patients and family members with migration backgrounds; they often turn to family members for translation, which is usually not the best solution. Due to these family interpreters' emotional involvement and lack of neutrality, patients may not feel free to discuss health problems and aspects related to sensitive or taboo topics, such as end-of-life care or poor prognoses.[47,48] Moreover, translations can be incomplete (resulting in information loss) and/or coloured by family members' insertion of their own points of view. A study conducted in a multi-ethnic critical care setting in Belgium showed that healthcare providers did not tend to explore patients' particular perspectives in the presence of family members.[49]

Especially when patients become critically ill and discussions about life and death are impossible due to their inability to communicate properly, healthcare professionals need to have optimal communication with patients' family members or legal representatives.[50] Ethnic-minority families are at greater risk of stress and potential conflict in this context than are ethnic-majority families due to their different ethno-cultural backgrounds.[51–53] Communication challenges and conflict with relatives can occur around critical medical decision making, the communication of bad news and the more practical aspects of patient care. [49] Healthcare providers also encounter difficulties in choosing suitable conversation partners due to the desire of extended family members to be involved.[49] Conflict between physicians and patients' surrogate decision makers occurs in nearly two-thirds of cases.[54] One topic causing such conflict, especially upon late and incomplete surrogate decision maker integration, is end-of-life decision making, such as about whether to limit life-sustaining treatment.[54,55] Such conflict may considerably threaten adequate care provision and critical care teams' well-being.[56] A study conducted in the intensive care unit of a multi-ethnic urban hospital in Belgium revealed conflict between healthcare professionals and patients' family members, related primarily to differences in views on what constitutes good care.[27] From healthcare professionals' biomedical point of view, good care entailed close attention to regulations (e.g. regarding visits), the removal of disease as well and quickly as possible with great scientific competence, structured communication and physicians' central responsibility for medical decision making; this perspective was found to be strengthened by the specific features of the critical care context (e.g. technological orientation, time pressure and medical uncertainty).[27] From family members' holistic point of view, good care included patient visitation and bedside care, exhaustive information seeking and participation in end-of-life decision making; this perspective was found to be reinforced by the specific characteristics of the ethno-familial care context (e.g. family structure, ethno-cultural norms and integration-related role expectations).[27]

End-of-life care and decision-making issues

As the proportion of older adults increases, the prevalence of chronic multimorbidity and proportion of deaths due to chronic illnesses such as cardiovascular disease, cancer, chronic respiratory disease and diabetes – and thus the need for palliative care – are also increasing.[57]

Palliative care aims to relieve suffering and improve the quality of life of patients and their family members facing challenges associated with life-limiting illness through the early identification, accurate assessment and treatment of pain and other physical, psychosocial and spiritual problems.[58] During their palliative care trajectories, older adults with such illnesses may be confronted with the need to make difficult decisions about their end-of-life care due to disease progression.[59] At the same time, serious illness may render them unable to make medical decisions for themselves. As a result, healthcare providers may ask family members to make treatment decisions. The inability to determine patients' preferences may contribute to the latter's significant distress.[60]

The unsolicited assignment of passive roles in decision making to patients and their relatives may evoke mental distress and contribute to an atmosphere of conflict in intensive care unit.[61] Aspects of end-of-life decision making (e.g. whether to withhold/withdraw life-sustaining treatment) should be discussed regularly and in a timely manner with patients and relatives, with sufficient patient involvement whenever possible.[62,63] When patients are unable to participate in such discussions, relatives' ability to carefully make decisions may be jeopardised by their difficulties in understanding medical information, tendency to claim major control in the process and emotional distress; they may make decisions that do not reflect patients' preferences.[64-66] Such decision making can be even more complex for people with certain migration backgrounds due to religious beliefs [e.g. in God's sovereign power over life and death (i.e. lifespan determined by God) and almightiness (i.e. belief in miracles)].[67] A mortality follow-back study conducted in the Netherlands showed that end-of-life decisions are made less frequently for patients with non-western migration backgrounds.[68] Most families of patients with Turkish and Moroccan migration backgrounds are against the withholding/withdrawal of life-sustaining treatment, preferring that patients receive maximal curative therapy until they die 'naturally' according to religious norms.[64] This perspective could lead to the failure to take patients' suffering into account. Although some family members may see the relevance of non-treatment decision making, doctors usually have difficulty overcoming disagreements between family members and obtaining whole families' support.[64] In a study conducted with patients with migration backgrounds in an intensive care unit in Belgium, Van Keer et al.[64] demonstrated that being correctly informed was challenged by ethno-cultural factors such as language differences and relatives' tendency to hide confronting, negative medical information from patients. They also found that patients' and families' contributions were limited during decision making; that the staff made treatment decisions without fully exploring patients' concrete preferences regarding therapy, jeopardising patients' autonomy; and that physicians did not ask disagreeing family members about patients' end-of-life preferences or values. [64] The consideration of culture in relation to end-of-life care is becoming increasingly important in the context of globalisation, migration and European integration.[69] Palliative care policy guidance reflects an increase in requirements for cross-culturally appropriate end-of-life care.[70]

1.2 Advance care planning: knowing and respecting older adults' preferences

In the United States, the lack of adequate communication about and documentation of cancer patients' values and preferences regarding the end of life has been associated with poor quality of life, anxiety, family distress, increased caregiver burden, prolongation of the dying process, undesired hospitalisation, physician burn-out, mistrust of the healthcare system and high healthcare costs.[71] Advance care planning (ACP) has been defined by European consensus as a process that enables individuals with decisional capacity to identify their values, reflect on the meanings and consequences of serious illness scenarios, define goals and preferences for future medical treatment and care and discuss them with family members and healthcare providers.[72] ACP addresses individuals' concerns across the physical, psychological, social and spiritual domains. [72] Individuals are encouraged to identify surrogate decision makers and to record and regularly review their preferences so that they can be taken into account should they lose decisional capacity, thereby preserving their autonomy.[72-76] ACP initiation is indicated upon worsening health, ageing, palliative care initiation and/or residential care home admission.[72] Most ACP research has been conducted with patients who were seriously ill, had dementia and/or were receiving residential or palliative care.[77,78] Although the discussion of end-of-life care in the context of ACP is commonly considered to be appropriate for chronically ill patients, it may also be appropriate with healthy aging people; there is a broad consensus that ACP should be initiated in a timely manner, prior to a health crisis or the terminal phase of life, when patients can make more informed decisions.[79-88] ACP is dynamic and ongoing in response to individuals' changing perspectives over time, and could be initiated with older people without life-threatening illnesses by discussing healthcare proxy preferences or care goals in hypothetical debilitating or terminal situations.[80] Upon the development of life-threatening illness, discussions could shift to decisions to administer, withhold or terminate specific treatments.[80] According to previous studies this approach could normalises ACP conversations and provides time for contemplation, communication and the re-evaluation of care preferences with changes in health.[59,85]

ACP has been argued to allow patients to maintain control, peace of mind and trusting relationships with their relatives, and to increase their quality of life and their surrogate decision makers' satisfaction.[89,90] It can reduce ambiguity in patient–family communication, family members' decision-making burden and anxiety, and decisional conflict; increase advance directive creation and surrogate decision makers confidence; and reduce care providers' ethical dilemmas.[89,91-93] Overall, ACP seems to improve end-of-life care, increase patient/surrogate decision maker satisfaction with communication, decrease surrogate decision maker/clinician distress and lead to increased use of hospice and palliative care over hospitalisation and life-sustaining treatment; it is thus encouraged widely to improve the quality of dying.[72,94-100] However, the international literature reveals a lack of ACP conversations with older people.[101,102]

ACP as a complex communication process

Despite the benefits of ACP, sole reliance on advance directives has been found to insufficiently enhance overall satisfaction and the patient-centeredness of end-of-life care.[77] Moreover, knowledge of patients' wishes may not always translate to the fulfilment of those wishes,[103] and some patients may not want their previously stated preferences to be followed.[104]

The diversity of findings has prompted ongoing discussion about future ACP research and goals in the last decade.[105-109] A primary question centres on the ability of ACP to enhance outcomes such as goal-concordant care, considered to be critical but challenging to operationalise and measure.[110] As patients' preferences may change in the moment, a reliance on retrospective chart review or advance directive documentation may lead to inaccurate decision making. [110] Additionally, ACP alone may not affect care quality, goal concordance or healthcare status and utilisation outcomes in the absence of equitable access to healthcare.[110] Recent comprehensive reviews of trials and systematic reviews provide nuanced insights into ACP's impacts on key outcomes. For instance, a comprehensive review of 80 systematic reviews published in 2018 highlights the compartmentalised nature of evidence, but suggests that ACP has the potential to improve outcomes through the implementation of a holistic approach involving patients, family members/surrogate decision makers and clinicians, with repeated interaction with knowledgeable individuals to address concerns.[111] Similarly, an umbrella review of ACP effectiveness and experiences among people living with dementia showed that ACP was associated with decreased hospitalisation, increased concordance of the care received with patients' prior wishes and increased completion of ACP documents.[112] The quality of the primary research included in that review, however, was variable.[112] Moreover, a 2021 scoping review of ACP-related randomised controlled trials revealed positive outcomes in areas such as processes (e.g. knowledge about ACP) and actions (e.g. communication with surrogate decision makers and clinicians) but revealed inconsistency among findings concerning ACP's effects on care and healthcare utilisation; outcomes related to quality of care (e.g. goal concordance), health status (e.g. quality of life), and healthcare utilisation were mixed and not uniformly positive.[100] A 2021 workshop held with ACP experts led to the identification of areas in which ACP could be improved, including effective communication to clarify the role of ACP, the preparation of clinicians for high-quality ACP conversations, the adoption of a person-centred approach, the refinement of evaluation criteria (e.g. whether people feel supported in decision making) and the shifting of ACP's focus to accommodate in-the-moment healthcare decision making by patients and surrogate decision makers.[113]

The conceptualisation of medical decision making has shifted toward a focus on communication about goals and preferences,[72,114] and it has been argued that ACP should be viewed as not only determining future care preferences, but also facilitating informed, in-the-moment decision making that considers patients' evolving values and needs.[59,115] This approach could enable healthcare providers to deliver person-centred care attuned to individuals' unique needs, circumstances, context and preferences.[116] It should be undertaken with the understanding that age and health status affect ACP uptake; the ACP-related needs and views of patients with progressive incurable conditions likely differ from those of healthier adults.[117] In addition, the ACP literature underscores the importance of involving families in future planning and encouraging effective communication of patients with their family members to enable the delivery of goal-oriented care.[118-120]

Goals-of-care ACP discussions

Ideally, ACP can lead to goal-concordant care even amid unpredictable serious illness trajectories. [121] However, it may also provide a false sense of security that patients' wishes will be revisited and honoured at the end-of-life.[121] Goals-of-care conversations are somewhat similar to ACP in that they involve the discussion of what matters most to patients.[121,122] They primarily delineate the aims of medical care as in-the-moment decisions for patients with active health issues.[122]

Patients' involvement in palliative care, including through goals-of-care discussions, improves outcomes such as quality of life and healthcare costs, and is thus supported and considered worthwhile by palliative care clinicians.[107,123] High-quality goals-of-care discussions may also improve family outcomes and lead to less inappropriately aggressive medical treatment at the end-of-life.[100] Researchers have argued that patient rapport should be established by asking about patients' emotions and through active listening and responding to their replies, exploring what patients know and wish to know about their prognoses and describing what they should expect.[124] It has also been argued that to improve alignment between ACP and high-quality goals-of-care discussions, researchers have recommended that health systems develop and prioritise systematic ACP assessments of patients' values (separate from decisions about specific medical goals and care) early in the disease process, regardless of the illness extent or prognosis, so that patients' voices can be heard, documented, revisited and honoured as clinically appropriate.[125] It has been argued that goals-of-care discussions should be more than just an ACP 'check box'. [126] Researchers have recommended that healthcare providers should initiate them early and ensure that they are ongoing and patient and family centred, reflecting patients' values and end-of-life preferences.[126]

1.3 ACP for people with migration backgrounds

ACP can be even more complex process when it comes to older adults with non-dominant social, cultural and spiritual views on end-of-life care.[127] To maximise the full potential of ACP, its impacts in different populations, settings and contexts, and the impacts of cultural factors (religiosity, trust in the health care system, patients' and clinicians' comfort with the discussion of death, and patient attitudes regarding decision making) on its acceptability, need to be understood.[111,117] Culture can be understood as a system of ideas, rules, meanings and ways of living and thinking that is built, shared, and expressed by a particular group of people, often of the same ethnic background.[128] Entailing race, ethnicity, religion, language and origin, it largely determines how people view life and death and, consequently, make end-of-life decisions.[127] Studies performed in countries such as the United Kingdom,[129] New Zealand,[130] the United States,[131] and Australia[132] have revealed significantly less uptake (i.e. acceptance of or engagement with) of end-of-life decision making and ACP support services among ethnic-minority than among ethnic-majority groups in multi-cultural settings, due mainly to a lack of knowledge, the major role of family members in aged care, distrust of the healthcare system and healthcare providers' overlooking of cross-cultural ACP perspectives.[129,130,133–135] Some studies suggest that the philosophy underlying ACP can be difficult to reconcile with the prevailing norms and values of some non-Western cultures, preventing successful implementation.[133] Across ethnic-minority groups in the United States, worse health status and good ACP knowledge were found to be facilitators of ACP and healthcare system distrust was found to be a barrier; collectivistic cultural values and spirituality/religion influenced ACP engagement.[131] Moreover, it has been argued that ACP awareness and attitudes may vary among ethnic-minority groups.[131] A study conducted in the Netherlands and a systematic review showed that decision making about end-of-life care for people with Turkish and Moroccan backgrounds is characterised by families' functioning as care management groups with 'equal' say.[136,137]

1.4 ACP in Belgium

Since 2002, three laws centred on patient dignity and autonomy have regulated end-of-life care and ACP in Belgium; they cover patients' rights (22 August 2002) and the rights to palliative care (14 July 2002) and euthanasia (28 May 2002).[138-141] The patients' rights law specifies the rights of patients to quality health services that meet their needs (art. 5); to receive all information concerning them that is needed to gain insight into their disease states and probable evolution (art. 7§1); and to provide informed, prior and free consent to all interventions proposed by healthcare professionals (art. 8§1).[139] Various forms of healthcare directive have been established in Belgium: an instructional advance directive for the refusal of medical treatment and intervention that is legally binding for medical professionals, a directive by which durable powers of attorney are appointed to act as patients' surrogate decision makers and an advance directive for the request of euthanasia in case of irreversible coma. [140,141] Euthanasia can also be requested according to specific criteria and procedures on consistent requests from capacitated patients enduring unbearable physical or psychological suffering in the absence of curative treatment options.[142]

Several initiatives to improve ACP uptake have been undertaken in Belgium; they involve standardised documentation, government-provided physician reimbursement codes and the implementation of quality indicators (including one for ACP) in hospitals and nursing homes.[138] Since 2010, interest in quality improvement indicators for benchmarking has increased. For instance, nursing homes in Flanders are required to measure and report such indicators, including one related to ACP: the number of residents with 'up-to-date plan[s] for end-of-life care'.[143] In September 2022, a rule for the reimbursement of general practitioners' ACP-dedicated time was implemented with the aim of enabling these care providers to share patients' preferences with other healthcare professionals involved in their care.[138] In February 2024, ACP is defined as the 'continuous process of reflection and communication between the patient, the healthcare practitioner(s), and, at the patient's request, the patient's loved ones, which aims to discuss the values, life goals, and preferences for current and future care'.[144]

Flanders palliative care federation in Belgium stipulate that ACP be performed with emphasis on patients' care goals and what they perceive and value as quality care, and extend to matters such as their preferences regarding the place and manner of burial and organ/body donation.[145] It has been argued that the goal of dialogue should be shared decision making about care objectives and agreements for incorporation into care plans.[145]ACP should also improve representatives' accurate understanding of patients' wishes.[145] Research shows that although most Western patients, including frail older Belgians, wish to talk about the end-of-life, few do so because they expect their doctors to take the initiave.[102, 146-148] In turn, many clinicians struggle to involve (especially older) patients in end-of-life decision making, despite having positive perceptions of the ACP process.[149-152] Barriers mentioned by general practitioners are the lack of the skills needed to handle patients ' vague requests, difficulty identifying the right moment to initiate discussion, the attitude that patients should initiate ACP and the fear of depriving patients of hope.[153]

Most patients in Belgium, especially older and chronically ill individuals, regularly consult general practitioners to obtain accessible, continuous and person-centred primary care.[154,155] Patients with terminal illnesses in Belgium highly value the continuity of care provided by their general practitioners, anchored in longstanding relationships built on mutual trust, and rely on these professionals to coordinate information exchange with specialist care providers.[156] Thus, general practitioners are the ideal initiators of ACP, while patients' health is relatively stable, although deficits in this process in Belgium have been identified.[157] A mortality follow-back study, published in 2011 and conducted using data collected through sentinel general practitioner networks in Belgium and the Netherlands, showed that general practitioners were aware of advance agreements about medical care for approximately 34% of deaths reported as non-sudden.[158] Another study conducted with sentinel network data through 2014 showed that general practitioners were aware of the medical treatment preferences of 53% of patients with cancer who died non-suddenly and of the surrogate decision makers preferences of 28% of these patients.[159]

Flanders palliative care federation in Belgium note, in their evidence-based guidelines for ACP, the importance of more research on the impact of multiculturalism on ACP discussions, and of the adaptation of these discussions based on demographic and cultural factors.[145] However, the patient groups targeted most often in ACP initiatives in Belgium are those with cancer and older adults; limited attention has been given to patients with low health literacy and other minority groups.[138] Recently, Van Keer et al.[64] found that no patient with a migration background in one intensive care unit in Belgium had an advance care plan.

Thus, despite the Belgian government's legislation and efforts to support the development and embedding of ACP throughout the healthcare system, ACP implementation remains sub-optimal.[138] Barriers to ACP in Belgium include the lack of a unified platform for the exchange of ACP discussion outcomes and advance directives among healthcare professionals and the predominant orientation toward documentation.[138] Researchers have recommended further efforts to regulate ACP and the processes involved, to create a single location for the storage of advance directives and other ACP information and to eliminate disparities.[138]

2. Dissertation aims and research questions

Studies of ACP engagement among older adults with Turkish and Moroccan backgrounds in Europe are lacking, although people with Turkish and Moroccan backgrounds are among the largest visible, and ageing, non-Western minority groups not only in Belgium, but also in France, Germany and the Netherlands.[1,3-5,160,161] A systematic literature review showed that diagnoses, prognoses, and end-of-life decisions are seldom discussed with incurably ill Turkish and Moroccan patients,[137] despite documented conflict among the viewpoints of healthcare professionals and ethnic-minority patients and family members in Belgium.[27] In addition, available research on ACP aggregates various ethnic-minority populations, assuming cultural homogeneity, which has led to inappropriate generalisation and the overlooking of within-group diversity.[162,163] Thus, an understanding of ACP knowledge, experiences, views, facilitators and barriers among older adults and family members of Turkish and Moroccan backgrounds, respectively, in Belgium is important. The adaptation of ACP to these groups' cultural needs, as well as their health status and setting (e.g. palliative care), might improve patients' and family members' well-being and enhance communication and shared decision making with healthcare providers.

The aims of this dissertation, explored in four qualitative studies, were to explore and describe ACP knowledge, experience, views, facilitators and barriers among older adults with Turkish (study 1) and Moroccan (study 2) backgrounds, older adults with Turkish background requiring palliative care (study 3), and family members of older adults with Turkish and Moroccan backgrounds (study 4) in Belgium.

The following research questions were explored in all studies.

1. **What ACP knowledge do the study participants have?**
2. **What ACP-related experiences have they had?**
3. **What are their ACP-related views?**
4. **What are the barriers to and facilitators of ACP in this group?**

In study 2, the willingness of older adults with Moroccan background to discuss ACP, as well as similarities and differences in their perspectives and those of older adults with Turkish background, were also investigated. In study 3, the results were compared with those of study 1. In study 4, the research questions were oriented toward ACP engagement for the participants' relatives.

3. Methodological approach

Study design

In all four studies, face-to-face semi-structured interviews were conducted to collect in-depth, contextualised information about participants' opinions, experiences and assumptions about ACP, and to determine whether they wished to engage in it.[164] The interviews were conducted in the participants' native languages [Turkish, Darija (Moroccan Arabic), Dutch and French]. The study methods and findings were reported according to the consolidated criteria for reporting qualitative research.[165] The 32-item checklist for these criteria guided the reporting of important aspects of the research team; study context, methods and findings; and analysis and interpretation.

Participants and recruitment

Study participants were recruited through general practitioners in Brussels, Antwerp and Mechelen. General practitioners serving older Turkish and Moroccan adults, identified via primary care and the research team's networks, were contacted. The studies were explained to them and they were asked to help identify patients born in Morocco and Turkey based on their knowledge of their personal histories and medical records.

For studies 1 and 2, the general practitioners recruited participants with no life-threatening illness or need for palliative care, according to the Palliative Care Indicators Tool.[166] For study 3, patients eligible for palliative care according to the criteria of this tool (incurable disease and two or more frailty indicators) were recruited. For study 4, the general practitioners recruited primary family members of participants in studies 1 and 2 who were aged ≥ 18 years and fluent in Dutch or French. For all studies patients with cognitive impairment (including dementia) were excluded.

The general practitioners asked eligible individuals whether they wished to participate in a face-to-face interview in their native language with a medical doctor researcher of Turkish (studies 1 and 3) or Moroccan (study 2) background about their views on possible future care planning. For patients who agreed, the general practitioners completed the Palliative Care Indicators Tool and, with consent, provided the results and contact information to the researcher. For study 4, the general practitioners initiated recruitment through conversations with study-1 and -2 participants. With consent, they requested the contact information of these participants' most significant family members. Researchers provided information to them about the study, scheduling interviews with willing participants, by telephone. For each of the four studies, participants were recruited until the analysis of data from the last three participants yielded no new relevant information, theme or code, signifying data saturation.

Thirty-three older adults (16 men, 17 women) aged 65–84 (mean, 71.7; median, 74.5) years participated in study 1, 25 older adults (10 men, 15 women) aged 65–90 (mean, 74; median, 72) years participated in study 2, 15 older adults (10 men, 5 women) aged 65–89 (mean, 79; median, 77) years were interviewed for study 3 and 22 family caregivers (10 men, 12 women) aged 25–64 (mean, 44.5; median, 44.5) years participated in study 4.

Data collection

All interviews were conducted at the participants' homes or locations of their choosing (e.g. general practitioner practice) and audio recorded with two devices (to avoid information loss in case of device malfunction) with consent. The interviewers collected information about participants' socio-demographic characteristics and took field notes immediately after each interview. The data collection and analysis phases were largely concurrent in all studies.

For studies 1 and 3, an interview topic guide was developed and forward-backward translated from English to Turkish. Before study 1 initiation, it was pilot tested once with six older adults from the target group to examine its content clarity, followed by revision to ensure that it was understandable and elicited relevant information. The guide contains open-ended questions about interviewees' ACP-related knowledge, experiences, views, facilitators and barriers. The interviewer (HD; a male general practitioner fluent in Turkish with experience in qualitative research and semi-structured interviews) first asked about participants' ACP knowledge without explaining the concept. He then introduced ACP as a form of in advance communication about the care and/or treatment a person would or would not like to receive should they no longer be able to communicate such preferences. Advance care planning is conceptualised as a broad approach that enables individuals to identify their values, define goals and preferences for future medical treatment and care, and address concerns across physical, psychological, social, and spiritual domains. Although not solely the focus, discussing medical end-of-life preferences and values usually is an important part of advance care planning conversations. During our interviews, we therefore explained advance care planning in general but additionally used examples to further explain the concept. This included of possible medical end-of-life care or treatment planning, such as preferences about life-prolonging treatment, care location (e.g. moving to a nursing home) or power of attorney, using a case example and clearly, simply worded comprehensive information. This approach intended to provide clear guidance to participants, particularly to those with low educational and health literacy levels.

For study 2, an interview guide based on that used in studies 1 and 3 was developed. Two researchers proficient in Darija and Dutch (RH and BC) independently translated the guide into Darija using a phonetic script. The translations were compared and back translated, and consensus on the final version was reached. The guide's clarity and comprehensibility were tested in two interviews with older Moroccans, which resulted in no modification. A general practitioner-in-training with semi-structured interview training (RH) conducted the interviews as in studies 1 and 3.

For study 4, an interview guide in Dutch and French was developed. A general practitioner-in-training who was fluent in Dutch and French and trained in qualitative interview techniques (WE) conducted the interviews.

Data processing and analysis

Data from studies 1 and 2 were analysed using the constant comparative method for open-ended data.[167] Constant comparative analysis is associated specifically with grounded theory and has the goal of theory development. [167] In contrast, the research team's goals were to identify and describe patterns (themes) in data and to interpret/explain those patterns and their mutual relationships. Moreover, we assigned the data to pre-defined categories. These goals and work method correspond to thematic analysis, [168,169] and the research team determined that subsequent work would benefit from the application of this approach.

For study 1, a non–research team member transcribed the interviews verbatim. The interviewer (HD) checked the first six transcripts for accuracy, which revealed no data loss, and then discontinued this practice. Researchers fluent in Turkish and English (HD and FZC) independently reviewed and coded the transcripts, regularly discussing the coding structure. For study 2, the interviewer (RH) transcribed all interviews and translated the transcripts into Dutch. Another researcher (BC) checked the transcripts of the first four interviews to rule out subjective influence; this practice revealed no data loss and was discontinued. RH and BC independently reviewed and coded the transcripts. For both studies, line-by-line review was conducted until codes had been applied to all transcript sections representing study-related concepts.[167] The codes were assigned to five a priori–defined categories based on the topic guides (ACP knowledge, experience, views, barriers and facilitators), then grouped into a concept hierarchy (tree) based on their similarities and differences. Coding was iterative, with comparison within and across interviews until overarching themes were identified. [168] The main researcher (HD) read the transcripts translated from Darija to Dutch and then reviewed the codes and overarching themes proposed by the other two coders (RH and BC) for accuracy. Codes and themes were compared by HD within and between transcripts. The main researcher (HD) met regularly with the two coders (RH and BC) to collaboratively create the final coding tree, a process that continued until consensus was reached. Following these meetings, they additionally met with another researcher (SD), to reflect on the process and explore initial insights. During this process, they also presented and discussed their findings with the entire research team every six weeks for a period of 6 months.

For studies 3 and 4, two researchers (HD and FZC and HD and WE, respectively) independently performed combined deductive/inductive coding reliability thematic analysis of the transcripts in.[170] They read the transcripts line by line and assigned the data to the a priori–defined categories used in studies 1 and 2, comprising the deductive component of the analysis. [170] The data in each category were further assigned to subcategories (inductive component), which were then grouped to form themes.[170] The coding was discussed monthly until consensus was reached. The objectivity, reliability and accuracy of coding were assessed by the examination of inter-coder agreement.[170] The whole process followed a six-phase thematic analysis guide and involved constant movement among the entire dataset, coded extracts and ongoing data analysis.[170]

For studies 1 and 3, verbatim transcripts in Turkish were initially analysed. Then, relevant parts of the transcripts were translated into English and the analysis was repeated. This bilingual data analysis permitted the consideration of cultural context and meaning-based interpretation and translation, ultimately reflecting participants' experiences as closely as possible.[171]

In all four studies, code list recording and analysis were performed using the NVivo12 software (QSR International, Melbourne, Australia). Upon the completion of analysis, relevant content was forward-backward translated into English as needed. The results of all studies were discussed with the entire research team every 6 weeks, with reflection on the process and the exploration of initial insights to enhance triangulation, limit bias and ensure the reliability of interpretations.

Ethical considerations

The Medical Ethics Commission of Vrije Universiteit Brussel approved studies 1, 3 and 4 (B.U.N. 143201838280, 143201838280 and 1432021000571 respectively). The Medical Ethics Committee of Ghent University Hospital approved study 2 (B.U.N. B670201942542) because the mentor of the general practitioners-in-training and co-researcher was affiliated with Ghent University. All research participants provided verbal and written informed consent to study participation and the publication of anonymised findings after the results had been presented to them and their questions had been answered. Participants are identified by numbers to maintain privacy and data confidentiality.

4. Dissertation outline

This dissertation consists of the following six chapters.

- Chapter 1. A general introduction to Turkish- and Moroccan-origin older adults in Belgium and ACP (in general and for ethnic minorities and in Belgium), presentation of the research aims and questions and description of the methodological approach.
- Chapter 2. The article entitled ‘Advance care planning among older adults of Turkish origin in Belgium: Exploratory interview study’ (study 1)
- Chapter 3. The article entitled ‘Advance care planning among older adults of Moroccan origin: An interview-based study’ (study 2)
- Chapter 4. The article entitled ‘Advance care planning among older adults in Belgium with Turkish backgrounds and palliative care needs: A qualitative interview study’ (study 3)
- Chapter 5. The article entitled ‘Views on advance care planning of family members of older adults with Turkish and Moroccan background: An exploratory interview study’ (study 4)
- Chapter 6. A general discussion of the main study findings, study strengths and limitations and implications for practice and future research, ending with a general conclusion.

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CHAPTER 2

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 Messages: Older people of Turkish origin in Belgium who participated in this study were not familiar with the term "advance care planning," indicating that this population requires tailored information about this practice. In this population, family relationships can facilitate or act as barriers to engagement in advance care 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 (PICT),(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 PICT 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 PICT 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).

Data Collection

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

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

Data Analysis

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

Fear of Triggering Negative Emotions

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

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

> "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 because it will damage my mood." (Respondent 11, 74-year-old woman).

Fear of Upsetting One's Children

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

> "The reason I didn't talk to anyone about my preferences is to not upset the children. If I say 'put me in a nursing home,' they will get stressed and say 'you do not trust us!'" (Respondent 25, 69-year-old woman);
>
> "It [ACP] is a difficult subject. It's actually a very nice thing, but our children will not be happy to talk about it…We don't talk so that the children are not upset." (Respondent 19, 65-year-old man).

Discussion

Main Findings

This study revealed that some older adults of Turkish origin in Belgium have had ACP discussions with family members, despite overall unfamiliarity with the term ACP in this population. Informed 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	*n*
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
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

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?

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

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

ACP, advance care planning.

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CHAPTER 3

ADVANCE CARE PLANNING AMONG OLDER ADULTS OF MOROCCAN ORIGIN: AN INTERVIEW-BASED STUDY

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ABSTRACT

Objective: To explore advance care planning (ACP)-related knowledge, experience, views, facilitators and barriers among older Moroccan adults in Belgium.

Method: General practitioners (GPs) recruited participants for semi-structured interviews. Data were analysed using the constant comparative method.

Results: The 25 interviewees (average age, 74 years) lacked ACP knowledge and had not discussed it with healthcare professionals. After a brief explanation, most interviewees did not find ACP useful. After more explanation with a specific example, they had fewer religious objections and were more willing to have discussions with their GPs and/or relatives. ACP barriers were a lack of knowledge, current good health, potential harm of talking about death, trust in one's children to make care decisions and fear of worrying one's children. Facilitators were GPs' information provision, children's involvement in ACP discussions and the desire to not depend on children.

Conclusion: Many older Moroccan adults lacked familiarity, but were willing to discuss ACP after receiving understandable concrete information. GPs should facilitate ACP discussions for these patients, ideally with adult children involved, with consideration of barriers, individual preferences and generally low educational levels.

Practice implications: GPs should provide comprehensible ACP information with case examples and consider potential barriers and facilitators in this group.

Key words: Advance care planning, end-of-life care, general practice, elderly, ethnic minorities, qualitative study

1. Introduction

Advance care planning (ACP) has been defined by European consensus to enable individuals to define goals and preferences for future medical treatment and care, discuss them with family and healthcare providers, and record and review them as appropriate. People engaged in ACP are encouraged to appoint representatives and record their preferences for consideration when they are unable to make decisions for themselves [1]. Patients can also document their preferences about matters such as the burial place and manner, organ/body donation and euthanasia [2]. ACP can increase patient/surrogate satisfaction with communication and decrease surrogate/clinician distress; findings for other hypothesised outcomes, such as improved goal-concordant care, quality of care and health status, are mixed [3].

ACP is complex, especially for older adults with non-dominant social, cultural and spiritual views on the end of life [4]. Culture (entailing race, ethnicity, religion, language and origin) largely determines how people view life and death and, consequently, make end-of-life decisions [4]. Studies conducted in New Zealand, the United Kingdom and the United States have revealed significantly less ACP participation among ethnic-minority than among ethnic-majority older adults, due mainly to a lack of knowledge, the major role of family members in elder care, and distrust of the healthcare system [5–8]. In addition, healthcare professionals often lack communication skills and knowledge of intercultural differences regarding end-of-life issues [9].

In Belgium, 12.7% of people aged ≥ 65 years or their parents have foreign first registered nationalities [10]. In large cities, this proportion is 10–39.3% [10,11]. People of Moroccan origin form the largest group with non-European backgrounds in Belgium, accounting for 1.2% of the population aged ≥ 65 years [12,13]. Research conducted with older Turkish adults in Belgium has revealed unawareness of the existence of ACP, although most respondents were willing to participate and saw ACP as useful when the concept had been explained to them [14]. Little is known about discussing ACP with people of Moroccan origin. People with Turkish and Moroccan immigration backgrounds (often Muslim) have experienced similar socialisation in Belgium due to their arrival as guest workers in the early 1960s [15]. Older people in both groups have less education and poorer health than do older people in Belgium without these immigration backgrounds [16]. Belgium is currently facing the ageing of these Muslim populations [16]. Available research on ACP aggregates various ethnic-minority populations, assuming cultural homogeneity, which leads to inappropriate generalisation and the overlooking of individual-level complexities [17,18]. Moreover, although some early work was conducted with healthy older adults [19], most ACP research has been conducted with patients who were seriously ill, had dementia and/or were receiving residential or palliative care [20,21]. Although end-of-life care discussions with chronically ill patients are commonly considered to be appropriate, ACP should also be considered for healthy people [22,23]. Ideally, ACP discussions should be initiated in a primary care/outpatient setting [24]. ACP is dynamic and ongoing in response to changing perspectives over time, and could be initiated with older people without life-threatening illnesses by discussing healthcare proxy preferences or care goals in hypothetical debilitating or terminal situations [22]. The goals of this study were to investigate the willingness of older Moroccans in Belgium to discuss ACP, and to compare their ACP perspectives with those of elderly Turks in Belgium. We explored this group's ACP knowledge, experiences, views, barriers and facilitators.

2. Method

2.1. Study design

For this qualitative study, semi-structured interviews were conducted to explore respondents' opinions, experiences and assumptions about ACP and to determine why they were or were not interested in it. The interviews were conducted in Darija (Moroccan Arabic), the participants' native language, after receiving their written and verbal informed consent, including for the publication of anonymised findings. The study was approved by the Ethics Committee of Ghent University Hospital (B.U.N. B670201942542) and registered with ClinicalTrials.gov (no. NCT04335214, protocol ID B670201942542).

2.2. Patient recruitment

Through general practitioners (GPs) in Brussels and Mechelen, we recruited Belgian residents of Moroccan origin aged $\geq$ 65 years in primary care without life-threatening illnesses (according to the Palliative Care Indicators Tool [25]) who could benefit from ACP discussions. Those with incurable diseases and two or more frailty indicators were considered to be eligible for palliative care and were excluded. The GPs asked eligible individuals whether they wished to participate in a face-to-face interview study about possible future care planning by speaking to a researcher in their native language. The GPs sent consenting individuals' contact information to the primary researcher (HD). One researcher (RH) contacted these individuals by telephone to provide further information about the study and to schedule interviews with willing individuals.

2.3. Data collection

One male researcher (RH), a GP-in-training with semi-structured interview training, conducted all interviews between November 2020 and July 2021 at the respondents' homes or locations of their choosing. After the respondents had filled in the consent form with the interviewer's assistance, the interviews were recorded with two audio recorders. Information about participants' socio-demographic characteristics was collected at the beginning of each interview. After each interview, notes were made to record any further relevant information. Interviews were conducted until they revealed no new relevant information.

The interview guide used in this study (Table 1) was based on that used in a study of ACP perspectives among elderly people of Turkish origin [14]. Two researchers (RH and BC) proficient in Darija and Dutch independently translated the guide into Darija using a phonetic script. The translations were compared and back translated, and consensus on the final version was reached. The guide's clarity and comprehensibility were tested in two interviews with older Moroccans, which resulted in no modification. Participants were asked open-ended questions about their ACP-related knowledge, attitudes, experiences, facilitating factors and barriers. The interviewer introduced ACP as a means of communicating in advance about the care and/or treatment a person would or would not like to receive in the case that he/she was no longer able to communicate such preferences. Because of the known low literacy levels in the study group, we included an example case (Box 1) and clearly, simply worded comprehensive information on ACP use (Box 2).

2.4. Data processing and analysis

The interviewer (RH) transcribed all interviews and translated the transcripts into Dutch. Another researcher (BC) checked the transcripts of the first four interviews to rule out subjective influence; this practice revealed no data loss and was discontinued. Two researchers (RH and BC) independently used the qualitative constant comparative method [26] to perform line-by-line iterative coding of the study-related transcript content, with comparison within and between transcripts until overarching themes were identified [27]. The code list was recorded, and analysis was performed, using NVivo 12 software (QSR International, Melbourne, Australia). Data collection and analysis were conducted concurrently with the interviews so that the topic guide could be modified slightly to pursue emerging lines of inquiry. The two researchers met regularly with other researchers (HD and SD) to reflect on the process and explore initial insights. When the analysis had been completed, the relevant content was translated into English using the forward-backward method.

Table 1. Interview guide topics

- Concerns about future care
  - What is your current state of health?
  - Do you have concerns about the future?
  - Have you thought about future care?
- Familiarity with the concept of ACP (advance care planning)
  - Do you know about ACP?
  - Do you know about certain parts of ACP?
- Experiences with ACP
  - Have you communicated your wishes to your next of kin?
  - Have you, or has someone you know, performed ACP?
- Detailed information about ACP
  - Presentation of the example case
  - Provision of comprehensive information about ACP use
- Opinions on ACP
  - What do you think of ACP as a whole, and about each of its parts?
  - Do you think that ACP is useful?
- Barriers and facilitators
  - What makes it difficult to talk about this?
  - What makes it easier to talk about this?
- Socio-demographic characteristics
  - Education, literacy, years in Belgium, marital status, children, profession, current living situation and emigration environment

Box 1. Example case

A 75-year-old patient has Alzheimer's disease (memory loss). She lives with her daughter. She tells her GP: ‘If I ever have a serious illness from which I will not recover, I do not want to be hooked up to machines or on drip feed in the hospital to prolong my life, like my husband. He was in pain for weeks before he died.’ Several years later, this patient becomes ill. She has a high temperature and a cough, and cannot eat or drink. Her GP wants to admit her to the hospital to give her a drip feed and antibiotics. The GP and the patient’s daughter decide to do so, but agree that if she does not improve within a few days, they will stop all treatments and discharge her to spend her final days at home. The patient recovers after 3 days and returns home.

Three years later, the patient’s dementia has become much worse and she has been admitted to a rest home. She can no longer get out of bed or out of an armchair, and she has stopped eating. Nothing gives her pleasure anymore; she doesn't recognise her own daughter either. In addition, she cannot make decisions about her own treatment. In this situation, the daughter asks the GP: ‘How about feeding her with an infusion?’ The GP says he doesn't think this is desirable because when the patient was healthy, she had expressed her wish to not be hooked up to machines or a drip feed if she was ever in a bad medical condition. After 2 painless months, the patient dies.

GP, general practitioner.

Box 2. Comprehensive information on the use of ACP

1. It is now possible to somewhat extend the life of someone who is seriously ill, unconscious and has no hope of recovery by giving them drips, a respirator and antibiotics. While you are in good health, you can choose to refuse such treatments should you ever fall into that condition.
How do you feel about discussing this now for the future?

2.You can specify now that you want to move to a residential home when you are very old and can no longer take care of yourself.
How do you feel about discussing this now for the future?

3. You can give someone authorisation (power of attorney) to act on your behalf. If you become seriously ill at some stage and cannot think about your treatment properly, this person can make decisions for you and ensure that your previously communicated wishes are met.
How do you feel about discussing this now for the future?

ACP, advance care planning.

3. Results

Of 31 potentially eligible individuals, 25 were interviewed. Four people indicated that they were no longer interested in being interviewed and two women wished to be interviewed only by a woman. The interviews lasted 43 minutes on average. In three cases, participants' children were present due to their interest in the topic, because of coincidence or to support their parents. None of the children interfered directly with the interviews.

3.1. Socio-demographic characteristics

The participants' average age was 74 (median, 72) years. All respondents were first-generation migrants, Muslim and Darija speakers, and had low literacy levels; 17 respondents were illiterate (Table 2). These characteristics are comparable with Flemish government statistics on elderly Moroccans [13].

Table 2. Participants' socio-demographic characteristics

Characteristic	Category	*n*
Age (years)	65–70	8
	70–80	10
	80–90	7
Gender	Man	10
	Woman	15
Highest diploma obtained	None	16
	Koranic school	2
	Military school	1
	Primary education	6
	Medium-level education	0
	University	0
Marital status	Married	17
	Widowed	7
Profession before retirement	Worker	10
	Clerk	2
	Housewife	13
Self-identified literacy	Illiterate	17
Living situation	Alone	7
	With partner	10
	With partner and children	8
Number of years in Belgium	0–20	4
	20–50	7
	>50	14

Number of children	0	4
	1–4	8
	4–6	9
	>6	4
Emigration environment	Town	18
	Rural	7

3.2. Themes

We identified from the interview data the following ACP-related themes: lack of familiarity with and awareness of ACP, reduced influence of religion after detailed information provision and impact of children on ACP views. We identified as barriers the lack of knowledge, current good health, trust in one's children to make care decisions, fear of worrying one's children and potential harm of discussions about death. We identified as facilitators GPs' provision of information, children's involvement in ACP discussions and the desire to not be dependent on children.

3.2.1. Lack of familiarity with and awareness of ACP

All interviewees lacked familiarity and experience with ACP. One person had heard that a representative granted power of attorney could make medical decisions for a patient who could not do so.

> 'No, I have never heard of this.' (Respondent 5, 68-year-old woman)

> 'Yes this [power of attorney] I know, the one you choose is always someone who knows you well and has your best interests at heart.' (Respondent 9, 67-year-old man)

Some respondents had discussed ACP issues (mainly burial, also care home residence) with their children and/or other family members.

> 'Yes, I brought all five of my children together and I discussed this [funeral wishes] with them. Afterwards, they said "Daddy, why are you bringing this up" or "Daddy, this is not nice talk". But I think this is an important subject and that is why I have discussed it with them. I also told them that this way they would always have a souvenir of me here in Belgium.' (Respondent 11, 72-year-old man)

> ‘I told the children that if our care becomes too burdensome, they can take us to a nursing home.’ (Respondent 18, 72-year-old woman)

3.2.2. Reduced influence of religion after detailed information provision

Most respondents initially stated that they did not find talking about future care to be useful or meaningful for religious reasons.

> ‘We always say that the future is in the hands of God; we don't know what will happen to us. I have already reserved a place [laughs] where I will be buried in my village in Morocco, but other than that I have nothing else to think about.’ (Respondent 15, 83-year-old man)

However, when ACP was explained in more detail using the example case, respondents expressed various opinions (largely positive) and had fewer religious objections. They felt that preparing for the future, especially while one can think clearly, was important.

> ‘I think that it is something good. But we also need to have faith in God. I agree to commit [to ACP] from now on, because my staying at home is difficult for my family.’ (Respondent 15, 83-year-old man)

> ‘I think it is good that someone is preparing while still in good health.’ (Respondent 17, 79-year-old man)

They were prepared to have ACP discussions, mainly about their desired burial location and refusal of futile care, immediately with their GPs and/or family members.

> ‘I will see my GP on the 15th, I will discuss it with him.’ (Respondent 6, 79-year-old man)

> ‘I will talk to my children about my burial place and refusing useless treatment.’ (Respondent 21, 68-year-old woman)

Some respondents still did not find ACP to be useful, for religious reasons.

> ‘I am not concerned with what might happen to us tomorrow or the day after. We cannot know what will happen to us tomorrow. God is the only one who knows. I think everything is in the hands of God, so I cannot limit my possibilities in advance.’ (Respondent 11, 72-year-old man)

3.2.3. Impact of children on ACP views

Some respondents indicated that ACP would not be useful because children typically care for parents in Moroccan culture.

> ‘I count on the support of my children here. In our culture, we continue to support our parents. I myself also supported my mother until her death. I don't think this is because of our religion. This is passed on from generation to generation. I think these are mostly traditions.’ (Respondent 19, 70-year-old woman)

They had confidence that their children would make decisions when they could not, although they had not spoken about it.

> ‘It will be my children who will decide. I have no preference. And my children will not abandon me, they will bury me where they want to. They will have to come together at that time to make a decision that suits them. I don't want to make a decision that they are going to have trouble with.’ (Respondent 13, 84-year-old woman)

Some respondents feared that their children would not take ACP discussions seriously or that such talk would trigger negative emotions (e.g. anxiety).

> ‘If I make my wishes known to my children now, I am going to cause them anxiety and stress, they are going to start crying and ask why I am bringing this up.’ (Respondent 7, 84-year-old man)
>
> ‘Yes, what can I say, I don't want them to laugh at me.’ (Respondent 5, 68-year-old woman)
>
> ‘I don't want to give my children headaches, a man should forget about this [death, illness, old age] because if you keep thinking about this, it creates other problems. As for your mental state, leave it in the hands of God and trust in God.’ (Respondent 4, 77-year-old man)

Other respondents realised that ACP could help relieve pressure on family members related to future care. They suggested that GPs should inform patients’ children about the benefits of ACP and stimulate their involvement in ACP conversations in the GP office and at home.

> ‘Indeed, ACP is useful, I don't want to be a burden on my children and wife.’ (Respondent 6, 79-year-old man)

> ‘It is a good idea that the GP gives information to the children, yes that is better, because then they will understand, and they will listen to the doctor.’ (Respondent 10, 65-year-old woman)

Some respondents indicated that they would like to undertake ACP in the future, after speaking to their children.

> ‘Now that you have brought this to my attention, I can speak to my children about it first, and think about it.’ (Respondent 1, 69-year-old woman)

In addition, some respondents with children mentioned that ACP could be useful for people who did not have children’s/family members’ support.

> ‘If I see that I am not getting support from my children, then I will ask for this, yes.’ (Respondent 21, 68-year-old woman)
>
> ‘For someone who is alone, this is a good option.’ (Respondent 1, 69-year-old woman)

3.2.4. Other ACP barriers and facilitators

Respondents mentioned their lack of knowledge about ACP as a barrier to ACP discussion; some respondents attributed this lack to their illiteracy.

> ‘No idea, we don't know anything. We have never studied, and we know nothing. I think if I had been literate [educated], I would know much more and perhaps have done more, but one who isn’t aware can’t do anything.’ (Respondent 21, 68-year-old woman)

Most interviewees had difficulty expressing opinions about (or even imagining) treatment restrictions in a medically hopeless situation, despite the example case. Those with experience of situations in which end-of-life decisions had to be made had opinions about the restriction of life-prolonging drug provision.

> Interviewer: ‘What do you think about a person stating in advance that they will not receive any more life-extending treatment if they are in a coma or have an untreatable disease, with the result that they [the person’s family/representatives] let that person die?’

> Respondent 10 (65-year-old woman): ‘No you can't say that, you can't say at that moment that you are going to let that person die. And you can't say it in advance either, you mustn't give up hope.’

Another ACP barrier was respondents’ current good health.

> ‘I am currently in good health and don't need it, but if I get sicker, I might do this.’ (Respondent 19, 70-year-old woman)

Other respondents indicated that their lack of organisation and taboos regarding the discussion of illness and death prevented them from discussing the end of life.

> ‘The problem we [Moroccans] have is that we don't do this, that we don't live our lives in an organised way and don't think beforehand.’ (Respondent 9, 67-year-old man)
>
> ‘Because this is taboo. Death is something everyone fears and avoids.’ (Respondent 9, 67-year-old man)

For most interviewees, GPs’ provision of understandable ACP information was the primary facilitating factor.

> ‘If this [ACP] is brought up, then yes [I would undertake ACP]. If he [the GP] doesn't bring it up, then no.’ (Respondent 20, 66-year-old woman)

4. Discussion and conclusion

4.1. Discussion

4.1.1. Summary

This study showed that older Moroccans had no ACP knowledge and had not discussed ACP with healthcare professionals. Many had discussed their wishes about burial and possible nursing home residence with family members. Upon being introduced to ACP as a form of advance communication, most respondents felt that ACP would not be useful or meaningful, mainly for religious reasons. However, after the provision of more information about what ACP entails, a large proportion of interviewees had fewer religious objections and were interested in discussing topics such as their burial location and the refusal of futile care. Persisting barriers were the lack of need or desire for ACP due to current good health, potential harm of talking about death, trust in one’s children to handle care decisions and fear of worrying one’s children. The respondents had some common reasons for starting or not starting ACP, but individual variation also existed. The facilitators mentioned were GPs’ provision of information, children’s involvement in ACP discussions and the desire to not be dependent on one’s children.

4.1.2. Strengths and limitations

Older adults with Moroccan backgrounds in Belgium are understudied [28], possibly due to the language barrier for many researchers. The interviewer and respondents in this study shared a language and background, enabling in-depth exploration of their views on ACP.

Qualitative research entails possible selection bias [29]. Presumably, patients and family members who are willing to participate in studies of this type have good relationships with their GPs. Those who do not wish to be interviewed may provide other ACP-related insights. In addition, the study population was less educated, and grasping ACP-related concepts was challenging for some, despite the interviewer’s effort to ask comprehensible questions. Moreover, the manner in which ACP was described could have led participants to adopt a positive perspective on it. These factors may have impacted their answers. In future research, the type of case example used could be varied across the sample to assess the influence of this factor.

4.1.3. Comparison with existing literature

Participants in this study attributed their lack of ACP knowledge to their low educational levels. More than half were illiterate and few had finished primary school, the highest educational level in this sample. This factor results in low health literacy [30] – limited knowledge of and participation in the health sector – which has been identified as an ACP barrier [31]. ACP knowledge has been associated with a higher ACP completion rate [32]. In contrast, language, rather than illiteracy, was an ACP barrier in an elderly Turkish population [14]. As a solution for this lack of knowledge, a frequently mentioned facilitator was GPs’ provision of ACP information. Systematic reviews have confirmed that patients and many GPs believe that the other party should initiate ACP discussions [33]. We acknowledge that information provision or education is a single step toward improved ACP implementation, which needs to be interpreted in the context of other barriers. Ethnic disparities in healthcare use could also lead to difficulty and unfamiliarity with understanding and documenting ACP [34]. Perceived discrimination in the healthcare system [35] and distrust arising from the interpretation of advance directives as a means of limiting care costs and resources at the end of life have been documented [36]. Although not directly mentioned by our respondents, their potential roles in this population should be studied further.

Doctors and care providers have reported that religious beliefs can make ACP discussions difficult [33], especially among older people of Moroccan and Turkish origin, who reject communication about end-of-life care [37]. In this study, however, most respondents mentioned religion as a barrier only at the beginnings of interviews, before having received a detailed explanation of ACP with a case example. Thus, doctors may misconceive the role of religion in migrants' resistance to ACP; the problem may be that their explanations of ACP are too brief. Our findings likely reflect our culture-sensitive approach, with the interviewer and interviewees sharing ethnicity, religion and language. Familiarity with and openness to cultural values can increase the success of ACP conversations [38,39], facilitated by or even requiring a good patient–clinician relationship.

Respondents in this study had great and diverse expectations of their children. Children's informal care provision was very important to them, as found for older adults with Moroccan backgrounds in Belgium and the Netherlands [40,41]. Some older Moroccan adults leave decisions about their future care entirely to their children and/or expect their children to care for them, as observed in African American and Latin American populations in the United States [42,43]. Our respondents indicated that children's elder care is common in Moroccan culture and passed down generationally; many did not discuss their expectations with their children (beyond burial preferences) because they feared that their children would become anxious or not take them seriously. These barriers have also been identified among elderly Turkish individuals in Belgium [14]. Similarly, Glass et al. [44] found that elderly people in the general American population trusted their children to make end-of-life choices for them, without discussion in the majority of cases. Such lack of discussion can lead to misunderstandings about expectations, which could be resolved by ACP. Our respondents indicated that their children's involvement in ACP conversations could be useful. Care providers should consider having such conversations when their elderly patients express this wish. The children's perspectives on such involvement remain unclear and need to be investigated.

After being introduced to ACP, our respondents had different perspectives on what actions they would take. Some wanted to avoid such burdening discussions, consistent with findings that other ethnic-minority groups viewed talking about death, negative information or serious illness as potentially harmful [45,46]. Some wished to undertake ACP as soon as possible, whereas others preferred to wait until they had thought about it further, discussed their preferences with their children or become sick(er). Overall, the results of this study reflect great variation in the Moroccan community in approaches to end-of-life decisions and reasons for starting or not starting ACP. Common factors include religion, possibly shared cultural beliefs and migration background, but major differences in language, customs, religiosity, education level and socio-economic background exist within this community [47]. Recognition of these social sub-identities and their influences on ACP-related conversations, decision making and communication with care workers is important for the success of ACP.

4.2. Conclusion

Despite their initial lack of ACP knowledge, many older Moroccans in Belgium were willing to discuss ACP and some wished to undertake ACP after receiving comprehensible concrete information in their native language. Persisting barriers were current good health, trust in children's care decisions, the perceived potential harm of talking about death and fear of worrying one's children. GPs should facilitate ACP discussions with these patients, ideally with adult children involved, with consideration of individual preferences and the generally low education level.

4.3. Practice implications

To improve the ACP participation of Moroccans in Belgium, patient and migrant associations, the government and GPs should raise awareness about ACP so that individuals know what steps to take when they are ready. Awareness-raising campaigns and good patient–doctor relationships are important to achieve this goal. Physicians should remain patient centred and be aware of patients' education levels [48]. In addition, they should pay sufficient attention to the way in which they describe ACP, which can determine the impact of discussions, as in this study.

This study also revealed the strong role of older adults' children in decisions about whether to undertake ACP. The extent to which older Moroccans assign caretaking and decision-making roles to their children varies widely, ranging from leaving all responsibility to children based on their experiences with their own parents to arranging everything themselves to avoid burdening their children. Further qualitative research on the children's views on ACP would be of interest.

Additional information

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"I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story."

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CHAPTER 4

ADVANCE CARE PLANNING AMONG OLDER ADULTS IN BELGIUM WITH TURKISH BACKGROUNDS AND PALLIATIVE CARE NEEDS: A QUALITATIVE INTERVIEW STUDY

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ABSTRACT

Background: Data on advance care planning (ACP) among migrants in Europe are lacking. Research has shown that few older migrants in the United States perform ACP due to healthcare system distrust, collectivistic values and spirituality/religion.

Objective: To explore the ACP knowledge and perspectives of older Turkish-origin adults in Belgium requiring palliative care.

Method: General practitioners (GPs) in Brussels and Antwerp recruited Turkish-origin participants aged ≥ 65 years with palliative care eligibility for this qualitative study. A GP conducted semi-structured interviews in Turkish in respondents' homes between May 2019 and February 2022 using a topic guide. Two researchers performed combined inductive/deductive thematic data analysis.

Results: All 15 interviewees (average age, 79 years) lacked ACP awareness and information. Some had discussed certain end-of-life preferences (e.g. care location, burial place) with family, but many did not feel the need to discuss future healthcare preferences, due mainly to trust in God and family for caretaking and decision making. Some respondents viewed ACP discussions as useful, relieving the burden on family and enabling proactive addressing of 'what if' questions. Self-identified ACP barriers were fear of making wrong decisions, 'living in the moment' and difficulty discussing death. Facilitators were obtaining sufficient ACP information and recent family illness or death.

Conclusion: Our sample of Turkish-origin older adults in Belgium requiring palliative care lacked ACP knowledge. Our findings suggest that their lack of engagement in discussing end-of-life medical care planning was linked to their family dynamics and religion. The findings have implications for healthcare providers to ethnic-minority groups.

Key words: advance care planning; end-of-life care; older adult; migrant; qualitative study

Key messages: The Turkish-origin older adults in Belgium with palliative care needs who participated in this study lacked knowledge of advance care planning. This group's lack of engagement in discussing end-of-life medical care planning may be linked to their family dynamics and religious backgrounds.

Introduction

Advance care planning (ACP) is defined by European consensus as ‘enabl[ing] individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate’ [1]. It allows patients to articulate future care priorities and caregivers to best meet patients’ care objectives should physical and/or mental health deterioration inhibit patients’ communication. ACP initiation is indicated upon worsening health, ageing, palliative care initiation and/or residential care home admission [1].

ACP allows patients to maintain a sense of control and peace of mind, increasing their satisfaction and quality of life [2]. It reduces the ambiguity of patient–family communication and families’ decision-making burden and anxiety [2,3]. It increases advance directive creation and reduces care providers’ ethical dilemmas [3]. However, ACP does not always achieve these outcomes or improve subsequent care, especially when it consists only of the establishment of advance end-of-life care directives [4]. A recent scoping review of randomised controlled trials revealed inconsistent findings concerning ACP’s effects on care quality, health outcomes and healthcare utilisation [5].

ACP and the designation of legal patient representatives are not prevalent in Belgium and are related primarily to the refusal of life-prolonging treatment [6,7]. In the United States, ACP uptake is lower in certain migrant populations than among older White Americans; across ethnic-minority groups, worse health status and good ACP knowledge are facilitators, and healthcare system distrust is a barrier [8]. Collectivistic cultural values and spirituality/religion influence ACP engagement [8]; the philosophy underlying ACP may be difficult to reconcile with prevailing norms and values in some non-Western cultures, preventing successful implementation [9]. For migrant populations in Europe, high-quality data to substantiate these hypotheses are lacking.

People of Turkish origin form one of the largest non-Western groups in Belgium (comprising 2.1% of the population) and nearby European countries [10]. Ageing Turkish immigrants in Belgium increasingly require formal care, but their health system access and receipt of appropriate end-of-life care are hindered by lack of knowledge about the system, language barriers, low education and health literacy, precarious financial situations and the perceived insensitivity of the system to their cultural and religious attitudes and values [11].

We previously explored the ACP knowledge, attitudes, barriers, facilitators and experiences of older Turkish adults in Belgium with chronic illnesses, but no palliative care need [12]. Age and health status affect ACP uptake, and ACP engagement is lower among migrants than non-migrants with serious illnesses in the United States [9,13]. The ACP-related needs and views of patients with progressive, incurable conditions likely differ from those of healthier adults [13]. In this qualitative study, we examined ACP knowledge, experiences, views, facilitators and barriers in the under-researched population of older Turkish-origin patients in Belgium requiring palliative care.

Method

Study design

We explored respondents' knowledge of and perspectives about ACP, especially end-of-life medical care planning, by conducting face-to-face semi-structured interviews in Turkish. We followed the consolidated criteria for reporting qualitative research in describing the methods and findings [14].

Patient recruitment

The principal researcher (HD) asked general practitioners (GPs) serving older Turkish adults in Brussels and Antwerp, identified via primary care and the authors' personal networks, to recruit Turkish-origin people aged ≥ 65 years who were living in Belgium and eligible for palliative care, according to the Palliative Care Indicator Tool (PICT) [15]. The GPs identified patients who were born in Turkey based on their knowledge of their personal histories and medical records. According to the PICT criteria, older people with incurable diseases and two or more frailty indicators were included [15]. Those diagnosed by their GPs with cognitive impairment or dementia were excluded.

The GPs asked eligible individuals whether they were interested in participating in a face-to-face interview about possible future care planning with a researcher/medical doctor in Turkish. The researcher contacted consenting individuals by telephone to provide further information, ascertain their willingness to participate and schedule home interviews with willing participants. Participants were recruited until no new relevant knowledge had been obtained in three previous interviews (i.e. data saturation).

Data collection

The principal researcher (HD), a male GP fluent in Turkish with experience in qualitative research and semi-structured interviews, conducted all interviews (one per participant; average length, 37 minutes) between May 2019 and February 2022. Each interviewee provided oral and written consent in Turkish, with the interviewer's and/or family members' assistance when needed, and the interviews were then audio recorded with two devices (to avoid information loss in case of device malfunction). The face-to-face approach was adopted to collect in-depth, contextualised information [16]. All 2019 coronavirus disease–related safety measures (i.e. masking, hand disinfection and distancing) were taken. The researcher recorded participants' socio-demographic characteristics at the ends of the interviews and any additional relevant information thereafter.

Fifteen respondents (10 men, 5 women) aged 65–89 (mean, 79; median, 77) years were interviewed. Three individuals approached by their GPs were not interested in participating. All interviewees were first-generation immigrants to Belgium and identified as Muslim. Respondents' children were present during 13 interviews, as they lived with their parents and/or were curious. Six respondents mentioned being in poor health. A majority had low educational levels; only two respondents had completed high school (Table 1).

Table 1. Participants' socio-demographic characteristics (*n* = 15)

Characteristic	**Category**	***n***
Age (years)	65–75	6
	80–89	9
Gender	Man	10
	Woman	5

Migration background	First generation	15
Educational level	Unable to read/write	3
	Some primary school (incomplete)	5
	Primary education	5
	High school or college	2
Profession before retirement	Homemaker	3
	Labourer	12
Marital status	Married	8
	Widowed	7
Living situation	Alone	3
	With spouse	5
	With children or spouse and children	7
Residence in Belgium (years)	20–45	3
	>45	12
Number of children	2, 3	4
	4, 5	7
	≥6	4
Serious illness*	Cancer	6
	Serious respiratory dysfunction	6
	Cerebrovascular accident	2
	Stage-4/5 renal failure	3
	NYHA class-4 heart failure	4

Self-perceived health	Good	1
	Neutral	8
	Poor	6
GP background	Turkish	10
	Belgian	5
Residence	Rural	9
	Urban	6

*Five respondents had multiple serious illnesses.

NYHA, New York Heart Association; GP, general practitioner.

We used the interview guide developed, forward-backward translated from English to Turkish, pilot tested, and revised for content clarity in our previous study [12]. It contains open-ended questions about interviewees' ACP-related knowledge, experiences, views, facilitators and barriers (Supplementary Box 1). The interviewer first asked about participants' ACP knowledge without explaining the concept. He then introduced ACP as a form of advance communication about the care a person would (not) like to receive should they no longer be able to communicate such preferences [1]. While assessing participants' ACP views, he explained the concept in greater detail. The interviews focused on aspects of end-of-life medical care planning that clearly conveyed ACP-related themes, such as preferences about life-prolonging treatment, care location (e.g. moving to a residential home) and power of attorney, with examples. The interviewer also described an example case to explain ACP use in lay terms.

Data processing and analysis

The interviews were transcribed verbatim. Two researchers (HD and FZC) independently conducted combined deductive/inductive thematic analysis of all transcripts [17]. The transcripts were read line by line, and the data were assigned to five a-priori–defined categories, based on the topic guide (deductive component; Supplementary Box 2). Data in each category were further coded into subcategories (inductive component), which were grouped to form themes. Code list recording and analysis were performed using the NVivo12 software (QSR International, Melbourne, Australia). The researchers, fluent in Turkish and English, worked independently to develop findings without meaning loss, enhance transparency during translation and manage sensitive data. They first analysed the Turkish transcripts, then forward-backward translated relevant portions into English and repeated the analysis with the English transcripts. When direct translation into English did not yield a clear result, indirect translation with meaning retention was performed (e.g. ‘don’t connect me to a ventilator’ instead of ‘don’t connect me to the machine’). The bilingual analysis permitted the consideration of cultural context and meaning-based interpretation and translation to most accurately reflect participants’ experiences [18]. Data collection and analysis were conducted concurrently with the interviews to pursue emerging lines of inquiry. The research team held monthly discussions to enhance triangulation, limit bias and ensure the reliability of interpretations.

Ethical considerations

The Medical Ethics Commission of Brussels University Hospital approved this study (B.U.N. 143201838280), registered at ClinicalTrials.gov (no. NCT03930823). All data were pseudonymised.

Results

In three cases, respondents’ children asked the interviewer beforehand (via telephone or in person with the respondents absent) to avoid mentioning ‘bad’ diagnoses or prognoses, which they explicitly stated were undisclosed. The interviewer respected these requests. One son cautioned:

> Don’t mention her [his mother’s] illness [lung cancer] in front of her! The doctor revealed her diagnosis, but we told her it was COVID-19–related and would pass. We managed to convince her that she has no major illness right now. (son of Respondent 15)

The ACP-related themes identified were the lack of ACP knowledge but some end-of-life care discussion with family, trust in God and family and positive ACP views. The barriers identified were the fear of making wrong decisions, ‘living in the moment’ and the fear of death. The receipt of sufficient ACP information and recent family illness or death were identified as facilitators.

Lack of ACP knowledge but some end-of-life care discussion with family

No respondent had heard the term ‘advance care planning’ before the interview. However, some respondents had discussed their preferences for future care should they develop serious illnesses or otherwise be in deteriorating health with family members:

> I keep praying to God, ‘please don’t let me be bedridden’. Bedridden people are so miserable. Who would help me eat or go to the toilet? I was talking to [grandchild], and I said, ‘you can’t take care of me once I’m bedridden. If that happens, leave me in a hospital or hire someone to take care of me at home.’ (Respondent 12, 86-year-old woman)

Others had discussed their preferred care and burial locations with family members because they were aware of the life-limiting nature of their illnesses:

> [My] illness is really serious. The chemotherapy is very hard on me … Of course I’ve talked to my family already about where I’d like to be buried. I told them, ‘just don’t bury me here [in Belgium]’. (Respondent 10, 65-year-old man)

Only one respondent had informed his family of his wish to not receive life-prolonging treatment should his condition worsen:

> I told my family to let me go without any fuss. I don’t want my life prolonged. What else is there to talk about? I am content with what God has given me. Death is a difficult thing [but] if you’re connected to [life-prolonging] machines, you’ll only suffer. (Respondent 5, 80-year-old man)

Trust in God and family

The majority of the respondents considered end-of-life care discussions to be futile, repeatedly mentioning their faith in God (as the only one who knows/decides what the future holds) and confidence in their relatives. They wished only to die with faith and were not interested in end of life–related medical discussions.

> I don’t want to talk about [life-prolonging treatment]. I don’t want to decide, life and death are in God’s hands. I wouldn’t take that responsibility away from Him. (Respondent 2, 83-year-old man)

They also trusted that their relatives (mainly spouses and children) would take charge and know what to do should their health deteriorate beyond decision-making capacity, obviating the need for a power of attorney or discussions about life-prolonging treatments.

Some participants who trusted in God and family, but required more care, had discussed their preferences (e.g. for care location) with family members:

> God is great. No worries with God… I leave these things [end-of-life medical care] to my children. They decide … I said to my children that I want to go to a nursing home. I don't want to burden them anymore. (Respondent 15, 71-year-old woman)

Some family members interrupted interviews to volunteer their views on ACP. They emphasised that their parents were looked after well and that this was sufficient, suggesting that we interview seriously ill people, whom they considered to be ready for such discussions:

> She [his mother] is good now. Her condition is improving, and the wound is healing. So there’s no need to talk about [end-of-life] matters. We [Turks] don’t have special preferences; everything comes from God. You should instead ask these questions of those nearing death. If, God forbid, she [his mother] was bedridden today, then she might want to [discuss ACP]. But for now, she feels in good health. (son of Respondent 15)

Some children indicated that they intuitively understood their parents’ wishes and no discussion was required:

> My father’s wishes are clear to us. We haven’t had discussions on this topic [ACP], but we know his wishes … we have that confidence [between parent and child] … There’s no need, we’ll take good care of him … everything is clear, the plan is clear – he will stay here [at home]. (son of Respondent 14)

Positive views on ACP

After ACP was explained with examples, some respondents considered the discussion of end-of-life care preferences with relatives and physicians (mostly GPs) to be useful and wanted to involve close family members. They mentioned the confidence that would come from having made plans in advance of deteriorating physical or mental health:

> It's good to talk in advance as it gives them [children] the chance to ask, 'tell us what you want before you die'. It's a good thing. Talking openly gives confidence; it's good for everyone. (Respondent 1, 80-year-old woman)

They viewed the discussion of topics such as life-prolonging treatments, care location and power of attorney as increasing certainty:

> It's beneficial to say it all beforehand when your eyes are still open [i.e. conscious], explaining, for example, 'I want this but not that [treatment]'. There's no need to hide these [preferences] from family. (Respondent 4, 75-year-old man)

They felt that advance specification of their preferences could prevent their suffering and avoid unduly burdening their families should the need for intensive care arise:

> This [ACP] should be discussed while you are healthy and conscious. I'm healthy now, but God only knows what will happen tomorrow. I don't want to burden my children. I can tell them, 'I don't want to go to a nursing home'. Also, I don't want to be miserable at the end. I will tell my doctor [GP], 'If I'm really ailing and can't talk, don't connect me to a ventilator'. When we talk about it [beforehand], then my son can say, 'my mother's wishes are this'. Or my doctor. He would be able to say, 'she told me [her end-of-life care preferences]'. (Respondent 9, 70-year-old woman)

ACP barriers

Fear of making wrong decisions

After explaining ACP and providing examples, some respondents emphasised their lack of education on the topic and fear of making wrong decisions or answering their doctors incorrectly. They felt uncertain about their ability to discuss end-of-life medical care, preferring to avoid discussions about life-prolonging treatments and leaving such decisions to their adult children:

> Talking beforehand is very good, but I don't understand much. I didn't even finish primary school and I'm afraid of making the wrong decision. I don't know anything, but he [son] does. My children can decide. (Respondent 6, 87-year-old man)

'Living in the moment' attitude

Some respondents were convinced that their current conditions were not critical, death was not imminent and it was better to take things as they come:

> My current situation is okay, although I can't clean and get to the shops like before. I don't think about the future because my health is not too bad right now. But if later I can't walk, then it will be different. (Respondent 12, 86-year-old woman)

Some expressed anxiety in this context:

> I get anxious about what will happen to me. But I remind myself that God is great, and where there is God, there is no worry. After that, I feel much better. What should I say? I'll talk when things get worse; there's no need right now. (Respondent 15, 71-year-old woman)

Difficulty talking about death

A few respondents were reluctant to discuss end-of-life care preferences because of the psychological discomfort of being reminded of death:

> I haven't thought about it [end-of-life care] until today. No one wants to think about his own death; it's too difficult to talk about. (Respondent 7, 70-year-old man)

ACP facilitators

Obtaining ACP information

The most frequently mentioned ACP facilitator was obtaining ACP information. With sufficient information and opportunities to ask questions, respondents indicated that they would feel comfortable expressing their wishes to their GPs and delegating a power of attorney.

> If we know enough about [ACP], we could tell them [children], ‘the doctor informed us about [ACP], and now we should discuss it together’. I could say, ‘If I get worse, you are authorised to make decisions; I grant you this authority’. (Respondent 13, 73-year-old man)

Family experience of serious illness or death

Some respondents’ recent family experiences of serious illness or death had prompted them to think and talk with relatives about their end-of-life care:

> My mother died within 40 days of my son-in-law. After all this bad news, I started thinking about it [ACP]. We all die, but after [a recent fall], I’m giving it more thought. I don’t want to go into care; I want to die at home. I’ll share my preferences with my children when I go to Turkey this year. (Respondent 9, 70-year-old woman)

Discussion

Main findings

The older Turkish-origin interviewees requiring palliative care in Belgium lacked ACP awareness and detailed information. Some had discussed their end-of-life preferences with family, but most felt no need to do so, due mainly to their trust in God and family for caretaking and decision making. Some respondents viewed such discussions as beneficial, mainly because they would relieve the burden on families and proactively address ‘what if’ questions. ACP barriers were the fear of making wrong decisions, ‘living in the moment’ and difficulty talking about death. Facilitators were the receipt of sufficient ACP information and recent family illness or death.

Strengths and limitations

This study's strengths include the interviewer's knowledge of the participants' native language and cultural background, which enabled direct, nuanced conversation. The respondents' socio-demographic characteristics align with those of the general population of older Turkish-origin adults in Belgium [19], supporting the transferability of our findings.

This research also has limitations. Interviewees' responses may have been biased due to family members' presence, and sometimes unprompted participation, in most interviews. However, we allowed family members to be present in cultural alignment with their important care roles, including end-of-life decision making [11,20]. Most interviewees' unawareness of the seriousness of their health conditions may have influenced their views and willingness to engage in ACP. The interviewer's authority-figure position as a male medical doctor may have influenced the respondents' assertiveness in their responses. Additionally, we focused on people with Turkish backgrounds in Belgium who were eligible for palliative care; the findings may be relevant for other groups with similar immigration histories, as found for Moroccans in Belgium without palliative care needs [21]. However, additional research is needed to understand the experiences of migrants from other ethnic groups requiring palliative care in other nations.

Comparison with the existing literature

Our participants' lack of ACP knowledge is consistent with findings for other cultural-minority groups, underlain by low educational levels, language barriers and the lack of tailored information [9,22]. Their age, education and chronic conditions and the language barrier likely contributed to their low health literacy, which is common and affects the likelihood of pursuing ACP among migrants [8,9]. Health literacy impacts patients' ability to understand and make decisions about their health and healthcare [23]. Our respondents were deemed by GPs to require palliative care and to be likely to die within 6–12 months, but they did not view death as imminent or discussions about end-of-life care preferences as necessary.

The ACP views of older Turkish adults in Belgium appear to differ according to the palliative care need. In contrast to the present findings, most of those without such need considered ACP discussions to be useful and were ready to engage [12]. Family members are often increasingly present for medical discussions as patients' care needs increase, which may increase their reticence regarding end-of-life care preferences. However, some interviewees in this study who needed more care and/or recognised the severity of their conditions had talked with family about their preferred care and burial locations. Previous research confirmed that Turkish-origin older adults in Belgium prepare for their funerals, preferring to be buried 'at home' and according to Islamic custom in Turkey [24]. Our respondents did not mention language issues as an ACP barrier, perhaps because the interviews were language concordant, although older Turkish adults mentioned the language barrier in our previous language-concordant research [12]. Another possible reason is the Turkish origin of most participants' GPs, which was not the case in our previous study.

The major influence of the respondents' values on ACP engagement is consistent with findings for people with migration backgrounds [9]. Older first-generation Turkish migrants in Belgium have been characterised as traditional, collectivist and family centred, with close family members largely responsible for (end-of-life) care decisions [11,20]. Most respondents expressed confidence that their children would care for them according to traditional filial responsibility and in line with some relatives' insistence during interviews that the family had the situation under control, seemingly discomfited at the suggestion that their parents might go to live in a care home. Other respondents wished to involve family members in ACP conversations, citing the value of avoiding worry or encumbrance. These and previous findings demonstrate that end-of-life decisions are affected by others' concerns and opinions [25,26].

Given their faith, many respondents expressed few worries about the future and felt no need to discuss end-of-life care preferences. They viewed God as determinative of all physical and spiritual well-being (including life and death) [9,22]. Individuals tend to become more religious with age to relieve illness-, loss- and death-associated stress [27]. Most respondents in our previous study did not cite religion as an ACP barrier, perhaps because they were younger on average [12]. Minority-group members' completion of ACP documents declines with increasing religiosity and positive spiritual coping [9,22]. We also assume that our participants' religious expressions reflected their reluctance to discuss the topic further.

The ACP examples and cases used in this study enabled deeper discussion, beyond concrete ACP aspects. We obtained meaningful insights into our respondents' thoughts, feelings, religious beliefs and cultural values, consistent with a recent public-health palliative care ACP approach that emphasises individuals' priorities, values and lived experiences [28]. ACP discussions should focus on what matters most to people, rather than narrowly emphasising harm reduction (i.e. avoiding unwanted treatments). Such approaches enable tailored planning and the provision of goal-oriented end-of-life care underpinned by patients' contexts and values, improving their experiences [29,30].

The ACP barriers and facilitators cited by our respondents were similar to those of native-Belgian older adults with limited prognoses (fearing death, trusting in God and family and non-acknowledgement of the end of life as barriers and bad experiences with death and loved ones' deaths as facilitators) in a qualitative study [30]. A marked difference was that many older native-Belgian adults were willing to discuss death and plan end-of-life care; some had written advance directives and/or ensured that their preferences were specified in their medical records [30]. Similar to our respondents, they were less interested in planning for end-of-life care aspects such as life-sustaining treatments [30]. In contrast to our respondents, native Belgians cited their limited trust in surrogates and wish to maintain control over end-of-life care as ACP facilitators. This difference could reflect our respondents' profound trust in family and fear of making wrong decisions.

Implications for practice and research

Providers of end-of-life care to members of collectivistic cultures (e.g. Turkish) should recognise the salience of family and, with patients' permission, involve close relatives in ACP discussions. The decision to involve family does not necessarily impede ACP discussions, as it can be seen as an aspect of patient autonomy [26]. Research conducted with family caregivers could provide more insight into their views, allowing healthcare providers to adapt their approaches to ACP discussion with Turkish-origin patients. Current ACP recommendations [1] highlight the importance of starting ACP conversations even in the absence of a life-threatening diagnosis. Healthcare providers could use ACP examples to determine their patients' views and wishes. The connection between diagnostic/prognostic disclosure and ACP could be investigated further from patients', family members' and healthcare providers' perspectives.

Conclusion

Our sample of Turkish-origin older adults in Belgium requiring palliative care lacked ACP knowledge. The findings suggest that their lack of engagement in discussing end-of-life care planning is linked to their family dynamics and religion. They have implications for healthcare providers to ethnic-minority groups.

Disclosure of interest

The authors have no conflict of interest to report.

Research ethics and patient consent

The study design was approved by the medical ethics committee of Brussels University Hospital (B.U.N. 143201838280, 6 February 2019) and registered at ClinicalTrials.gov (no. NCT03930823). The interviews were conducted after receiving written and verbal consent, including for the publication of anonymised findings, from the participants.

Data management and sharing

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

Supplementary Box 1. Interview topic guide.

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/why not? Have you done something about your concerns and worries? Have you planned something for the future?

Can you explain further?

How do you feel about this?

What knowledge does the respondent have about advance care planning?

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 able to express your thoughts and wishes. Older people do this planning to communicate their thoughts and wishes regarding future healthcare and even end-of-life situations. Such planning is essential for people to prepare for situations where they cannot speak or make decisions due to their future illnesses. 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 such situations?

What experience does the respondent 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?

What are the respondents' views about advance care planning?

Before you become severely ill, do you wish to discuss your future wishes with someone in advance? Why/why not? How do you feel about discussing illness and death?

For some people, their wishes must be known by others to prepare themselves for future situations where they will be unable to express their wishes and make decisions because their physical or mental condition is very poor. I am now going to give you three examples of these subjects.

1. It is now possible to slightly prolong the life of someone who is seriously ill, is not conscious, and has no hope of recovery by drip feeding them, on a ventilator, and using antibiotics. While you are in good health, you can choose to refuse such treatments, should you ever fall into that state. What do you think about discussing this now for the future?

2. You can now specify that you would like to move into a residential home when you are very old and unable to look after yourself anymore. What do you think about discussing this now for the future?

3. You can give someone authority (power of attorney) to act on your behalf. If at some stage you fall seriously ill and can't think properly or make decisions about your treatment, then this person will be able to make decisions for you and ensure that your previously communicated wishes are fulfilled.

What do you think about discussing this now for the future? Do you wish to give authority on your behalf to someone? Why/why not?

Even if you do not have such a serious illness at the moment, what are the advantages and disadvantages of discussing your wishes for the future?

I'm now going to give you an example of an advance care plan. A 75-year-old patient has Alzheimer's (memory loss) disease. She lives with her daughter. She says to her doctor, 'if I ever have a serious illness from which I will not recover, I do not wish to be wired up to machines in the hospital, like my husband. He was in pain for weeks before he died.' So, one day this patient falls ill. She has a high temperature, is coughing, and cannot eat or drink. Her general practitioner wants to hospitalise her as she may recover through intravenous (through a drip) feeding and antibiotics. The family doctor and her daughter decide that if she does not improve within a few days, they will stop the treatments and discharge her to spend her last days at home. The patient recovers after three days and returns home.

Three years later, her dementia has become much worse. The patient can no longer get out of bed or her armchair and has stopped eating. Nothing gives her pleasure anymore. She does not even recognise her own daughter. She is not able to make decisions about her own treatment. Her daughter says, ‘how about feeding her with a drip?’ Her doctor says that he does not wish to subject the patient to treatment anymore because when she was healthy, she had expressed her wish to not be connected to any machines if she ever contracted such a severe illness. After two painless months, the patient dies. What do you think about this story?

What do you think about the patient communicating her wishes, in advance, while she is still healthy/conscious?

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?

Supplementary Box 2. Categories used for data coding.

1. Knowledge about ACP
2. Experience with ACP
3. Views about ACP
4. Barriers to ACP
5. Facilitators of ACP

ACP, advance care planning.

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CHAPTER 5

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

This chapter has been accepted in *“Palliative Medicine”*:

Demirkapu H, Edally W, De Vleminck A, Van den Block L, De Maesschalck S, Devroey D. Views on advance care planning of family members of older adults with Turkish and Moroccan background: An exploratory interview study. *Palliative Medicine*. 2024. doi:10.1177/02692163241261207

ABSTRACT

Background: Significantly fewer individuals with migration backgrounds than native-born individuals undertake advance care planning. Older adults with Turkish and Moroccan backgrounds represent one of the largest ageing non-Western minority groups in Europe. Their relatives could play important roles in facilitating or hindering advance care planning, but their views remain underexplored.

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

Design: Qualitative thematic analysis of semi-structured interview data.

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

Results: Participants had limited advance care planning knowledge and had not discussed it with healthcare professionals. Some found discussing end-of-life preferences with relatives beneficial; others opposed the discussion of specific topics or felt discussions were unnecessary, as they felt responsible for caregiving and trusted by their relatives to make future decisions. Barriers included personal and relational characteristics, emotional difficulty and perceived non-urgency. Facilitators included information in older adults' native languages, general practitioners' cautious initiation and the involvement of several family members.

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

ClinicalTrials.gov no. NCT05241301

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

Key statements

What is already known about the topic?

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

What this paper adds

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

Implications for practice, theory or policy

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

Introduction

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

The views of people with diverse ethnocultural backgrounds in Europe on advance care planning remain under-studied. Uptake has been found to be lesser among migrants than native-born individuals in New Zealand, the United States, Australia and the United Kingdom.[6–9] Cultural factors such as religiosity, comfort with the discussion of death, and attitudes toward decision making affect the acceptability of advance care planning.[10] Turks and Moroccans are among the largest visible and ageing non-Western minority groups in Belgium, France, Germany and the Netherlands,[11–13] and our previous research revealed family members' significant roles in facilitating or hindering advance care planning conversations in these groups in Belgium.[14–16] Some older adults recommended that healthcare providers increase awareness of the advantages of advance care planning among their children, involving them in conversations to avoid 'burdening' them with end-of-life decisions and to reduce dependence on them.[14–16] Others preferred not to involve their children to avoid triggering negative emotions or because they trusted their children to make the right decisions.[14–16]

Research on the advance care planning views of relatives of older adults with Turkish and Moroccan backgrounds is lacking, despite recognition of the importance of involving family members in future planning.[17–19] Effective communication with family members reduces the surrogate decision-making burden and is crucial for goal-oriented care.[20] This study explored advance care planning knowledge, experiences, views, facilitators and barriers among relatives of older Turkish and Moroccan adults in Belgium.

Method

Design

We adopted a qualitative approach in this study, as advance care planning engagement is often the result of a complex interplay of individual-constructed meanings, events, processes and assumptions.[21] We used thematic analysis, a widely used qualitative method for the identification and examination of themes in datasets, which yields rich and detailed descriptions.[22] This essentialist approach emphasises the straightforward reporting of experiences and meanings, assuming their direct relationships with language.[22] The consolidated criteria for reporting qualitative research checklist guided the reporting of important research team aspects; the study context, methods and findings; and data analysis and interpretation.[23]

Setting

Interviews were conducted at participants' homes or preferred locations (mostly general practitioners' offices) in Brussels, Mechelen and Antwerp, Belgium.

Population

We included the main family caregivers of participants in our previous research: older adults (age ≥ 65 years) with Turkish and Moroccan backgrounds in the studied cities in Belgium.[14,15] Additional inclusion criteria were age ≥ 18 years and Dutch or French fluency. No exclusion criterion was applied.

Sampling and recruitment

Participants were identified by older adults who participated in our previous advance care planning studies.[14,15] These older adults' general practitioners inquired about the willingness of their most significant family caregivers to participate in the research, and gave interested parties' contact information to the researchers. Two researchers (HD and WE) contacted willing participants by telephone to provide further study information and schedule interviews. Participants were recruited until no new relevant information, theme or code emerged from the last three participants' data.

Data collection

We conducted face-to-face semi-structured interviews to collect in-depth, contextualised information about participants' opinions on, experiences with and assumptions about advance care planning for their relatives.[24] One male researcher (WE), a general practitioner with qualitative interview training, conducted audio-recorded interviews (mean duration, 50 minutes) in Dutch or French (at interviewees' preference) with no other individual present between April 2022 and January 2023. The authors developed an interview guide (Textbox 1), ensuring that it was understandable and elicited relevant information about participants' perspectives on advance care planning for their relatives. Socio-demographic information (age, gender, educational level, background, work time, informal care duration, birthplace, relation to older adult, living situation, number of children) was collected and field notes were made at the interviews' conclusions.

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

Textbox 1. Interview topic guide summary.

Introductory questions

Relationship to, health status of cared-for relative

Effects of relative's health on interviewee, experience of caregiving, concerns about late-life care

Extent of involvement in decisions about relative's healthcare

Advance care planning knowledge

Pre-interview awareness/knowledge of advance care planning, advanced written communication of wishes to family members/doctors

[Definition of advance care planning]

Knowledge of ability to refuse future treatment, designate power of attorney, record care location preferences [with explanations]

Experience related to advance planning of relatives' care

Pre-interview conversation with relative about future care needs, wishes, priorities

  If yes: conversation topic, participants, occasion; interviewee's experience, triggers; concrete plans made

Possession of knowledge needed to make decisions for relative

Advance care planning experience [with examples]

  If yes: describe/contextualise further

Views on advance planning of relatives' care

Opinion on advance care planning

Importance/advantages/disadvantages of relative's communication of wishes

[Presentation of example case (Supplementary Textbox 1)]

Opinion on example case, including wish communication while healthy

Post–example case importance of relative's communication of wishes, factors influencing view

[Provision of comprehensive advance care planning information (Supplementary Textbox 2)]

Thoughts on/emotions about future wish communication of relative without serious illness

Effect of relationship with relative on thoughts/emotions, difference from other family member(s)

Effect of culture/religion (if applicable) on views on advanced planning of relative's care

Perceived openness of relative to end-of-life conversations/advance care planning

  If yes: who should be involved, interviewee's preferred role

Openness of interviewee upon relative's desire to have advanced care planning conversation

Respect of relative's advance care planning choices, dealing with disagreement with those choices

Possession of knowledge needed to make decisions for relative

Barriers to and facilitators of advance planning of relatives' care
Open conversation with relative about advance care planning
Factors making conversation harder/easier
Timing of conversation

Final questions
Feeling about interview
Helpfulness of discussion to Turkish/Moroccan community in Belgium?
Most important topic discussed, why

Data analysis

One researcher (WE) transcribed all interviews verbatim. Two researchers fluent in Dutch and French (HD and WE) independently conducted combined deductive/inductive coding-reliability thematic analysis of all transcripts to identify and richly describe patterns (themes) in the data.[22,25] Through line-by-line reading and structured coding, they deductively assigned the data to five a priori–defined categories based on the interview guide (advance care planning knowledge, experience, views, barriers and facilitators), then inductively assigned the category data to subcategories, which were grouped into themes. Coding objectivity, reliability and accuracy were ensured by pre-defined category use and the assessment of inter-coder agreement.[25] The researchers regularly discussed and compared their code-related findings and subcategory and theme development. In case of discrepancy or disagreement, they re-read the relevant transcripts together and discussed until they had reached consensus. The process followed a six-phase thematic analysis guide, with constant movement between the entire dataset and coded extracts and concurrent analysis.[22] Code recording and analysis were performed using NVivo12 (QSR International, Melbourne, Australia). The results were discussed with the research team during 6-weekly meetings to reflect on the process and explore initial insights, enhancing triangulation, limiting bias and ensuring interpretation reliability. The final results were forward-backward translated into English.

Ethical considerations

The interviewees provided written informed consent, including for the publication of pseudonymised findings. Participants were aware of their right to withdraw consent at any time without being required to provide a reason. The European Union's 2018 general data protection regulation was observed and confidentiality was guaranteed. The study was approved by the Medical Ethics Commission of Brussels University Hospital (B.U.N. 1432021000571, 2 February 2022) and registered at ClinicalTrials.gov (no. NCT05241301, protocol ID ACP2021M&T).

Results

Participant characteristics

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

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

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

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

Advance care planning themes

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

Textbox 2. Advance care planning themes and subthemes.

1. Limited advance care planning knowledge
2. Lack of advance care planning experience with healthcare providers, but some end-of-life care discussions with family
3. Varying views on relatives' engagement in advance care planning
   A. Honouring relatives' preferences and avoiding emotional/psychological burden
   B. Opposition to certain advanced care planning discussions/actions
   C. Lack of need due to commitment to care and trust
4. Advance care planning barriers
   A. Personal and relational characteristics
   B. Emotional nature of discussing end-of-life issues
   C. Lack of urgency

5. Advance care planning facilitators
   - A. Distribution of advance care planning information in relatives’ native language
   - B. Initiation of advance care planning discussions by general practitioners
   - C. Involvement of several family members in advance care planning discussions

Limited advance care planning knowledge and experience

The participants, excepting two who were general practitioners, had no advance care planning knowledge. Some struggled to grasp the concept, requiring multiple definitions and explanations. Although they had never heard about advance care planning as an integrated concept, some participants knew that people could refuse certain future treatments and express care location preferences to their doctors and relatives in advance.

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

No participant had discussed advance care planning with healthcare providers or helped relatives prepare official documents (e.g. advance directives). Some interviewees’ relatives had expressed their wishes regarding care and burial locations, life-prolonging treatment, organ donation and/or surrogate decision makers to family, usually following acquaintances’ nursing-home admission or death or the viewing of a television programme on organ donation.

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

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

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

Varying views on relatives' advance care planning engagement

Honouring relatives' preferences and avoiding emotional and psychological burdens

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

> *For me, it's important to discuss things so that we don't find ourselves in situations afterwards where our minds might be clouded by emotions and we won't be able to make the right decisions. So it's better to discuss things beforehand.* (Respondent 18, 48-year-old son, Moroccan origin)

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

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

Opposition to certain advanced care planning topics

Some interviewees were reluctant to discuss topics such as nursing homes and the stopping of life-prolonging treatment, but were open to discussing their relatives' preferences regarding, e.g. home care, burial location, organ donation and legal representative designation. Interviewees who completely opposed advance care planning discussions also specifically mentioned nursing homes and life-prolonging treatment. Interviewees in both groups were unsure that they could respect and fulfil their relatives' preferences due to possible conflict with their own views. For example, some participants opposed life-prolonging treatment cessation due to their belief in God's omnipotence and sovereignty over life and death.

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

Some participants were against nursing home admission due to cultural norms regarding care duties as a recognition of the parental care that they had received, and felt that this obviated the need for discussion even if contradictory to their relatives' wishes.

> *Talking makes them feel better...They don't want to donate their organs. We have discussed this and they told me 'I want to keep everything inside me'…We can't talk about nursing homes. I'd never put my parents in a nursing home. That's not up for discussion with us. My parents have helped me grow up. I'm helping them until they die...Power of attorney, I think it's useful…It could be a good option. My parents have already said to my sisters and brothers 'He's the eldest, he's going to make all the decisions'.* (Respondent 15, 51-year-old son, Turkish origin)

Some participants, including some of those open to advance care planning discussions, opposed official advance care planning document preparation. They considered verbal agreements within families to be easier, avoiding administrative tasks, and trustworthy. Moreover, some feared that document revision upon changes in their relatives' preferences would be impossible.

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

Lack of need due to care commitment and trust

Some interviewees felt that anticipatory end-of-life conversations were entirely useless, as caring and decision making for ill parents were their duties and recognition of the parental care they had received, in line with their cultural and religious norms, values and practices.

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

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

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

Advance care planning barriers

Personal and relational characteristics

Some interviewees who were open to advance care planning discussions indicated that such discussions with their relatives would be impossible, based on relatives' clear indications or interviewees' assumptions. Reasons for this (assumed) refusal included relatives' stubbornness, non-acceptance of ageing or reduced independence, lack of concern about their future care, and the difficulty or taboo nature of discussing end-of-life aspects. These interviewees felt that end-of-life discussions would be painful, causing fear and sadness (and thus interviewees' guilt) and making their relatives feel that the end of life was approaching. They feared that their relatives would react poorly and think that they (largely children) did not want to provide care.

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

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

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

Emotional nature of discussing end-of-life issues

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

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

Lack of urgency

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

> *Difficult in the sense of you can hardly empathise now. I think when the moment comes, only then will you really experience it and you can actually make decisions. At the moment, she* [mother] *is stable. If she's bedridden in a year or two, unable to do anything, then you're in a totally different situation. You're also going to decide in a different way then. It's not correct to decide things in advance. You can talk about possibilities now, but you can't expect them to make decisions now. Depending on pathologies, family circumstances, decisions may change.* (Respondent 17, 48-year-old son, Moroccan origin)

Advance care planning facilitators

Distribution of advance care planning information in relatives' native language

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

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

General practitioners' initiation of advance care planning discussions

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

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

Involvement of several family members in advance care planning discussions

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

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

Discussion

Main study findings

This study showed that the relatives of older adults with Turkish and Moroccan backgrounds had limited knowledge about advance care planning as an integrated concept and had not discussed such planning for their relatives with healthcare professionals. Some participants had spoken informally with their relatives about end-of-life preferences seeing it as beneficial to alleviate their emotional burden and honour their relatives' preferences. Others felt that the discussion of certain topics was unnecessary due to their commitment to care or their relatives' perceived trust. Identified barriers were personal and relational characteristics, emotional difficulty and perceived non-urgency. Facilitators included the provision of information in relatives' native languages, general practitioners' cautious initiation of discussions and the involvement of several family members.

Strengths and weaknesses

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

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

Comparison with existing literature

This study revealed marked diversity in participants' advance care planning perspectives. Whereas some participants acknowledged the emotional relief associated with advance care planning discussions, others dismissed the significance of such conversations. The perspective that advance care planning discussions can reduce the fear of making incorrect decisions is shared by relatives of native-Belgian older adults.[26] The contrasting reluctance to engage in anticipatory end-of-life conversations reflects the deeply ingrained cultural values of filial responsibility and reciprocal love in collective societies, as evidenced in our previous research with older adults with Turkish and Moroccan backgrounds.[14–16,27–29] The variation in views on advance care planning observed in this study underscores the need to recognise and tailor care strategies to individual preferences. This finding is consistent with research emphasising the importance of understanding personal beliefs and values when undertaking advance care planning.[18]

The significant roles of family members were reflected strongly in interviewees' responses in this study. Participants' recommendation to involve family members in advance care planning to facilitate future decision making and mitigate potential conflict aligns with previous findings, including those from older adults with Turkish and Moroccan backgrounds.[14–16,30] In collectivistic communities, family members often function as cohesive care management units, sharing communication and decision-making responsibilities. [31] Participants referred specifically to trust among family members. Some of them showed reluctance to formalise advance care planning with official documents due to strong trust in verbal agreements in familial contexts, echoing our previous findings for older adults with Turkish and Moroccan backgrounds.[14–16] Concerns about the immutability of advance directives may reflect previously reported issues such as perceived discrimination in healthcare systems and cost-reduction motives. [32,33] Moreover, certain participants expressed confidence in making decisions for their relatives without discussion, despite evidence suggesting potential inaccuracies in understanding loved ones' wishes.[34] Some even stated that they would override relatives' plans, particularly regarding life-sustaining treatment cessation, for religious reasons, which aligns with observations made among migrant groups in Belgium, the United States and Australia.[17,35] Decision making about life-prolonging treatment is challenging for individuals with Muslim backgrounds due to beliefs about God's sovereignty over life and death.[36]

Challenges with advance care planning discussions were also attributed to factors such as older adults' reluctance to accept ageing and discomfort in addressing their (future) dependence and mortality, consistent with the preference of older adults with Turkish and Moroccan backgrounds to 'live in the moment' and their difficulty discussing death.[14–16] Participants' concerns about patriarchal authority are consistent with cultural norms in Turkish and Moroccan families.[37,38]

These findings underscore the importance of culturally sensitive approaches to advance care planning, with recognition of and respect for diverse beliefs while navigating complex familial dynamics and decision making. Such insights are crucial for healthcare professionals aiming to facilitate effective advance care planning discussions and ensure alignment with patients' and families' preferences and cultural backgrounds.

Implications for practice and research

Care providers should acknowledge Turkish and Moroccan relatives’ significance in advance care planning, addressing their concerns and emotions to facilitate effective, ongoing planning and engagement, and initiate discussions to reduce the possible interference of older adults’ personal characteristics.[39] Opposition to official document (e.g. advance directive) preparation should not hinder advance care planning engagement.

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

Conclusion

Relatives of older people with Turkish and Moroccan backgrounds were unfamiliar with advance care planning and had highly variable views on its usefulness. People need to be given opportunities to discuss advance care planning in a culturally appropriate manner, and the diversity of perspectives on whether and how to engage in such planning needs to be recognised.

Authorship

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

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Declaration of conflicting interests

The authors declare that they have no conflict of interest.

Research ethics and patient consent

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

Data management and sharing

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

Supplementary Textbox 1. Example case

A 75-year-old patient has Alzheimer's disease (memory loss). She lives with her daughter. She tells her GP: 'If I ever have a serious illness from which I will not recover, I do not want to be hooked up to machines or on drip feed in the hospital to prolong my life, like my husband. He was in pain for weeks before he died.' Several years later, this patient becomes ill. She has a high temperature and a cough, and cannot eat or drink. Her GP wants to admit her to the hospital to give her a drip feed and antibiotics. The GP and the patient's daughter decide to do so, but agree that if she does not improve within a few days, they will stop all treatments and discharge her to spend her final days at home. The patient recovers after 3 days and returns home. Three years later, the patient's dementia has become much worse and she has been admitted to a rest home. She can no longer get out of bed or out of an armchair, and she has stopped eating. Nothing gives her pleasure anymore; she doesn't recognise her own daughter either. In addition, she cannot make decisions about her own treatment. In this situation, the daughter asks the GP: 'How about feeding her with an infusion?' The GP says he doesn't think this is desirable because when the patient was healthy, she had expressed her wish to not be hooked up to machines or a drip feed if she was ever in a bad medical condition. After 2 painless months, the patient dies.

GP, general practitioner

Supplementary Textbox 2. Comprehensive information on the use of ACP.

I am now going to give you three examples on the use of ACP.

1. It is now possible to somewhat extend the life of someone who is seriously ill, unconscious and has no hope of recovery by giving them drips, a respirator and antibiotics. While this person is conscious he/she can choose to refuse such treatments, should he/she ever fall into that condition.

What would be your reaction, if your relative already does an ACP and mention that he/she refuse such treatments, should he/she ever fall into that condition?

2. A patient can specify now that he/she would like to move into a nursing home when he/she get very old, and can no longer take care of himself.

What would be your reaction, if your relative already does an ACP and mention that he/she would like to move into a residential home when he/she get very old, and unable to take care of himself?

3. A patient can give someone authorisation (power of attorney) to act on his/her behalf. If he/she become seriously ill at some stage and cannot think about

What would be your reaction, if your relative already does an ACP and mention that he/she would give authority (power of attorney) to someone to act on his/her behalf?

Would you be the legal representative of your relative to take end of life decisions for his/her?

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CHAPTER 6

GENERAL DISCUSSION

The aim of this dissertation was to explore and describe ACP knowledge, experience, views, facilitators and barriers among older adults of Turkish and Moroccan origins (chapters 2 and 3), older adults of Turkish background requiring palliative care (chapter 4) and family members of older adults with Turkish and Moroccan backgrounds (chapter 5) in Belgium. In this chapter, the main findings of the four studies are summarised, and the studies' strengths and limitations are discussed. Thereafter, the main research findings and implications for practice and future research are discussed, followed by a general conclusion.

1. Summary of main findings

1.1 ACP among older adults of Turkish origin in Belgium

The older adults of Turkish origin living in Belgium who participated in this study lacked ACP knowledge and experience with healthcare providers. However, several of them had discussed end-of-life preferences (e.g. about life-prolonging treatment, nursing home admission, burial location) with their partners and/or children.

In general, several participants indicated that ACP could be useful, helping them to express their preferences while their mental health was good and allowing them to prepare for a more comfortable end-of-life period. Most of them did not feel that ACP was against their religion (Islam), finding it to be compatible with their religious beliefs and practices. They were ready to engage in conversations about ACP, which was presented to them as thinking ahead, discussing future healthcare wishes with relatives and doctors and voicing preferences while still in good health and able to do so. Six ACP barriers were identified in this study. The most frequently mentioned barrier was respondents' lack of knowledge about ACP, and consequently lack of its discussion with their healthcare providers. The second barrier was the language issue with Belgian general practitioners. The participants felt that they could not speak properly about ACP topics with doctors who did not speak Turkish. The third barrier was some participants' lack of urgency regarding ACP discussion. Fourth, some participants' reliance on familial support was a barrier to engagement in ACP. These participants had high-quality relationships with their children and trusted them to take responsibility for their care and health-related decision making. Fifth, some participants were reluctant to have ACP conversations due to the fear of triggering negative emotions in themselves, related mainly to the fear of death. Lastly, some participants feared that end-of-life discussions would upset their children, leading them to make incorrect assumptions, such as that their parents distrusted them.

Four ACP facilitators were identified. The most frequently mentioned facilitator was the provision of tailored information about ACP. The participants stated that access to more ACP information would facilitate their engagement. The second facilitator was concern about future care needs, expressed by participants who were not certain that they could rely on their children in this regard. Third, some participants stated that their children's increased awareness of the advantages of ACP would facilitate ACP-related conversations. The fourth facilitator was participants' desire to avoid 'burdening' their family members or saddening them via end-of-life decision making.

1.2 ACP among older adults of Moroccan origin in Belgium

The older adults of Moroccan origin living in Belgium who participated in this study lacked ACP knowledge and had not discussed ACP with healthcare professionals. However, some participants had discussed ACP issues (mainly burial, also nursing home admission) with their children and/or other family members.

After receiving a brief explanation of ACP as planning for end-of-life care, most interviewees did not find that it would be useful, for religious reasons (i.e. 'only God knows about the future'). Provided with a more detailed, simply worded explanation ("thinking ahead about the future, discussing future healthcare preferences with relatives and doctors, voicing preferences while being still in good health, and be able to express own thoughts and preferences including highlighting the possibilities to refuse treatment when a seriously ill person would not recover, move to a nursing home when needed, or identify a legal representative in case someone loses capacity) with a specific example, their attitude toward ACP seemed to change; they felt that preparing for the future, especially while one can think clearly, could be important. After the interviews, the participants appeared to be more willing to have ACP discussions with their general practitioners and/or relatives.

Five ACP barriers were identified in this study. The first barrier was participants' lack of ACP knowledge, which they attributed to their illiteracy. The second barrier was participants' current good health status (lack of severe illness), which led them to feel that action was not necessary and to lack urgency regarding ACP discussions. Third, the participants considered the potential harm of talking about illness and death, taboo subjects, to be a barrier. Fourth, they trusted in their children to take care of them and make care decisions. Lastly, some participants indicated that they would avoid ACP discussions due to the fear of worrying or triggering negative emotions (e.g. anxiety) in their children.

Three facilitators were identified. For most participants, general practitioners' provision of understandable ACP information was the primary facilitating factor. The second facilitator was the involvement of the participants' children in ACP discussions. The interviewees felt that general practitioners should inform patients' children about the benefits of ACP and stimulate their involvement in ACP conversations. The third facilitator was the participants' desire to not depend on their children. They considered that ACP could help relieve pressure on family members related to future care.

1.3 ACP among older adults in Belgium with Turkish background and palliative care needs

The older adults of Turkish origin with palliative care needs who participated in this study also lacked ACP awareness and information. However, some of them had discussed specific end-of-life preferences (e.g. care location, burial place) with family members. Some had discussed their preferences for future care should they develop serious illnesses, and a few had done so because they were aware of the life-limiting nature of their illnesses.

Still, many participants did not feel the need to discuss future healthcare preferences, attributed mainly to their trust in God (as the only being who knows and decides the future) and family members (mainly spouses and children) for caretaking and decision making should they lose their decisional capacity. These perspectives obviated the need to designate power of attorney or have discussions about life-prolonging treatment. However, some participants considered that ACP discussions were applicable after ACP had been explained to them with examples. They felt that ACP could relieve the burden on their family members and enable the proactive addressing of 'what if' questions. They mentioned that they would gain confidence and certainty by making plans in advance of deteriorating physical and/or mental health.

Three ACP barriers were identified in this study. First, the participants feared that they would make the wrong decisions due to their lack of education. Thus, they preferred to avoid discussions about end-of-life medical care and leave such decisions to their adult children. Second, they had a 'living in the moment' attitude. Some participants were convinced that their current conditions were not critical, death was not imminent and it was better to take things as they come. Lastly, some participants had difficulty discussing death due to the psychological discomfort of the topic.

Two facilitators were identified. The most frequently mentioned facilitator was the receipt of sufficient ACP information. Some participants indicated that they would feel comfortable expressing their wishes to their general practitioners if they were given sufficient information and opportunities to ask questions. Second, some respondents considered recent family experience with severe illness or death to be an ACP facilitator because it prompted them to think and talk with relatives about their end-of-life care.

1.4 ACP views of family members of older adults with Turkish and Moroccan backgrounds

The family members who participated in this study, excepting two who were general practitioners, had no ACP knowledge and had not been involved in discussing such planning for their relatives with healthcare professionals. Some participants' relatives had initiated family discussions in which they expressed their preferences regarding care and burial locations, life-prolonging treatment, organ donation and/or surrogate decision maker designation.

The participants had highly variable views on the usefulness, benefits, limits and possibilities of ACP. Some considered such discussions to be beneficial, alleviating their emotional/psychological burdens and facilitating their honouring of their relatives' end-of-life preferences. Some participants opposed the discussion of specific ACP topics (e.g. nursing home admission, life-prolonging treatment cessation, official document preparation), but were open to discussing their relatives' preferences regarding, e.g., home care, burial location, organ donation and legal representative designation. Others felt that such discussions were completely unnecessary due to their commitment to and confidence regarding (decision making about) their relatives' care, as their duty and in recognition of the parental care that they had received, in line with their cultural and religious norms, values and practices. Some participants presumed that they knew their relatives' wishes without discussing them. They felt that their relatives would not be interested in end-of-life discussions because they trusted their family members to make all future decisions.

Three ACP barrier themes were identified in this study. The first theme encompassed personal and relational characteristics, such as relatives' stubbornness, non-acceptance of ageing or reduced independence and lack of concern about their future care; the difficulty or taboo nature of discussing end-of-life topics; and parental authority. Second, some participants, especially those who were daughters, felt that end-of-life conversations were too emotionally difficult. Lastly, some participants lacked urgency and felt that ACP discussions should occur when their parents were seriously ill and when they had concerns.

Three facilitators were identified. First, some participants felt that the distribution of relevant information in older adults' native languages could facilitate ACP discussions. Second, some participants felt that general practitioners' cautious initiation of ACP discussions, using examples of other people to avoid hurting their relatives' feelings, would be a facilitator. They noted that general practitioners could influence and motivate their relatives because their relatives liked to listen and speak openly about their concerns with them. Lastly, some participants expressed that the involvement of several family members would facilitate ACP discussions and future conflict-free decision making.

2. Methodological considerations: strengths and limitations of the four studies

2.1 Strengths

The research conducted for this dissertation has several strengths. First, it was pioneering, as it provides in-depth insight on ACP views in the two largest, and understudied, non-Western migrant populations in Belgium and other European countries.(1–4) These populations' lack of engagement in ACP and the facilitators identified in this research are often missed by healthcare professionals and constitute areas for improvement in practice. The insight gained into the ethno-culturally constructed ACP views, particularly barriers and facilitators, of people with Turkish and Moroccan backgrounds in Belgium constitutes a novel contribution to the literature. To our knowledge, the topic has not been an explicit focus of previous research, and has not been described from multiple nuanced perspectives as in the present research. The inclusion of older adults with Turkish and Moroccan backgrounds and their primary family members also enabled the triangulation of findings.

Second, the interviewers' Turkish and Moroccan migration backgrounds, fluency in the participants' native languages (Turkish, Darija, Dutch and French) and familiarity with their religious and cultural orientations facilitated the development of trust, resulting in direct and nuanced conversations in which the participants were encouraged to speak freely. This process yielded high-quality, reliable interview data that permitted the exploration of respondent-constructed meanings, experiences, processes and assumptions, and the determination of whether participants wished to engage in ACP. In addition, this approach overcame a potential reason for the lack of previous studies of older people with migration backgrounds, namely the language barrier for interviewers.

Third, the participants' socio-demographic characteristics (e.g. migration pattern, living situation, having many children and little education) align with those of the general populations of older Turkish and Moroccan adults in Belgium, supporting the transferability of the research findings.(5–7)

Fourth, the performance of separate studies with the populations examined helped to avoid the generalisation of findings to all older adults with migration backgrounds. In previous ACP research, data from various ethnic-minority populations have been aggregated with the assumption of cultural homogeneity, leading to inappropriate generalisation and the overlooking of individual-level complexities.(8,9) Healthcare providers should recognise the variety of values and preferences among diverse racial and ethnic groups.(10) Moreover, the ACP-related needs and views of patients with progressive, incurable conditions likely differ from those of healthier adults,(11) which the present research was able to capture through the performance of a separate study with older Turkish adults with palliative care needs.

Lastly, the validity of the findings was safeguarded in several ways.(12) The interview topic guide was pilot tested before study initiation with six older Turkish migrants and two older Moroccans to examine its content clarity. The researchers then revised it to ensure that it was understandable and elicited relevant information. To enhance data triangulation and respondent verification, the interviewers paraphrased interviewees' responses and asked participants to provide comments and/or corrections during the interviews. They also took field notes immediately after each interview. Although the researchers' cultural backgrounds inevitably shaped the research, as one's understanding of the world is inherently shaped by one’s cultural assumptions,(13) this approach increased the reliability and accuracy of the findings. In each study, two researchers fluent in the participants’ language(s) independently coded and analysed the data to achieve consistency.(12) The objectivity, reliability and accuracy of the coding were ensured by the examination of inter-coder agreement,(14) and results were discussed with the entire (culturally and professionally diverse) research team every 6 weeks, with reflection on the process and the exploration of initial insights to enhance triangulation, limit bias and ensure the reliability of interpretations.

2.2 Limitations

This research also has several limitations. First, the adult children of the older-adult participants were present during several interviews, which could have biased the interviewees’ responses, especially concerning their trust in their children. For example, older adults with palliative care needs mentioned their trust in their children to take care of them and make future care decisions more frequently than did other groups, and children were present in 13 of 15 of these interviews. Some adult children even participated in the interviews unprompted. However, we allowed family members to be present in cultural alignment with their essential roles in care provision, including end-of-life decision making.(4,15)

Second, the older-adult participants had low educational levels, and some had difficulty grasping ACP-related concepts despite the interviewers’ efforts to ask comprehensible questions and use of examples. This was also true for some family members who participated in the research, although they were more educated than the older adults. This factor may have impacted participants’ responses.

Third, qualitative research is inherently subjective. The researchers’ own identities could have influenced their interaction with the participants. The way in which ACP was described could have led participants to adopt positive perspectives on it. Moreover, the interviewers were male medical doctors of Turkish and Moroccan origins, and thus authority figures. This factor could have affected the interviewees’ responses, biasing them toward social acceptability and reducing older adults’ assertiveness.

Fourth, qualitative research entails possible selection biases.(16) Because our participants can be hard to reach for participation in research, we choose to recruit them through GPs due to their longstanding relationships. Participants’ trust in their GP gave them the reassurance which indirectly made them trust the interviewers which facilitated the in-depth interviews. Hence, the research sample may have comprised mainly people who had good relationships with their general practitioners and with the health system, as participants were recruited based on their willingness to be interviewed. This factor may have biased the findings, for example towards more positive views on ACP. However, some participants had negative views on ACP and were completely against ACP discussions. Moreover, we specifically elicited participants' self-identified barriers to ACP discussions.

Finally, the findings might not be generalisable to other populations with migration backgrounds in Belgium. Although older people with migration backgrounds share some general characteristics, such as large and transnational family structures, migration histories, language barriers and low educational levels, that contribute to difficulties in communication, decision making and planning for future care needs, this group is culturally heterogeneous, with diverse perspectives.

3. General discussion of the main research findings

3.1 Limited ACP knowledge

The lack of ACP knowledge among nearly all participants in this research is consistent with findings for people with diverse cultural and ethnic backgrounds in several countries, such as individuals of non-white ethnicity (e.g. Hispanics and African Americans) in the United States;(11,17) people from Black, Asian and other ethnic-minority groups in the United Kingdom;(18) and aboriginal and Pacific populations in Australia and New Zealand.(19,20) As in other studies, the Turkish and Moroccan older adults who participated in this research had low education levels, with a high prevalence of illiteracy and other language issues.(15,21) Their lack of ACP knowledge could be attributed to these factors and to the lack of provision of tailored information, as demonstrated for other ethnic minorities.(17,22) The lack of ACP knowledge among family members also aligns with the lack of accurate ACP knowledge among family members of older adults of Belgian origin.(23)

3.2 Conversations about ACP related topics mainly with family members

No participant in this research had had an ACP discussion with a healthcare professional, in marked contrast to the situation with native-Belgian older adults.(24) For example, some terminally ill and frail older persons with Belgian backgrounds reported having written advance directives and/or ensured that their preferences were specified in their medical records.(24) This finding confirms that older people of Turkish and Moroccan origin lack familiarity with the Belgian healthcare system.(4,21) Ethnic disparities in healthcare use, such as poorer communication with ethnic-minority patients, could also lead to difficulty in understanding ACP and unfamiliarity with related documentation.(17) Furthermore, the accessing, understanding, appraisal and application of health information require adequate health literacy,(25,26) which is less common among less-educated older adults and non-Western migrants in Belgium.(27) The participants' low education levels and language barriers likely contributed to their low health literacy, which is common and affects the likelihood that migrants will pursue ACP.(17,28)

Some participants' reporting of family end-of-life discussions is consistent with the previous finding that older adults with migration (e.g. Turkish and Moroccan) backgrounds prepare for their funerals, desiring to be buried 'at home' and according to Islamic custom.(29) Most discussions that the participants in this research mentioned were initiated by the older adults, usually following acquaintances' nursing-home admission or death or the viewing of a television programme on organ donation. Thus, such moments may trigger engagement in open conversations and ACP discussions.

3.3 Diversity of views on ACP discussions and engagement

The diversity of views on ACP among participants in this research, ranging from acceptance to dismissal but consisting mostly of the recognition that ACP is useful and the willingness to engage to some extent in ACP discussions, is in line with findings for most Western patients, including Belgian older persons with frailty.(24,30) In these earlier studies older adults wished to talk about their end of life (24,30) and expected that healthcare providers will initiate such conversations.(31) In contrast, a systematic review of research conducted in other countries revealed a lack of ACP interest among ethnic-minority older adults.(11) Several factors may have contributed to our participants' interest in ACP, explaining this contradictory finding.

The first factor is the interviewers' provision of understandable information with examples in interviewees' native languages. The use of understandable information, examples and scenarios involving incurable illness could improve the understanding of the importance of ACP discussions among people with low educational levels and thus low health literacy. Good ACP knowledge has been associated with increased ACP prevalence, utilisation and completion.(28,32–34) Moreover, native language use has been confirmed to increase ACP acceptance.(34)

Second, the participants' perspectives align with older Turkish and Moroccan immigrants' awareness of a decline in family caregiving, identified in other studies and due mainly to adaptation to Western values and norms (e.g. fewer multigenerational households, men's and women's employment outside of the home), which prompts uncertainty about future care and reduced trust that children will provide it.(21,35) Such awareness about children's changing caregiving roles with acculturation to the majority culture has also been found to change the perspectives of ethnic-minority elders in the United States.(36) However, children's informal care provision was very important to some participants in the present research, as found for older adults with Turkish and Moroccan backgrounds in Belgium and the Netherlands.(37,38) These participants, especially older adults requiring palliative care, expressed confidence that their children would care for them in fulfilment of the traditional filial responsibility that characterises collective societies.(5,38,39) First-generation Turkish and Moroccan older adults in Belgium have been characterised as traditional, collectivist and family centred, with close family members taking primary responsibility for (end-of-life) care decisions.(4,15) The same has been observed in other ethnic-minority groups, such as African American and Latin American populations in the United States(36,40) and Asian populations in Malaysia, Japan, China, South Korea and Taiwan.(41) Family members are often increasingly present for medical discussions as patients' care needs increase, possibly increasing patients' reticence regarding end-of-life care preferences. Some family members of Turkish and Moroccan older adults in the present research confirmed this perspective, reflected in their strong commitment to care and their relatives' trust in their decision making. This significant influence of participants' values on ACP engagement is consistent with findings for people with migration backgrounds,(17) and stands in contrast to findings for Belgian family members, most of whom perceived the initiation of conversations about death and dying as burdensome.(23)

Third, most participants in this study considered ACP to be compatible with their religious beliefs and practices, in line with a previous report on religious leaders' ACP acceptance.(42) The preparatory nature of ACP was expressed as a means of considering death while one is still capable, which instilled a sense of control despite future dependence. Notably, some older-adult participants of Moroccan origin were initially opposed to ACP discussions due to their religious beliefs, but the provision of detailed information reduced these religious objections. This finding provides insight into general practitioners' and caregivers' reporting that religious beliefs can make ACP discussions difficult,(43) especially for older people of Moroccan and Turkish origin, who reject communication about end-of-life care;(44) healthcare providers' offering of only brief explanations may be insufficient, leading them to misconceive the role of religion in migrants' resistance to ACP. However, importantly, some older adults of Turkish origin who required palliative care remained reluctant to discuss ACP for religious reasons; religiosity – or the self-perceived importance of religion – has been found to substantially influence decision making about end-of-life care, particularly among devout individuals.(22,28,36,41,45–47) Religious people, like the participants requiring palliative care in the present research, seem to be less likely to engage in planning because of beliefs about God's control over life and death and values dictating the use of all available treatments.(47,48) In particular, the completion of ACP documents seems to decline with increasing religiosity and positive spiritual coping,(17,22) and individuals tend to become more religious with age to relieve illness-, loss- and death-associated stress.(49) These factors could explain the difference in views between older Turkish adults with and without palliative care needs, the latter of whom were younger on average, in this research.

Among the family members of older adults who participated in this research, some considered ACP discussions to be useful, reducing the emotional burden associated with the fear of making incorrect decisions, similar to the views of some family members of native-Belgian older adults.(23) Others, however, felt confident in making well-informed decisions for their relatives without discussion, believing that they understood their relatives' desires. Previous research, however, has shown that surrogates' predictions of patients' treatment preferences are often inaccurate.(36,50)

Another group of participants in the present research opposed the discussion of specific ACP topics (e.g. nursing home admission, life-prolonging treatment cessation, official document preparation), and still others expressed the intention to override their relatives' plans, especially regarding life-sustaining treatment cessation, for religious reasons. Studies conducted with the family members of ethnic-minority individuals in Belgium and people with advanced cancer in the United States and Australia yielded similar findings.(51,52) Decision making about life-prolonging treatment is challenging for people with Muslim backgrounds due to beliefs about God's omnipotence and sovereignty over life and death.(53)

3.4 Self-identified barriers to ACP

The lack of ACP knowledge was the main barrier to ACP engagement, attributable to most participants' low educational levels (and thus health literacy), language barriers, and the lack of tailored information provision.(17,22) Low health literacy – limited knowledge of and participation in the health sector –has been identified as an ACP barrier in previous studies.(48,54) Language difficulties can prevent effective doctor–patient communication and may make ACP difficult,(55) and have been confirmed to hamper such communication about sensitive end-of-life issues for older adults with Turkish and Moroccan backgrounds.(4,21,56)

A second barrier found in this research was the reliance on familial support, care and decision making (confirmed by older adults and their children), which can be explained by two factors: the assumption of care responsibilities (as a filial and religious duty) by family members and immediate social networks in collectivistic cultures(5,57) and older adults' (especially those with palliative care needs) difficulty making appropriate decisions because of their low education levels and health literacy.(26) The older-adult participants' children were born in Belgium and better understood the host language and rules, which better positioned them to make decisions. Reliance on family members' decision making has also been found to be a barrier to ACP among migrants in other countries and (frail) Belgian older adults.(24,36,48,55,58,59)

A third barrier to engagement in ACP was the perceived burden or taboo nature of talking about serious illness and death. The participants expressed that ACP discussions may trigger negative emotions such as stress and anxiety, in contrast to the statement that these discussions rarely provoke such emotions in patients and their family members, as stated by the Flanders palliative care federation in Belgium.(60) Some family members in the present research were concerned that end-of-life conversations would cause their relatives pain and fear and felt that active ACP engagement would be burdensome. This finding is congruent with that reported for the relatives of native-Belgian older adults.(23) Some older adults in this research expressed the same concerns regarding their children, as did older adults of

Turkish origin in the Netherlands.(35) This reciprocal fear of triggering negative emotions was also found to be a barrier to ACP discussions among ethnic-minority groups in the United States and in other contexts.(17,23,35,36,41,61,62)

A fourth identified barrier was the perceived lack of urgency and a focus on living well now, a well-known ACP barrier that is present in other populations, such as ethnic minorities in the United States and frail older adults in the United Kingdom.(17,63–65) Participants with palliative care needs also had this perspective, potentially due in part to low health literacy,(26) and were convinced that their current conditions were not critical and death was not imminent. The proper understanding of their illnesses (e.g. prognoses) was shown to be an important initial step in Asian patients' decisions about whether they needed to have further conversations about their goals and future care plans.(41)

Lastly, the family members who participated in this research identified personal and relational characteristics as barriers to ACP discussions. Some children hesitated to engage in end-of-life conversations due to their fathers' authority, consistent with the traditional gender hierarchy in Turkish and Moroccan families.(66,67)

3.5 Self-identified ACP facilitators

The ACP facilitator mentioned most frequently by the participants in this research was the distribution of ACP information to older adults in their native languages; consistently, good ACP knowledge has been associated with increased ACP prevalence, utilisation and completion.(28,32–34) Also consistent with previous findings, some participants, especially family members of older adults, felt that general practitioners should cautiously and sensitively initiate ACP discussions, taking a prominent role as figures to whom older adults will listen.(68,69) Most patients in Belgium, especially older and chronically ill individuals, regularly consult general practitioners to obtain accessible, continuous and person-centred primary care.(70) Patients with terminal illnesses in Belgium highly value the continuity of care provided by their general practitioners, anchored in longstanding relationships built on mutual trust, and rely on these professionals to coordinate information exchange with specialist care providers.(68) Thus, general practitioners could be seen as the ideal initiators of ACP.(71)

Related facilitators were older adults' children's increased awareness of ACP and the involvement of family members in ACP discussions, to streamline future decision making and avoid worries and conflict, in agreement with previous findings from other groups.(72) Healthcare professionals may wish to facilitate communication between patients and their family members, and must understand that decision making with patients of Turkish and Moroccan origins seldom involves one-on-one communication; family members often operate as care management groups with equal roles, particularly in end-of-life decisions such as treatment withdrawal or withholding.(52,56,73) In particular, extended family members with migration backgrounds in Belgium have been found to wish to be involved in communication,(74) and end-of-life decisions in this context have been found to be affected by others' concerns and opinions.(75,76) Family members' presence also seems to increase the likelihood that patients complete advance directives.(77) Thus, overall, ACP knowledge could help older adults of Turkish and Moroccan origins and their family members make informed choices and facilitate effective communication about future care.

Second, and in contrast to participants with other perspectives, some older adults identified their concerns about future care needs and lack of trust in their children to fulfil them as ACP facilitators, in alignment with older Turkish and Moroccan immigrants' awareness of a decline in family caregiving in Western host country contexts.(21,35) Similarly, some native Belgians have expressed that limited trust in surrogates and the wish to maintain control over end-of-life care are ACP facilitators.(24)

Third, and also in contrast to participants with other perspectives, some older adults identified the desire to avoid burdening their children as an ACP facilitator. The fear of burdening one's children with later care needs has also been documented in other populations, including first-generation Muslim immigrants in the United States.(41,65,78,79) Systematic reviews have confirmed that decision making by family members who are unable to determine patients' wishes can contribute to their significant distress,(80) and that older adults with advanced cancer were willing to engage in ACP to benefit their family members.(52)

Lastly, participants in this research who required palliative care considered recent family experience with severe illness or death to be an ACP facilitator. The same has been found in other populations, including native-Belgian older adults with life-limiting prognoses.(24,48,65,79,81)

4. Implications for practice, policy and future research

4.1 Recommendations for practice and policy

4.1.1 Provision of tailored ACP information in older adults' native languages

The present research reveals the importance of greater ACP awareness and knowledge among older adults of Turkish and Moroccan origins and their family members in Belgium, and particularly of the dissemination of tailored information in older adults' native languages. This information should be compatible with recipients' educational and (health) literacy levels(82) and include relatable examples. The present research demonstrates that the provision of examples and cases enables deeper discussion of ACP. Healthcare providers should pay attention to the ways in which they describe ACP, which this research suggests can determine the impact of such discussions. To improve the ACP participation of these groups in Belgium, patient and migrant associations, the government and clinicians should raise awareness about ACP so that people know what steps to take when needed. Awareness-raising campaigns with the distribution of information about the aims, content and legal status of ACP and how it can be accessed, and good patient–doctor relationships, are important to achieve this goal.(83) Such efforts have been shown to prompt older adults to have conversations with family members about their values and wishes before potential diagnosis with life-limiting illnesses.(84) They could be deployed through advertising in hospitals and (especially) general practitioners' waiting rooms, on social media and/or television programmes, and at migrant organisation facilities and other gathering places such as non-profit cultural associations and mosques. Community events with multidisciplinary panels consisting of older adults and their family members, healthcare providers and faith leaders who provide ACP information and moderate discussions concerning perspectives thereon could also encourage further reflection on ACP in community members' cultural contexts.(85) Bilingual, bicultural community health workers could provide information in community members' native languages; these professionals have knowledge of relevant cultural sensitivities and can bridge the gap between non-native community members and the healthcare system, contributing to the optimisation of these people's end-of-life care.(86,87) Their involvement has been found to increase ACP documentation.(88) General practitioners could hold group informational meetings with their older-adult patients to provide ACP information and encourage engagement.(89) They could also bring up ACP during consultations when patients' health conditions (are likely to) deteriorate and they and/or family members begin to express concerns, wishes and preferences.(89) Such actions could improve healthcare access, fulfilling accessibility dimensions such as approachability (i.e. ACP exists and can be started) and availability.(90) Notably, the use of a single approach, such as education or informational pamphlet distribution alone, without further discussion, was found to make no difference in ACP initiation.(91) Combination of approaches to the initiation of ACP discussions seem to be most successful.(91)

As the Flanders palliative care federation in Belgium recommend the use of simple, clear language in documents and forms,(60) existing ACP information should be translated and adapted to the generally lower educational levels of older adults with Turkish and Moroccan background. In addition, visual information (e.g. as short films, leaflets and posters) could be presented to patients and their family members to raise awareness about ACP as a broad and person-centred communication process. This undertaking would be particularly salient for speakers of Darija, which has no written form. Overall, visual information should be created with a view to its recognisability and understandability to people from the Turkish and Moroccan cultures. As some respondents in this research mentioned their family members' lack of knowledge about the potential benefits of ACP, which can contribute to family readiness for engagement,(92–94) healthcare providers should include family members (according to older adults' preference) in such information provision. We acknowledge that information provision is a single step toward improved ACP implementation that needs to be interpreted and employed in the context of other barriers.

4.1.2 General practitioners' cautious initiation of ACP discussions

As indicated by the family members who participated in this research, general practitioners play an important role in enhancing ACP discussions and have multiple opportunities to do so during consultations when patients' health is relatively stable.(71,95) This role is often based on the longstanding, trust-based relationships that general practitioners have with patients and their family members and their provision of continuous, patient-centred care, as is common in Belgium.(68,70) However, a systematic review showed that both patients and many general practitioners believe that the other party should initiate ACP discussions.(43) Thus, general practitioners could take the initiative in this regard, but cautiously to avoid provoking stress, anxiety or other negative emotions.(71,96) Carefully identifying and planning of opportunities to initiate ACP discussions in primary care settings is needed to shift from the frequent neglect of such conversations to their broaching, carefully and with dignity.(91) Indirect communication approaches to the initiation of end-of-life care discussions, such as the use of others' experiences as examples and/or the framing of the conversation as part of standard policy, could be taken to determine patients' readiness.(97)

A key goal of ACP is to give patients opportunities to reflect on and plan future care. General practitioners could begin by listening to patients and using good communication skills, such as those described in the Cardiff six point toolkit (appropriate use of comfort, language, question style, listening/use of silence, reflection and summarising).(98) According to this approach, healthcare providers should first obtain permission to have a conversation, ensuring that the patient is physically comfortable and has time to talk.(98) Afterwards, general practitioners could then encourage patients to reflect on their conditions, explore their understanding of their prognoses, and ask if they are willing to discuss ACP.(98) They could introduce the concept of planning ahead and explain the types of things they may want to discuss in the process.(99) Socio-culturally sensitive communication involves the effective use of open-ended questions about patients' goals, values and priorities, the demonstration of respect and the building of rapport, and is critical for ACP conversations.(100) By contrast, according to clinicians in previous study conversations that start with the discussion of treatments are likely to engender or perpetuate mistrust.(100)

4.1.3 Culture-sensitive ACP approaches emphasising individuals' priorities and values

The openness of most participants in this research to discuss ACP likely reflects the culture-sensitive approach taken, with the interviewers sharing the interviewees' ethnicities, religion and languages. Healthcare professionals must be mindful that issues may arise when they do not share a patient's culture or religion. As people may initially react very differently than expected, consideration of the things that matter most to people considering their future (e.g. religion and/or family) is important. As ACP involves person-centred communication, it should not be reduced to discussions about advance directives or end-of-life decisions; people with migration backgrounds might want to discuss other aspects of ACP, such as from whom and where they will receive care and where and how they will be buried. Healthcare professionals should not make 'blanket' assumptions about individuals' degree of interest in ACP or engage in stereotyping based on cultural/religious backgrounds or host language fluency;(20,101) they should recognise that ACP awareness and attitudes may vary among and within ethnic-minority groups(11) and focus on – and be open to – the possible influence of culture-specific values and the roles they may play in patients' lives.(102,103) For example, they should explore whether and to what extend religion underlies a patient's reluctance to initiate ACP discussions and, if so, explain that ACP is largely considered to be compatible with the patient's religious beliefs and practices, in line with the perspectives of some respondents in the current research and a report on religious leaders' ACP acceptance.(42)

We also want to highlight the considerable similarities we found between Turkish, Moroccan, and ethnic majority Belgian individuals regarding their differing views on ACP. Cultural and religious aspects are crucial when opening or considering conversations about ACP. Since the topic involves existential aspects of life and death, culture and religion play significant roles in these discussions and decisions. However, life and death are universal human experiences, and thus, we may share more similarities in views and expectations than anticipated. Therefore, a thorough, person-centred and goal-oriented approach is essential in providing equitable end-of-life care to people with different religious or cultural backgrounds from the healthcare providers. Moreover, since 'culture' in the broadest sense encompasses more than religion and ethnicity, the native Belgian population can also have diverse views on ACP. Thus, a goal-oriented, person-centred approach with cultural sensitivity is key to any successful ACP implementation. In alignment with the goals of person-centred care and the international consensus supported by the European Association for Palliative Care, ACP should focus on the achievement of a shared, culturally sensitive understanding of patients' values, needs and desires through the encouragement of open communication (including family members when patients prefer).(28,104–107) Ethnic minorities who had received more targeted, culturally adapted information demonstrated the desire to engage in more formal documentation of their preferences and to initiate ACP discussions.(36) A culturally sensitive approach to ACP could also improve healthcare accessibility (e.g. acceptability and appropriateness).(90)

As culture is a dynamic construction, changing in response to factors such as acculturation and globalisation, and may be heterogeneous down to the individual level,(108) healthcare providers should strive to know their patients and their expectations within their larger social contexts.(102,109) Overall, the results of this research reflect great variation in the communities studied in approaches to end-of-life decisions and reasons for (not) initiating ACP, as well as the degree and rapidity of changes in these perspectives. Common factors include religion, possibly shared cultural beliefs and migration backgrounds, but major differences frequently exist in customs, religiosity, education levels and socio-economic backgrounds.(110,111) The recognition of these social sub-identities and their influences on ACP-related conversations, decision making and communication with healthcare workers is important for the success of the process. Healthcare providers' gaining of meaningful insight into their patients' thoughts, feelings, religious beliefs and cultural values, rather than, for example, focusing narrowly on harm reduction (i.e. avoiding unwanted treatment), is consistent with a recent public-health palliative-care approach that emphasises individuals' priorities, values and lived experiences in tailored planning and goal-oriented end-of-life care and has been shown to improve patients' experiences.(23,112,113) The Flemish institute for primary care also emphasises goal oriented care, which starts from the person in need of care and looks at what care goals are important and what really matters to individuals' life.(114) Healthcare providers could strengthen the possibilities to maximise quality of life by starting exploring the person's goals of care during ACP discussions.

A deeper understanding of ACP barriers at the individual level may help healthcare providers to prioritise and address them.(63) For example, the unjustified fear of family members in the present research that choices would be irrevocable is in line with previous findings,(58,65) but opposition to the preparation of official documents (e.g. advance directives) should not hinder engagement in ACP conversations. In turn, broader, communication-focused approaches to ACP have been shown to be more cross-culturally acceptable than processes focused on formal documentation.(11) Thus, overall, the adoption of a communication-focused approach may be valuable in harm reduction (i.e. avoiding unwanted treatments) and the adaptation of ACP to meet the needs of diverse populations.(11)

4.1.4 Use of professional interpreters in ACP

The distribution of ACP information to older adults in their native languages was the most frequently mentioned facilitator in this research. When a language barrier exists, professional interpreters can be used, especially for emotionally difficult and complex (i.e. ACP) conversations, to increase the likelihood of effective communication.(34,115) Moreover, ACP conversations can elicit various emotions, often communicated implicitly through cues and concerns.(116) Consequently, it is argued that healthcare providers should be attentive to patients' implicit emotional expressions.(116) These expressions contain hints about what truly matters to the patient and offer opportunities to engage them in personalized ACP conversations.(116) Therefore, physicians and interpreters should pay attention to all of the (verbal and nonverbal) ways in which emotions and reactions are expressed and interpreted to guarantee effective communication.(117) Cultural differences in these emotion-related factors among interpreters, patients and physicians may lead to discrepancies in interpretations and actions.(117) In the context of the present research, and with patients' and family members' permission, the use of intercultural mediators (widely acknowledged to deal effectively with challenges accompanying ethno-cultural diversity) is recommended.(118–120) In addition to offering linguistic assistance, such mediators can clarify misunderstandings, explain cultural differences (cultural brokerage), support patients and healthcare workers in their roles and advocate for patients and relatives in ACP communication and decision making.(121) This approach aligns with the patients' rights act mandate that healthcare professionals provide patients with information in clear language that gives them insight into their health conditions and their probable evolution.(122)

4.1.5 Involvement of several family members in ACP processes

Healthcare providers should seek permission to involve close relatives in ACP discussions with patients from collectivistic cultures. Based on this research, such involvement does not necessarily impede ACP discussions, but could rather be viewed as an aspect of patient autonomy and culturally adapted care, particularly as many participants highlighted the important role of family for them.(76,93) Relational autonomy has been proposed to be foundational to ACP.(123) Multidimensional aspects of autonomy should be included in the characterisation of this approach. Family and cultural contexts impact how people construct their autonomy and are known to influence patients' decision making about end-of-life care.(123) End-of-life situations occur in interpersonal settings characterised by harmonious dependence, where family members may aid and be affected by patients' autonomous decision making.(123) Patients should have the opportunity to ask their family members for advice, as long as they maintain independence and the ability to reject that advice. To ensure that (especially end-of-life) care is patient centred, with decisions guided by patients' values, healthcare providers should take relational autonomy into account, allowing vulnerable patients to exercise self-determination while including family members in decision making.(76,123) Moreover, people with non-Western cultural backgrounds may be more likely than others to be guided by family determination and moral responsibility, reflecting their cultural and social values.(76) In the present research, older adults' children played major roles in their parents' decisions about undertaking ACP, but the extent of their involvement in (future) caretaking and decision making for their parents varied widely. A nuanced approach to ACP that considers the family network is required in multicultural family-centric communities.(124) Thus, healthcare providers should seek to become familiar with the roles, perspectives and needs of family members and establish trust-based relationships with them.(124) It has been argued that this can be achieved by asking family members open questions (including about their feelings), ensuring that they correctly understand the information given, showing empathy and giving them sufficient time to speak.(124) The findings of the present research and of a systematic review suggest that healthcare providers' engagement with family members (including the addressing of their concerns and emotions) during ACP discussions, with the facilitation of family communication, indirectly motivates individuals to have such discussions and increases the likelihood of further family dialogue (i.e. helps to remove ACP barriers and potentially improves outcomes).(52) As highlighted in a study of Belgian family members, however, the consideration of family dynamics in this setting is important.(23) The involvement of several family members in initial and ongoing ACP discussions is recommended to streamline decision making and avoid conflict among adult children,(125) especially in the context of migrants of Turkish and Moroccan origins, as suggested by the findings of the present research. In addition, family members are often important sources of information about their relatives' disease trajectories and preferences until the end.(52) However, as demonstrated in some of the interviews conducted for this work, healthcare providers need to ensure that family members do not obstruct effective communication (e.g. of bad news) and decision making. When family members' preferences (e.g. regarding the continuance of futile medical care) put patients' rights at risk, efforts should be made to first understand these preferences (e.g. the knowledge on which they are based) and then to provide explanations from healthcare providers' medical viewpoints and together find solutions that are acceptable for all parties. Healthcare providers can also establish with their patients the acceptable roles of family members in ACP discussions and decision making.

4.1.6 Timely initiation of ACP discussions

In this research, most older Turkish adults who did not require palliative care felt that ACP discussions would be useful, whereas those requiring such care (who were older) largely did not. The roles of increasing religiosity and family member presence in this difference, especially among ethnic minorities, have been discussed above. In Belgium, general practitioners can request single-use billing codes for ACP conversations with patients with palliative care needs.(126) However, the present research findings support the broad consensus that ACP should be initiated in a timely manner, before a health crisis occurs or palliative care needs arise.(64,83,127–132) Most chronically ill patients are more conscious and able to communicate (and thereby be empowered) than are intensive care patients.(133) Moreover, recently revised Belgium's patients' rights act describes ACP as a 'continuous process of reflection and communication'.(134) The use of a single billing code for ACP discussions could lead to the occurrence of single ACP discussions between general practitioners and their patients. Thus, the current government reimbursement practice does not match the concept of good ACP. General practitioners in Belgium also receive additional payment for the maintenance of global medical records for patients aged 30–85 years with chronic conditions.(135) In addition to the single-use billing code for initial ACP discussions, this payment could be contingent on at least annual discussions of ACP. Healthcare providers' initial ACP discussions should centre on the eliciting and understanding of patients' values and worries, rather than only on highly specific decision making about future medical treatment.(127) With a patient-centred, sensitive approach, the topic can be revisited periodically and plans updated to reflect changes in patients' preferences over time and/or with changing personal situations or health conditions.(60,83,136) Such an approach normalises ACP conversations, allows time for contemplation and communication and provides opportunities for re-evaluation.(72,127)

4.2 Recommendations for research

4.2.1 Research on ACP among diverse groups

As the ACP views of older Turkish adults differed according to the palliative care need in this research, exploration of the views of older Moroccan adults with palliative care needs, and comparison with the views of those without such needs, would be of interest. In addition, the present research did not include the interviewing of family members of patients with palliative care needs, as most of the latter died during the interview period. The inclusion of such work (with family members of Turkish and Moroccan patients) to gain insight into these groups' views on ACP would expand this body of research.

The present research involved only patients of Turkish and Moroccan backgrounds and their relatives. Research with older adults with other migration backgrounds and their family members in Belgium would broaden our knowledge of (similarities and differences in) diverse ACP perspectives, enhancing the ability to provide culturally adapted and sensitive ACP information to specific populations and enhancing provider–patient–family communication.

4.2.2 Exploration of methods for effective ACP communication involving several family members

ACP communication commonly involves single primary caregivers. Participants in the current research recommended the involvement of several family members, challenging this common practice and the assumptions underlying it. The exploration of methods for effective ACP communication involving several family members could facilitate future decision making about care and minimise conflict. Interventions could be developed, and studies could be performed to assess their subsequent implementation.

4.2.3 Examination of the effects of discrimination in the healthcare system and distrust of advance directives on ACP

People with ethnic-minority backgrounds often have more difficulty than do ethnic-majority groups with health system access and use and the receipt of quality care.(137) Distrust of the healthcare system is a common ACP barrier across ethnic-minority groups in the United

States.(28) Other documented barriers include perceived discrimination in the healthcare system,(138) distrust arising from the interpretation of advance directives as means of limiting end-of-life care costs and resources,(10) and lack of trust in physicians and other healthcare providers to respect the wishes of patients and families via advance directives.(46) Although participants in this research did not directly mention such factors, their potential roles in this population should be studied further. The existence of discrimination in and distrust of the healthcare system, and its role in patients' opposition to ACP, could be explored via qualitative interview studies. Moreover, directly comparative international research could generate more insight about differences among countries. The perspectives of migrants and their counterparts in their countries of origin could be compared.

4.2.4 Examination of the connection between diagnostic/prognostic disclosure and ACP

Most participants in this research whom general practitioners had deemed to require palliative care and to be likely to die within 6–12 months did not view death as imminent or discussions about end-of-life care preferences as necessary. Doctors have been found to be influenced strongly by relatives at times, regardless of potential detriments to patients' rights, for example avoiding the communication of negative prognoses to patients.(139,140) The harsh truth that a patient's condition is incurable, which is a precondition for palliative treatment, is often avoided.(102) Some older Turkish adults requiring palliative care in the present sample were not aware of the degree to which their illnesses were life limiting. In some cases, family members asked the interviewer to avoid mentioning 'bad' diagnoses or prognoses, which they explicitly stated were undisclosed. Whether knowledge of their diagnoses and prognoses would change these older adults' ACP views remains unknown. Thus, the connection between diagnostic/prognostic disclosure and ACP could be investigated further from patients', family members' and healthcare providers' perspectives.

5. Conclusion

The older adults of Turkish and Moroccan origins and their family members in Belgium who participated in this research lacked ACP knowledge and experience with healthcare providers, but some had discussed certain end-of-life preferences within their families. The findings of this research suggest that these groups need to be more informed about and aware of ACP. The participants' ACP views were highly variable, ranging from acceptance to dismissal. Rather than avoiding ACP discussions based on assumptions related to patients' racial/ethnic backgrounds, limited host-language fluency and/or religious beliefs, clinicians must consider patients' diverse cultural values and maintain an open attitude toward them when engaging with individual patients. People with different backgrounds need to be given opportunities to discuss ACP in a culturally appropriate manner, and the diversity of perspectives on whether and how to engage in such planning needs to be recognised. Some older-adult Turkish and Moroccan participants wished to undertake ACP, many with family members, after receiving comprehensible concrete information in their native languages, suggesting that the common stereotypes of passive or only family-centred decision making are too narrow. This evidence emphasises the importance not only of avoiding East/West cultural stereotypes, but also of identifying individual patients' personal values, needs and preferences for engagement in medical decision making, in line with person-centred care provision. In particular, a deeper understanding of ACP barriers may help healthcare providers to prioritise and address them.

When older-adult patients' family members play important roles in decision making, healthcare providers should also inform them about the potential advantages of ACP to facilitate conversations. When a language barrier exists, professional interpreters such as intercultural mediators should be used, especially for emotionally difficult and complex (i.e. ACP) conversations, to increase the likelihood of effective communication. A lack of engagement in ACP discussion could be linked to patients' family dynamics and religion, with implications for those providing care to people with migration backgrounds. General practitioners should facilitate ACP discussions with these patients, ideally with adult children involved, with the consideration of individual preferences and this population's generally low education level.

Many of the ACP barriers (e.g. fear of death, trust in God and family members and non-acknowledgement of the end of life) and facilitators (e.g. experiences with loved ones' deaths) cited by the participants in this research were similar to those of native-Belgian older adults and other groups. Thus, this research demonstrates that both homogeneity and heterogeneity on ACP views exist within and among populations. This evidence further emphasises the effectiveness of person-centred ACP approaches, rather than a focus on differences between native Belgians and people with Turkish and Moroccan backgrounds. In the absence of such approaches, native-Belgian healthcare providers' difficulties with non-natives may be blamed on the latter. Healthcare providers should seek to gain insight into what matters most to individual patients, identifying their personal preferences and needs to achieve goal-oriented care.

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SUMMARY

Belgium's growing ethno-cultural diversity brings challenges, especially for older adults with Turkish and Moroccan backgrounds. These groups face healthcare barriers due to linguistic, educational and cultural differences, which hinder the understanding and discussion of (end-of-life) medical issues and decisions. Advance care planning (ACP) enables individuals to outline their end-of-life care preferences while relatively healthy. Ethnic-minority groups engage less with ACP due to limited knowledge, familial elder care, perceived conflict with religious beliefs, healthcare system distrust and healthcare providers' neglect of cross-cultural perspectives. Belgium's patients' rights law outlines entitlement to person-centred healthcare, with comprehensive information provision and the right to consent. ACP, which involves ongoing discussion among healthcare providers, patients and their loved ones, is a significant component of these rights. ACP discussions cover patients' values, goals and end-of-life care preferences and choices (e.g. about burial and organ donation), with the goal of mutual plan development. However, many patients, especially older adults, expect doctors to initiate such discussions, and clinicians struggle to involve patients and family members.

More research on the impacts of cultural diversity on ACP discussions in Belgium is needed to guide appropriate ACP adaptation. ACP implementation in Belgium remains inadequate, especially among minority groups and individuals with low (health) literacy. Studies of ACP engagement among older adults with Turkish and Moroccan backgrounds, members of large migrant populations in several European countries, are scarce. The current literature reveals poor communication and conflicting perspectives of healthcare professionals and ethnic-minority patients and family members, but complexities have been overlooked due to the assumption of cultural homogeneity.

For this dissertation, four qualitative studies were performed to characterise ACP knowledge, experiences, views, facilitators and barriers among older adults of Turkish and Moroccan origins (studies 1 and 2), older Turks requiring palliative care (study 3) and family members of older Turks and Moroccans (study 4) in Belgium. General practitioners facilitated recruitment, and face-to-face semi-structured interviews were conducted in participants' native languages. The data were analysed using the constant comparative method (iterative coding and categorisation of ACP-related transcript content; studies 1 and 2) and combined deductive/inductive coding-reliability thematic analysis (additionally involving theme

identification; studies 3 and 4). The research team regularly reviewed preliminary findings and refined insights together to enhance the credibility and reliability of the findings.

Consistent with findings for diverse groups with low educational levels, literacy and healthcare system familiarity worldwide, participants in all studies lacked ACP knowledge and experience with healthcare providers. This differs notably from the commonness of advance directive preparation and/or preference specification in medical records among native-Belgian older adults. Many participants, however, had discussed preferences for end-of-life aspects such as life-prolonging treatment, nursing home admission and burial location with family members. The participants had diverse perspectives on ACP, ranging from acceptance to dismissal. Most considered it to be useful and expressed willingness to address their end-of-life care, similar to Belgian frail older adults. The provision of understandable information in the older adults' native languages during interviews increased ACP acceptance, aligning with findings highlighting the impact of native language use on ACP understanding. Some participants' views reflect a decline in traditional family caregiving dynamics among Turkish and Moroccan immigrants, whereas other participants retained confidence in their children's caregiving based on traditional filial responsibilities common in collectivist societies. Many participants considered ACP to be compatible with their religious beliefs, with initial religious objections diminishing after the receipt of detailed explanations and examples. However, religious beliefs shaped participants' views on end-of-life discussions, especially those requiring palliative care, many of whom emphasised God's determinative role in life and death. Some family members, similar to those of native-Belgian older adults, felt that ACP discussions would reduce the emotional burden and uncertainty of end-of-life decision making, whereas others were resistant to the discussion of some topics or were confident that they understood their relatives' desires without discussion, which has been shown in related research to often be inaccurate. Some participants' intention to override their relatives' wishes for religious reasons echoes ACP-related challenges observed among other individuals with Muslim backgrounds.

The primary barrier identified was the lack of ACP knowledge, which participants attributed to their low education levels and language barriers. This factor leads to low health literacy, impacting involvement in healthcare decisions, as seen previously among older Turkish and Moroccan adults. The second barrier was the reliance on familial support, particularly among participants with strong collectivistic cultural values and low educational levels, who prioritised filial caregiving responsibility and felt unsure about making appropriate decisions.

Some family members of older adults also expressed such reliance, reflecting their relatives' trust in their judgment over personal involvement, which has been documented in several frail older-adult (including native-Belgian) populations. The third barrier was the avoidance of ACP discussions due to the taboo nature of discussing illness and death and the perceived emotional burden on older adults and their family members. This perspective contradicts the assertion in the Belgian ACP guidelines that ACP conversations rarely induce stress or anxiety, and indicates the importance of healthcare providers' sensitivity. The fourth barrier was the perceived lack of urgency for ACP discussions while the older adults were in good health, which aligns with the general tendency to prioritise immediate well-being over future planning documented in ACP research. The fifth barrier was related to personal and relational characteristics, including older adults' stubbornness and/or parental (especially paternal) authority. These factors reflect traditional (gender) hierarchy dynamics in Turkish and Moroccan families.

The primary ACP facilitator was the distribution of ACP Information in older adults' native languages, which has been associated with increased ACP acceptance and completion rates. Family members emphasised the need for general practitioners to cautiously initiate ACP discussions using examples to avoid distressing their relatives, given the typically trusting nature of doctor–patient relationships in Belgium. The second facilitator was increased ACP knowledge among older adults' children to streamline future decision making and mitigate potential worries or conflict. The encouragement of family members' involvement in ACP discussions was also seen as vital. The third facilitator was older adults' concern about future care needs, driven in some cases by a lack of trust in their children's ability to manage such needs. This perspective is rooted in the awareness of changing family structures and caregiving norms, aligning with similar concerns seen among native Belgians and other immigrant groups adapting to Western values. The fourth facilitator, also documented in other populations (e.g. first-generation Muslim immigrants in the United States), was some older adults' desire to avoiding burdening their children. The fifth facilitator, also recognized in other populations, was recent family experience of severe illness or death, which prompted discussion of end-of-life care preferences, especially among older Turkish adults requiring palliative care.

Based on these findings, several practice recommendations can be made. Older adults of Turkish and Moroccan origins and their family members should be given easily understandable ACP information in their native languages, and ideally culturally adapted visual information (e.g. short films or posters). Awareness campaigns could be implemented (e.g. via social media, waiting rooms and cultural associations). General practitioners should initiate ACP discussions in a culturally sensitive, person-centred manner (rather than generalising) while patients are relatively healthy, and use relatable examples beyond reference to concrete aspects of ACP. These discussions would be improved by the use of professional interpreters (e.g. intercultural mediators) and the (carefully mediated) involvement of multiple family members.

ACP studies conducted with the palliative care populations of older Moroccan adults and family members of older Turkish and Moroccan adults are needed to complement the present research. Effective methods for the involvement of multiple family members in ACP conversations, challenging the assumption of single primary caregiver involvement, also need to be explored. Moreover, similar research could be conducted with older adults and family members with other migration backgrounds in Belgium, to enable culturally sensitive ACP information provision. The roles of perceived discrimination in the healthcare system, distrust of advance directives and poor diagnosis/prognosis disclosure in ACP engagement among ethnic-minority groups should also be examined. Upon implementation, the above practice recommendations should also be assessed.

SAMENVATTING

De groeiende etnisch-culturele diversiteit in België brengt uitdagingen met zich mee, vooral voor ouderen met een Turkse en Marokkaanse achtergrond. Deze groepen worden geconfronteerd met barrières in de gezondheidszorg als gevolg van taalkundige, educatieve en culturele verschillen, die het begrijpen en bespreken van medische kwesties en beslissingen rond het levenseinde bemoeilijken. Voorafgaande zorgplanning (VZP) stelt mensen in staat om hun voorkeuren voor zorg rond het levenseinde te bepalen, terwijl ze nog relatief gezond zijn. Etnische minderheidsgroepen maken minder gebruik van de VZP omwille van beperkte kennis, familiale ouderenzorg, vermeend conflict met religieuze overtuigingen, wantrouwen in het gezondheidszorgsysteem en verwaarlozing door zorgverleners van interculturele perspectieven. De Belgische wet op patiëntenrechten bepaalt dat patiënten recht hebben op persoonsgerichte gezondheidszorg, met uitgebreide informatieverstrekking en het recht op toestemming. De VZP zorgt voor een voortdurend gesprek tussen zorgverleners, patiënten en hun naasten en is een belangrijk onderdeel van deze rechten. Tijdens VZP-gesprekken komen de waarden, doelen, voorkeuren en keuzes van patiënten aan het levenseinde aan bod (bijvoorbeeld over de begrafenis of over orgaandonatie), met als doel het opstellen van een gezamenlijk plan. Veel patiënten, vooral ouderen, verwachten echter dat artsen dergelijke discussies initiëren, maar artsen hebben moeite om patiënten en familieleden erbij te betrekken. Er is meer onderzoek nodig naar de impact van culturele diversiteit op VZP-gesprekken in België om te kunnen zorgen voor een aangepaste VZP-benadering. De implementatie van de VZP blijft ontoereikend in België, vooral bij minderheidsgroepen en personen met een lage (gezondheids)geletterdheid. Studies over de betrokkenheid in de VZP van ouderen met een Turkse en Marokkaanse achtergrond, leden van grote migrantenpopulaties in verschillende Europese landen, zijn schaars. De huidige literatuur toont een niet-optimale communicatie en conflicterende perspectieven aan tussen zorgverleners en patiënten en hun familieleden van etnische minderhedengroepen, alhoewel de complexiteiten over het hoofd gezien worden door de aanname van een culturele homogeniteit.

Voor dit proefschrift werden vier kwalitatieve studies uitgevoerd om de kennis, ervaringen, opvattingen, facilitatoren en barrières van de VZP te onderzoeken onder ouderen met Turkse en Marokkaanse achtergronden (studies één en twee), ouderen met een Turkse achtergrond die palliatieve zorg nodig hebben (studie drie) en familieleden van ouderen met Turkse en Marokkaanse achtergronden in België (studie vier). Huisartsen zorgden voor de rekrutering en face-to-face semi-gestructureerde interviews werden afgenomen in de moedertaal van de deelnemers. De gegevens werden geanalyseerd met behulp van de constante vergelijkende methode (iteratief coderen en categoriseren van VZP-gerelateerde transcriptinhoud; studies één en twee) en met behulp van een gecombineerde deductieve/inductieve thematische analyse (aangevuld met thema-identificatie; studies drie en vier). Het onderzoeksteam beoordeelde samen regelmatig de bevindingen en verfijnde de inzichten om de geloofwaardigheid en betrouwbaarheid van de bevindingen te vergroten.

In alle vier de studies hadden de deelnemers een gebrek aan VZP-kennis en -ervaring met zorgverleners, wat in overeenstemming is met de bevindingen van diverse groepen met een laag opleidingsniveau, geletterdheid en vertrouwdheid met het gezondheidszorgsysteem wereldwijd. De bevindingen verschillen wel met autochtone Belgische ouderen die wel de gewoonte hebben om een wilsverklaring op te stellen en/of hun voorkeuren te specificeren in medische dossiers. Veel deelnemers hadden echter met hun familieleden voorkeuren besproken voor sommige aspecten van het levenseinde, zoals een levensverlengende behandeling, een opname in een woonzorgcentrum en de plaats van de begrafenis. De deelnemers hadden verschillende visies op de VZP, gaande van aanvaarding tot afwijzing. De meesten vonden het nuttig en waren bereid om hun levenseindezorg te bespreken, net zoals Belgische kwetsbare ouderen. Het verstrekken van begrijpelijke informatie in de moedertaal van de ouderen tijdens de interviews verhoogde de aanvaarding van de VZP, wat overeenkomt met de bevindingen die de impact van het moedertaalgebruik op het begrijpen van de VZP benadrukken. De opvattingen van sommige deelnemers weerspiegelen een achteruitgang in de traditionele zorgdynamiek binnen het gezin bij Turkse en Marokkaanse immigranten, terwijl andere deelnemers vertrouwen bleven houden in de zorg door hun kinderen op basis van traditionele verantwoordelijkheden van kinderen die gebruikelijk zijn in collectivistische samenlevingen. Veel deelnemers vonden dat de VZP niet in strijd was met hun religieuze overtuigingen, waarbij aanvankelijke religieuze bezwaren afnamen na het ontvangen van gedetailleerde uitleg en voorbeelden. Religieuze overtuigingen beïnvloedden echter de visie van deelnemers op de gesprekken over het levenseinde, vooral van degenen die palliatieve zorg nodig hadden, van wie velen de nadruk legden op Gods bepalende rol in leven en dood. Zoals de familieleden van autochtone Belgische ouderen, vonden sommige familieleden dat de VZP-gesprekken de emotionele last en onzekerheid rond de beslissingen aan het levenseinde zouden verminderen. Daartegenover waren er ook andere familieleden die zich verzetten tegen de bespreking van sommige onderwerpen of ervan overtuigd waren dat ze de wensen van hun familieleden begrepen, zonder een gesprek hieromtrent, wat in gerelateerd onderzoek vaak onjuist bleek te zijn. Het voornemen van sommige familieleden om de wensen van hun familieleden om religieuze redenen terzijde te schuiven, komt overeen met de VZP-gerelateerde uitdagingen die werden waargenomen bij andere personen met een moslimachtergrond.

Er werden vijftal belangrijke barrières benoemd door de deelnemers. De belangrijkste barrière was het gebrek aan kennis over de VZP, wat de deelnemers toeschreven aan hun lage opleidingsniveau en aan de taal. Deze factor leidt tot een lage gezondheidsvaardigheid, wat invloed heeft op de betrokkenheid bij beslissingen over de gezondheidszorg, zoals eerder werd gezien bij oudere Turkse en Marokkaanse volwassenen. De tweede barrière was het vertrouwen in de steun van de familie, vooral onder de deelnemers met sterke collectivistische culturele waarden en een laag opleidingsniveau. Deze deelnemers gaven prioriteit aan de verantwoordelijkheid van de familie voor hun zorg en voelden zich onzeker over het nemen van de juiste beslissingen. Sommige familieleden van oudere volwassenen uitten ook een dergelijk vertrouwen, dat het vertrouwen van de ouderen weerspiegelde, in het oordeel van hun familieleden boven de persoonlijke betrokkenheid van de ouderen zelf. Dit werd ook gedocumenteerd in andere studies met verschillende kwetsbare ouderen (inclusief autochtone Belgen). De derde barrière was het vermijden van VZP-gesprekken omwille van het taboe op het bespreken van ziekte en dood en de emotionele belasting voor ouderen en hun familieleden. Dit perspectief is in tegenspraak met de bewering in de Belgische VZP-richtlijnen dat VZP-gesprekken zelden stress of angst veroorzaken. De zorgverleners moeten aandachtig zijn voor deze perspectieven. De vierde barrière was het gepercipieerde gebrek aan urgentie voor VZP-gesprekken wanneer de ouderen nog een relatief goede gezondheid hebben. Dit komt overeen met de algemene tendens in VZP-gerelateerde onderzoeken om prioriteit te geven aan de huidige gezondheid en niet op de toekomstige planningen. De vijfde barrière had te maken met persoonlijke en relationele kenmerken van de ouderen, waaronder koppigheid en/of ouderlijk (vooral vaderlijk) gezag. Deze factoren weerspiegelen de traditionele (gender-)hiërarchische dynamiek in Turkse en Marokkaanse gezinnen.

Er werden ook vijftal belangrijke facilitators benoemd door de deelnemers. De belangrijkste facilitator van de VZP was de verspreiding van informatie over die VZP in de moedertaal van de ouderen, wat in eerdere onderzoeken in verband werd gebracht met een grotere acceptatie en voltooiing van de VZP. Familieleden benadrukten het belang van de huisartsen, wegens hun vertrouwensrelatie, om VZP-gesprekken voorzichtig te initiëren aan de hand van voorbeelden, om zo te vermijden dat hun familieleden overstuur zouden raken. De tweede facilitator was een verhoogde VZP-kennis bij de volwassen kinderen van ouderen om de toekomstige beslissingen te stroomlijnen en potentiële zorgen of conflicten te verminderen. Het aanmoedigen van de betrokkenheid van familieleden bij VZP-besprekingen werd ook als vitaal beschouwd. De derde facilitator was de bezorgdheid van ouderen over toekomstige zorgbehoeften, in sommige gevallen gedreven door een gebrek aan vertrouwen in de zorg door de kinderen. Dit perspectief is geworteld in het bewustzijn van de veranderende gezinsstructuren en zorgnormen. Autochtone Belgische ouderen en andere immigrantengroepen die zich aanpasten aan westerse waarden vertoonden dezelfde bekommernissen in eerdere studies. De vierde facilitator was de wens van sommige ouderen om hun kinderen niet te belasten. Dit werd ook gedocumenteerd in andere populaties, zoals moslimimmigranten van de eerste generatie in de Verenigde Staten. De vijfde facilitator, die ook in andere populaties werd herkend, was recente familie-ervaring met ernstige ziekte of overlijden. Dit zorgde voor gesprekken over de zorgvoorkeuren aan het levenseinde, vooral onder ouderen met een Turkse achtergrond die palliatieve zorg nodig hadden.

Op basis van de bevindingen in deze proefschrift kunnen er verschillende praktische aanbevelingen worden gedaan. Ouderen van Turkse en Marokkaanse achtergronden en hun familieleden moeten gemakkelijk begrijpbare informatie over de VZP krijgen in hun moedertaal en idealiter met cultureel aangepaste visuele informatie, zoals korte films of posters. Er kunnen bewustmakingscampagnes gevoerd worden via sociale media, in wachtkamers en in cultureel-etnische verenigingen. Huisartsen moeten discussies over de VZP op een cultuursensitieve, persoonsgerichte manier initiëren (in plaats van te generaliseren), terwijl patiënten relatief gezond zijn en gebruikmaken van relateerbare voorbeelden die niet enkel verwijzen naar concrete aspecten van de VZP. VZP-gesprekken kunnen optimaler verlopen door het gebruik van professionele tolken, zoals interculturele bemiddelaars en de (zorgvuldig bemiddelde) betrokkenheid van meerdere familieleden.

Om het huidige onderzoek aan te vullen, zijn er nog onderzoeken nodig over de VZP-perspectieven van de palliatieve patiënten met een Marokkaanse achtergrond en de familieleden van palliatieve ouderen met een Turkse en Marokkaanse achtergrond. Ook moeten effectieve methoden onderzocht worden voor het betrekken van meerdere familieleden bij VZP-gesprekken, in plaats van de aanname van betrokkenheid van één primaire mantelzorger. Bovendien zou gelijkaardig onderzoek kunnen worden uitgevoerd met ouderen en familieleden met andere migratieachtergronden in België, om een cultureel gevoelige informatieverstrekking over en het toepassen van VZP mogelijk te maken. De rol van ervaren discriminatie in het gezondheidszorgsysteem, het wantrouwen ten opzichte van wilsverklaringen en de niet-optimale bekendmaking van de diagnose/prognose in de betrokkenheid bij de VZP onder etnische minderheidsgroepen, moeten ook worden onderzocht. De bovenstaande praktijkaanbevelingen (zijnde gemakkelijk begrijpbare informatie, bewustmakingscampagnes, tijdig initiëren van VZP gesprekken door huisartsen, professionele tolken en betrokkenheid van meerdere familieleden) moeten ook worden geëvalueerd na hun implementatie.

CURRICULUM VITAE

Hakki Demirkapu was born on 26 July 1984 in Ghent, Belgium. He attended high school in Ghent, graduating in Science-Mathematics in 2003. Dr Demirkapu obtained Bachelor's degrees in Biomedical Sciences (2005) and Medicine (2007), and went on to obtain a Master's degree in Medicine at Vrije Universiteit Brussel in 2010. In 2012, he completed his Master-after-Master's degree in Family Medicine. In 2013, he founded the multidisciplinary Medisina Medical and Dental Clinic, where he works as a general practitioner and tutor for general practitioners in training. In 2017, he initiated his PhD project in the Department of Family Medicine and Chronic Care of Vrije Universiteit Brussel. His research focuses on advance care planning among people of Turkish and Moroccan origin living in Belgium. The findings of his doctoral research have been published in high-impact, peer-reviewed international journals and disseminated through presentations at national and international conferences. He also has a special interest in person-centred care, which takes patients' cultural and religious values into account. Dr Demirkapu gives lectures on medical care for individuals with migration backgrounds and serves as a board member for several associations dedicated to health and education.

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