Vroegtijdige zorgplanning bij ouderen van Marokkaanse origine in België:
Vergelijking van niet-palliatieve en palliatieve ouderen

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Brahim Chater
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Abstract (Nederlands)

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Context. Vroegtijdige zorgplanning (VZP) is een continu proces van dialoog tussen patiënten, hun familieleden en zorgverleners, waarin getracht wordt om voor de patiënt belangrijke waarden en zorgdoelen voor het levenseinde te verkennen, te verduidelijken en te documenteren. VZP heeft een aantal voordelen zowel voor de patiënt, de familie als voor professionele zorgverleners. Sinds meer dan een halve eeuw kent België een aanzienlijke instroom van Marokkaanse migranten. De eerste generatie van hen veroudert gestaag en heeft steeds meer nood aan gepaste levenseinde-zorg. VZP-participatie onder deze ouderen is evenwel beperkt en tevens slecht bestudeerd.
Doel van de studie. Exploreren van de kennis, opvattingen en houdingen omtrent VZP bij palliatieve ouderen van Marokkaanse origine, evenals nagaan welke factoren VZP-deelname faciliteren en belemmeren in deze populatie, en dit vergelijken met bevindigen bij niet-palliatieve Marokkaanse ouderen.
Methode. Deze exploratieve, kwalitatieve studie is gebaseerd op 32 semi-gestructureerde interviews met ouderen van Marokkaanse origine, wonend in België (leeftijd ≥ 65 jaar), uitgevoerd in het Marokkaans-Arabisch aan de hand van één en dezelfde *interview topic guide*. Tweeëntwintig interviews werden afgenomen bij niet-palliatieve ouderen en tien bij palliatieve bejaarden, zoals geïdentificeerd aan de hand van de *Palliative Care Indicator Tool* (PICT). De interviews werden woordelijk vertaald naar het Nederlands en vervolgens in NVIVO geanalyseerd, gebruik makend van een *constant comparative method.*
Resultaten. Belangrijke gelijkenissen tussen niet-palliatieve (PICT-negatieve) en palliatieve (PICT-positieve) deelnemers waren een algemeen gebrek aan kennis over VZP en beperkte communicatie over bekommernissen omtrent gezondheid en toekomstige zorg. In beide groepen hadden bevraagden reeds onbewust informeel aan VZP gedaan, hetzij alleen, hetzij met familie. Dit betrof voornamelijk het regelen van repatriëring na de dood, de begraafplaats en bespreken van verhuis naar een rusthuis. Bij de palliatieve ouderen was bijna de helft hertrouwd teneinde toekomstige zorg te garanderen. Na heldere, eenvoudige informatie over VZP ontvangen te hebben waren de meeste niet-palliatieve patiënten bereid te praten over VZP-topics en dit niet alleen met familie maar ook met de huisarts. Palliatieve deelnemers waren terughoudender om deel te nemen en vooral om een VZP formeel a.d.h.v. documenten te laten optekenen. Gemeenschappelijke barrières voor meer VZP-participatie waren gebrek aan kennis over VZP, gebrek aan initiatief van huisartsen, zelfs de Marokkaanse, en het rekenen op familie voor toekomstige zorg en het nemen van beslissingen. Andere obstakels waren het zich nog te goed voelen en het verlangen tweedracht en verdriet onder familieleden te vermijden. Enkele palliatieve deelnemers vermeldden ook hun financieel moeilijke situatie als belemmering. Wat voorkeuren betreft, waren niet-palliatieve deelnemers meer open voor rusthuisopname.
Conclusie. Zowel niet-palliatieve als palliatieve ouderen van Marokkaanse origine in België zijn niet op de hoogte van VZP. Overheden en professionele zorgverleners moeten cultuur- en religie-sensitieve informatie op maat verstrekken. Dit moet gebeuren vóór de palliatieve toestand wordt bereikt, gezien bereidheid tot participatie aan meer formele VZP schijnbaar nog groter is dan. Huisartsen moeten beter opgeleid en meer aangemoedigd worden om kennis van VZP bij deze patiënten te vergroten en om zelf VZP-gesprekken met hen aan te gaan. Campagnes en interventies om VZP-kennis en –deelname te stimuleren moeten ook gericht zijn op het betrekken van nauwe verwanten van deze ouderen en moeten rekening houden met het traditionele beslissingsmodel in deze gemeenschap, waarin de familie centraal staat en dat belangrijker wordt naar het levenseinde toe.

Abstract

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Context. Advance care planning (ACP) is a continuous process of dialogue between patients, their relatives and health care providers, which seeks to explore, clarify and document the values and care objectives most dear to the patient towards the end of life. It's been shown to have several benefits for patients, family members and care professionals. For over half a century Belgium has seen a considerable influx of Moroccan immigrants, the first generation of whom is now steadily aging and increasingly in need of appropriate end-of-life (EOL) care. ACP engagement among these elders is however low and poorly studied.
Objectives. To explore the knowledge, attitudes, facilitators and barriers towards ACP among palliative elderly individuals of Moroccan origin living in Belgium and to compare these findings with findings from non-palliative elderly Moroccans.
Methods. This exploratoy qualitative study was based on a total of 32 semistructured interviews with elderly persons of Moroccan origin living in Belgium (age ≥ 65 years) using one same interview topic guide in their native tongue (Moroccan Arabic). Twenty-two interviews were conducted among non-pallitiave and ten among palliative elderly individuals, as identified with the Palliative Care Indicator Tool (PICT). Verbatim translations were analyzed in NVIVO using a constant comparative method.
Results. Important similarities between non-palliative (PICT-negative) and palliative (PICT-positive) participants were a general lack of knowledge of ACP and limited communication about health concerns and future care. In both groups respondents had however informally engaged in certain ACP behaviors either alone or with relatives, mainly concerning talks about repatriation after death, burial and moving to a nursing home. Additionally among palliative respondents nearly half had remarried in order to ensure future care. Upon receiving clear and basic information about ACP most non-palliative patients expressed their willingness to talk about ACP topics, not only with family members but also with their GP. Palliative participants were more ambiguous and expressed reluctance to have ACP formalized in written documents. Commonly mentioned barriers to higher ACP uptake among both groups were lack of knowledge about ACP, lack of initiative by the GPs, even the Moroccan ones, and strong reliance on family for future care and decision making. Other barriers were the desire to avoid strife among relatives, fear to cause sorrow to family members and a perception of no present need for medical care. One barrier mentioned only by palliative patients was financial hardship. As for preferences for future care, non-palliative interviewees seemed to be more open to the idea of moving to a nursing home than palliative participants.
Conclusion. Both palliative and non-palliative elderly individuals of Moroccan origin in Belgium are unaware of ACP. Health authorities and care professionals should provide information that is tailored and culture and religion sensitive. This should be initiated before individuals attain palliative status, when willingness to engage in more formal ACP is seemingly still higher. GPs should be better trained and more encouraged to raise awareness about ACP and to initiate EOL and ACP talks. Campaigns and interventions to raise awareness and uptake should also target close relatives of these elders and take into account the family-centered models of decision making prevalent within Moroccan tradition, that become more dominant as EOL approaches.

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A. Introduction

Advance care planning (ACP) is a continuously ongoing and dynamic process of voluntary reflection about values, preferences and desires concerning eventual care in the future, particularly at the end of life.(1-2) This process of ongoing dialogue takes place between patients, their family members and health care providers. It is centered around the patient's autonomy and seeks to explore, clarify and document the values most dear to the patient and the primordial care objectives in end-of-life (EOL) issues.(2) The aim of ACP is therefore to encourage patients to reflect about and express the values, the convictions and the preferences concerning future care that are most important to them so that they can be taken into account by caregivers in case an eventual deterioration in physical or mental health inhibits patients to think and communicate about these issues for themselves.(1-2) In reality ACP is usually initiated towards the end of life, often triggered by diagnoses of life-limiting illnesses, life-threatening medical events or significant health deterioration, but it's recommended to already initiate the process before that.(1-2) Ideally the ACP process results in the production of formal, written documents that can be regularly reviewed or periodically updated through dialogue between patients and caregivers, as preferences of patients might change over time.(1-3)

1. ACP history

The ratification of the Patient Self-Determination Act (PSDA) in 1991 in the US resulted in an increased attention for the autonomy of patients and for their involvement in decision making.(4) This in turn led to the rise of formal advance directives such as living wills and durable power of attorney.(4) Initially the concept of ACP was limited to this kind of formal documentation of patients' preferences and of the appointment of proxy decision makers, which is now commonly referred to as formal ACP.(1, 4, 75) Over time the concept of ACP itself gained a broader meaning, and came to also refer to a holistic, patient-centered process of reflection and dialogue that encompasses the identification of values as well as the defining of goals and preferences for future medical treatment and care.(1-2, 4) The latter, broader discussion-based process is often referred to as informal ACP.(41, 75) During this process goals and preferences are discussed with the patient's family and health-care providers, with a scope that is broader than just the physical domain and can include concerns across the emotional, psychological, social, and spiritual domains.(1)

In Belgium the concept of ACP (or "*vroegtijdige/ voorafgaande zorgplanning (VZP)*" in Dutch) gained attention in 2002 with the passage of a number of laws regulating EOL decisions ('Wet betreffende de euthanasie' and 'Wet betreffende de palliatieve zorg') and the rights of patients ('Wet betreffende de rechten van de patiënt').(2, 5-8) A first guideline on ACP with practical advice for physicians and other involved health care providers was published in 2014.(2, 5)

2. Benefits of ACP

Although there is some discussion about the impact of ACP on actual EOL care improvement,(9-16) there exists a substantial body of research that has shown that ACP uptake is associated with several benefits for patients, family members and professional health care providers.(1, 17-21) It allows patients to maintain a sense of control and ensures peace of mind regarding EOL questions and concerns.(21-22) Furthermore, the ACP process leads to a clearer, less ambiguous communication and a better understanding between patients and their entourage, and enables a better concordance between their

preferences and eventual received care.(17-21) It is also believed to result in higher patient satisfaction and a better quality of life.(17-21) Family members experience less of a decision-making burden as difficult decisions are anticipated and anxiety and worries concerning future care are reduced when ACP is present.(3, 20) Moreover, after a patient has passed away, his surviving relatives tend to experience less stress, anxiety and depression, when EOL discussions have been conducted and ACP has been present.(20)
ACP uptake results in more advanced directives and decreases the ethical dilemmas care providers will have to face.(3) It also reduces pressure on the health system as it results in a decrease of unwanted hospital admissions and life-prolonging treatments, as well as in an increase in palliative care.(1, 19-20)

3. Prevalence of ACP

Despite the clear benefits of undertaking ACP, uptake remains rather low in most Western countries.(3, 23-26) More than a decade after the passage of the PSDA, according to one follow-back survey of deaths in the US, there was at least one advance directive present in 71% of nontraumatic deaths, but completion of directives in the broader general population was estimated to be only somewhere between 18% and 30%.(4, 27) In Europe these numbers are even lower as several studies have demonstrated.(3,5,21,28)

In Belgium, discussions about preferences for EOL care remain rare and haven't been conducted systematically. A cross-sectional interview study by De Veminck et al. using a large sample, representative for the general population, found that merely 4,4% of all respondents had ever had a discussion with the general practitioner (GP) concerning care at the end of life.(5) Research by Meeussen et al. in Belgium and the Netherlands showed that only in 34% of all non-sudden deaths ACP had been in place, and that it mostly focused on foregoing life-prolonging treatments.(4) In only 8% of all non-sudden deaths a formal, written ACP was made with the patient, while in 23% of non-sudden death cases care was planned exclusively with the family without involvement of the patient.(4)

4. Barriers

Research has shown that there are numerous barriers that impede the uptake of ACP.

Various patient-related factors contribute to this low uptake. They include avoidance of the subject for fear of dying, shame to talk about it with others and a desire not to be a burden to relatives.(3, 21) Another, much discussed barrier is low health literacy. The latter is the capacity of an individual to access, understand and process health information in order to subsequently make informed decisions. Health literacy plays a crucial role in ACP uptake, with some studies even suggesting that low health literacy is the main obstacle to higher ACP uptake.(29-33) Young age and good health have also been linked to lower ACP uptake, whereas advancing age and deteriorating health were associated with higher uptake.(5, 34) Another important barrier is the patients' expectation that their GP should initiate EOL discussions, not they themselves.(17) Finally, several more practical issues such as a lack of time or of a convenient occasion to complete the documents as well as financial difficulties are often mentioned as barriers.(1-3, 17)

There also exist a number of physician-related factors that prevent a higher uptake of ACP. Physicians often avoid engaging in discussions on EOL care and ACP because of the time-consuming nature of these conversations.(17, 35) Moreover, many physicians still think it's up to the patients to initiate conversations about ACP.(17, 35) Physicians often avoid initiating ACP talks because they feel they lack the necessary skills and competence to conduct such conversations.(17, 35) Lack of knowledge of complex diagnoses, of their

treatment and of how to communicate them also daunts physicians into avoiding to start the dialogue.(35)

However the most important reason why ACP uptake remains low to this day, is a general lack of knowledge of its existence and its different aspects, not only among laypeople but also among many health care providers.(3, 17, 35)

5. ACP in minorities

a. International context

It has been observed that ACP uptake is even lower among certain ethnic and cultural minority groups.(36-39) Moreover, it is believed that some norms and values that prevail in certain non-Western cultures, are rather difficult to reconcile with the philosophy behind ACP and prevent a successful implementation of ACP among minorities from these backgrounds.(2, 38) Studies focusing on ACP in minority groups have mainly been conducted in the US and predominantly focus on African Americans, Asians and Hispanics.(38) There have also been a number of studies in Australia, the UK and New Zealand.(40-42) Studies among minority groups in European context remain rather scarce despite increased interest in ACP.

The main barrier to a higher uptake of ACP in minorities is a lack of knowledge and awareness of the existence of ACP and of EOL care options due to a broader, general lack of knowledge of the health system and its services.(33, 43-47) Contributing factors are language barriers, lack of targeted tailor-made and easily accessible information and a dearth of educational interventions by health care providers and authorities among minorities. When knowledge of ACP does exist, it is often flawed by numerous misconceptions (e.g. irreversibility) that in turn prevent uptake.(33, 48) Moreover, health literacy levels among minority groups are usually lower than in the general population, resulting in more difficult communication between physicians and patients, in misunderstanding of terminology or even in avoidance of EOL and ACP discussions altogether.(29, 33, 49)

Other factors, related to the health system, complicate matters even further. Several studies have suggested that a patient's financial situation is an important determinant in the uptake of ACP.(50-52) Thus, experiencing financial problems and not being able to get appropriate health insurance formed an obstacle for certain impoverished minority groups in the US.(53-55) Perceived discrimination by the health care system and unprofessional attitudes of health care professionals towards certain minorities formed another obstacle.(55)

Cultural and religious elements also play an important role in the uptake of ACP among certain minority groups. ACP was born in the context of ethical principlism, which forms the fundamental framework of Western bio-ethical thought, with autonomy being privileged as the preeminent principle and as the principal guide to ethical decision making in health care.(56) Yet in many ethnic and cultural minority groups, group consensus and decision making by family are more valued than individual decision making.(56) Within these groups family-sovereignty and family-determination tend to supersede individual sovereignty and self-determination as principles for guiding decision making at the end of life. (56) The perceived culturally insensitive approach of ACP thus contributes to the reticent attitude of certain minority groups towards ACP.(56-57) Conversely, increasing acculturation of minority groups is associated with higher ACP uptake.(38, 58-61)

Religiosity, practicing and regularly attending religious services as well as having positive religious and spiritual coping, were linked to lower ACP uptake.(33, 52, 62) In some minorities God is considered to be the only one who controls both physical as well as

spiritual well-being and health, and the one who rules over life and death, making ACP by human beings less relevant.(33, 46) Some religions also promote a decisional model in which the family unit is central.(33)

Studies on ACP in an Islamic context are scarce. Palliative care and ACP are rather new concepts in the Islamic world and their implementation has been very limited hitherto.(63-69) Unfamiliarity with the concept and its different aspects and nuances has been one of the main obstacles in its implementation, besides the absence of a legal framework and the prevailing of certain cultural values.(65) Important in this context is the fact that in many Islamic societies illness is considered to be a matter that concerns the whole family and not merely the individual.(65) Consequently the family will also play a prominent role in taking up care for the patient and making decisions on his behalf.(65)

Several studies show there's no intrinsic incompatibilty of Islam with ACP.(63-69) The topic of death is ever-present in Islam and talking about death is encouraged.(63-65, 68) An individual's consent is mandatory when initiating treatments or making decisions, and nobody can be forced to undergo a treatment he or she doesn't want.(63-65, 68) Stopping or not starting life-prolonging treatments that don't really benefit the patient is permitted. (63-65, 68) A study in Saudi Arabia among Muslims of different nationalities and careers showed that respondents were willing to undertake ACP and take matters into their own hands as far as EOL decisions were concerned.(63) It has been observed however that participation in ACP among Muslims in the US was low and lower than in other minority groups.(39) Lack of knowledge was assumed to be the main driver behind this and even among this group there was a willingness to participate.(39)

b. ACP and minorities in Belgium

For over half a century there has been a considerable flux of migrants from Morocco to Belgium. As the first generation of these immigrants is now steadily aging, there's an ever increasing need for appropriate EOL care. Studies that focus on ACP or even EOL care in this group are very scarce in Belgium and the Netherlands.(70-72) They point out that these aging immigrants will soon need increasingly more formal care, but they also show that as of yet these generally poorly acculturated elderly persons have great difficulties finding access to the health system and to appropriate EOL care. This is due to a lack of knowledge of this system, language barriers, low levels of education and low health literacy, besides financial precarious situations and last but not least a perceived insensitivity of the system to their specific backgrounds and to certain cultural and religious attitudes and values they hold dear.(70-72)

Until now only one published study focused on ACP among a minority group in Belgium.(73) Through face-to-face interviews, this qualitative study explored the knowledge, attitudes and experienced barriers and facilitators concerning ACP among elderly, yet not severely ill Turkish individuals in Belgium. It found that these respondents were mostly unaware of the existence of ACP but that once the concept had been explained to them most respondents were willing to participate in ACP, with most participants seeing it as a useful thing. Moreover, it observed that most of the interviewees had already undertaken informal talks with close ones or engaged in ACP behaviors. It also discerned a number of barriers in the uptake of ACP in this minority group, with lack of knowledge being the most prominent one, besides language barriers, lack of urgency of care, trust in help from family members and a desire not to cause grief and negative feelings to themselves nor to their relatives. It points out that a more culturally sensitive approach and tailor-made information about ACP for this minority is desirable.(73)

6. Aim of our study

To our knowledge only one study has focused on ACP among Moroccan elderly people in Belgium until now.(74, in press) Through face-to-face interviews it attempted to explore the knowledge, attitudes and experiences concerning ACP, as well as barriers and facilitators towards ACP in this group and focused on non-palliative Moroccan elderly individuals.

As has been observed by previous studies, age and health condition play an important role in ACP uptake.(38, 59, 75) Within minorities, as is the case for the general population, engagement in ACP was higher for individuals with serious illnesses in comparison with the average community residents.(38, 59, 75) Also the needs and views on ACP of patients with progressive, incurable conditions seem to be different from those of more healthy adults.(75-76) The present study, which constitutes the second part of the study conducted by Demirkapu et al.,(74) intends to add to the present state of knowledge by aiming to explore the knowledge, attitudes, and experiences concerning ACP, as well as facilitators and barriers towards ACP uptake among palliative elderly persons of Moroccan origin, and by subsequently inquiring which similarities and differences exist between the findings in this group and those in non-palliative elderly Moroccans.

B. Methodology

1. Study Design

For this exploratory study we chose a qualitative approach using face-to-face semistructured interviews in order to gauge the knowledge, experiences, attitudes, opinions and assumptions concerning ACP among elderly people of Moroccan origin residing in Belgium. Throughout the interviews we also tried to explore their willingness to participate in ACP and the barriers and facilitators in uptake of ACP among this population. The semistructured format allows for standardization of the interviews, yet it also permits elaboration by the interviewees on topics that were not anticipated.

2. Participants, Recruitment Criteria and Recruitment process

We recruited elderly people of Moroccan origin aged > 65 years, residing in Belgium and who according to the criteria of the Palliative Care Indicator Tool (PICT, cf. Appendix 1) were either eligible for palliative care (PICT-positive) or not having "palliative status" (PICT-negative). The PICT-tool allows to identify patients eligible for palliative care, based on a three-step algorithm that consecutively enquires about life expectancy, presence of frailty factors and presence of criteria of incurable conditions. A person is identified as having palliative status (i.e. PICT-positive) when the answers to all three questions concerning these three criteria are affirmative. This tool has been validated for use in Belgium. Consequently in our study the PICT-positive group only included those people who had a life expectancy of 12 months or less with two or more frailty indicators and at least one criterion of incurability of a potentially lethal medical condition. Excluded were people with severe cognitive impairment or dementia. Also excluded were patients considered to be in the terminal phase with only an extremely short life expectancy.(cf. Appendix 2 for protocol of PICT-positive group; for PICT-negative group cf. Hajji 2021 (77))

General practitioners of Moroccan elderly persons in the Flemish and Brussels region were contacted by mail, phone or through on-site visits and through associations of general physicians. Information about the study and use of the PICT-tool was provided to them. GPs willing to participate were subsequently asked to explain the research and its objectives to those patients who were eligible for inclusion. After obtaining at least their oral informed consent the former completed a PICT-form for each patient. Contact information of each respective patient was handed over to the main researchers - more specifically to HR for PICT-negative and CB for PICT-positive individuals - so that the participants could be contacted by phone by the researchers. After their personal oral and/or written consent a meeting for the interview at a location of the participants' choosing (usually at their respective homes) would be arranged.

3. Data Collection & Analysis

A topic list to guide the semistructured interviews was developed in Moroccan Arabic, based on a topic guide designed by and used in an earlier study with Turkish elderly people.(73) Our Moroccan version was translated from Dutch into Moroccan Arabic and verified using forward-backward translation procedures (cf. Appendix 5 for Dutch version; also in Hajji 2021 (77)). Prior to the start of the actual study, three pilot test interviews with Moroccan elderly people were conducted in september 2020 in order to identify possible issues with the clarity of the questions and of the concepts used. Afterwards revisions to the topic guide were

made accordingly. From October 2020 until April 2022, the 2 researchers respectively conducted 22 interviews with PICT-negative participants (by HR) and PICT-positive patients (by CB). The eventual interviews were conducted in the participants' native language (mainly Moroccan Arabic), using the same topic guide for both groups, and were audio-recorded. The interviews were then translated into Dutch and subsequently anonymized, analyzed and comprehensively coded in NVIVO, independently by the 2 researchers (CB and HR) using a constant comparative method of qualitative data analysis.(78) Furthermore, after data collection all data was pseudonymized and stored on the hard disks of the 2 researchers and the co-supervisor with access restricted to the participating researchers. The data from the PICT-negative group has already resulted in a forthcoming separate publication.(74) The codes and themes from the previous analysis were reevaluated and reinterpreted in the context of the present comparative research. The data from the PICT-positive group have not been the subject of any previous publication.

4. Ethical approval

Ethical approval was obtained from the Medical Ethics Commission of the University Hospital of Ghent (B.U.N. B143201838280 for the PICT-positive group and B.U.N. B670201942542 for the PICT-negative group).(cf. Appendix 3, for PICT-positives)

C. Results

1. Sociodemographics

Twenty-two PICT-negative, aged 65-90 years (mean 74 years) and ten PICT-positive participants, aged 74-87 years (mean 80.4 years), eventually participated in our exploratory study. Of the initially 31 PICT-negative candidates recruited by different GPs, only twenty-two were eventually interviewed. The other nine dropped out due to lack of time or interest or because they had to be contacted through their children but the latter refused participation for them. Of the PICT-positive candidates, two individuals had given their consent to participate to their GP, but eventually refused participation after having been contacted by the researcher, citing deteriorating health as the main reason. Family members of six PICT-positive participants refused participation of their relative when we contacted them to arrange

	Pict negative (N=22)	**Pict positive (N=10)**
Patient characteristics:		
Age		
65-70	7	0
70-80	8	4
80-90	7	6
Gender		
Male	10	8
Female	12	2
Education		
Secondary school or less	22	9
Beyond Secondary school	0	1
Literacy		
Illiterate	14	3
Literate (at least Arabic)	5	5
No answer provided	3	2
Marital Status		
Married	16	6
Divorced	1	2 (both remarried)
Widowed	5	2 (both remarried)
Remarried	unknown	4
Professional Category		
Manual Laborer	10	8
Employee	2	1
Housewife	10	1
Living situation		
Alone	5	2
With partner	9	3
With children	8	5
Time in Belgium		
>50 years	10	9
<50 years	12	1
Number of children		
<6 children	18	5
>6 children	4	5
View on current health		
Good health	15	4
Deteriorating or bad	2	5
Neither	5	1
GP		
Belgian	13	5
Moroccan background	6	5
Other	3	0

Table 1. Sociodemographic characteristics of participants

for an interview, citing fear for covid-contamination, lack of interest and physical and mental unfitness due to advanced disease as main reasons. All respondents were first generation immigrants to Belgium. More than half of the PICT-negative and nearly one third of the PICT-positive participants were illiterate.(Table 1)

We will first list a number of similar findings for both groups of interviewees and subsequently point out some of the differences between them.

2. Similarities

1. *No previous knowledge of ACP*

In general we found knowledge of the term "advance care planning" to be fully lacking among participants. None of the interviewees in neither the PICT-negative nor the PICT-positive group had ever heard of the concept of ACP before, when explicitly asked about it using the most commonly used terminology in both Dutch ('*Vroegtijdige Zorgplanning'*) and French ('*Projet de soins anticipés et personnalisés'* or '*déclarations anticipées'*).

"No I've never heard about this planning before."
(PICT-negative participant 8, 68-year-old man)
"*I don't know it. Hand me those letters … Could you write it down please? What is it about? What is it?"* (*PICT- positive participant 9, 79-year-old man*)
"*No, I'm not aware of it" (PICT-positive participant 6, 80-year-old man)*

Only one PICT-negative patient claimed he had already heard of certain elements pertaining to ACP, saying he was aware of the possibility of granting authority to someone to act on one's behalf concerning medical issues and that he also knew of advance declarations to refuse certain treatments.

"I know that someone who's still lucid but severely ill, can choose not to be treated anymore by signing a certain paper. But the planning you've just talked about, I don't [know it]"
(PICT-negative participant 9, 67-year-old man)

2. *Limited concerns and communication about future care*

Around half of the patients in both groups said that they hadn't really thought about their future nor their desires concerning future care and planning thereof. Having confidence in the help from family members and a firmly held belief that only God knows what the future will bring, were the most often cited reasons for the lack of reflection on future care.

"No, I don't give it too much thought. My children visit me every day. When I'm very ill, I just call my daughter or one of my other children to come over. If they're unable to help me, I can always call on my neighbors." (PICT-negative participant 13, 84-year-old woman)
"We're muslims, we believe in destiny, coming from God. So we don't have any reason to be afraid." (PICT-negative participant 11, 72-year-old man)
"No, I'm at ease. I have a good wife at my side. I'm at ease. She takes care of me (...) Only God knows the future. (...) Why should I worry? I'm a muslim. I pray. I praise God." (PICT-positive participant 9, 79-year-old man)

“I don’t have any worries. My children are good with me and we don’t have any problems. None whatsoever. God be praised. Why should I worry?” (PICT-positive participant 2, 72-year-old woman)

Another often cited reason for not having concerns about future care, mentioned not only by PICT-negative but also by PICT-positive participants was the perception of still being in good health. At least two PICT-positive participants thus seemed to be either downplaying or oblivious to the severity of their medical condition and to the eventual inevitability of additional care in the future.

“God be praised, I don’t think about it [i.e. getting appropriate care in the future]. I only think about the fact I’m in good health.” (PICT-positive participant 4, 87-year-old man)
“Why should I get care? I’m not ill. I can’t see why I should get care. Why should I get care?” (PICT-positive participant 6, 80-year-old man)

The other half of the interviewees did admit to reflecting at least sometimes about their health status and future care, but among them only a few voiced actual concern about their future and about being able to obtain the necessary medical care in the future.

“I just think about these things. About how my health status will be in the future. About how I will be.” (PICT-negative participant 20, 66-year-old woman)
“Because of my age. I think about it, because I’m old. When you’re old, you’re always in need of some kind of treatment. - Don’t you worry? - No, God be praised.” (PICT-positive participant 4, 87-year-old-man)
“Worried? Well you know how it goes. One thinks. If I’ll fall again, who’s going to be there for me? (...) You can’t restore what’s deteriorating. That hurts.” (PICT-positive participant 5, 75-year-old man, living alone)

While roughly half of the participants in both groups explicitly confirmed to have thought about future care, only a few of them stated that they had talked about their concerns with relatives, yet most hadn’t spoken neither with family nor with care providers.

“Yes, always [I think about it]. Ask my husband (...) About what I’ll do when I won’t be able to move anymore. I think about everything.”(PICT-negative participant 16, 83-year-old woman).
“It’s a difficult thought. It’s necessary to talk about it, but still it’s difficult to speak about it or hear about it. It’s a bit frightening.” (PICT-negative participant 21, 68-year-old woman)
“I’m thinking about it. But who’s there to think with me? What are they to say? Nobody will say anything.” (PICT-positive participant 5, 75-year-old man)

3. *Informal discussions on and arrangements for ACP matters*

While many participants had explicitly denied having thought about their future, further questioning revealed that most interviewees in both groups had nevertheless already had limited preliminary discussions with their relatives in which they had communicated certain preferences for the future and many of them had even made certain arrangements, thus informally engaging in the planning of matters pertaining to ACP.

“No, I don’t have any documents. But I talk and by that I mean with my wife and my children.” (PICT-positive participant 8, 74-year-old man).

The limited discussions and arrangements made, mainly concerned taking on insurance for the repatriation of their bodily remains to Morocco after death as well as the prefered burial location. Another topic already discussed by participants of both groups, albeit to a lesser extent, were nursing homes.

"Yes, they know about this. When we're on holiday in Morocco and we're visiting my parents' grave, I always tell them 'Look, this is my spot. Here I want to be buried when I die. Nobody should take this away from me!'" (PICT-negative participant, 83-year-old man, about having talked to his children).
"I've spoken about this with my wife and children. Both my wife and I have done this [i.e. got an insurance]" (PICT-positive participant 6, 80-year-old man)
"We talked about burial when we were in Morocco. - Did you speak with your children? - Yes." (PICT-positive participant 10, 82-year-old man)

"I laugh about it with my husband. I always say that if no one will support me, I'll just go to a nursing home."(PICT-negative participant 5, 68-year-old woman)

4. *Common barriers to ACP participation*

    a. Lack of knowledge

As mentioned earlier, none of the participants were familiar with the terminology or concept of ACP. This lack of knowledge was mentioned by participants from both groups as a reason why ACP had never been systematically discussed before with family or care providers.

"The thought would have never occured to me, to talk about this with my family doctor. Never. Because I didn't know that I should talk to my doctor or he with me about such things." (PICT-positive participant 8, 74 year-old man).
"These are new concepts for us. We didn't know this." (PICT-negative participant 15, 83-year-old man)

    b. Lack of initiative by the physician

Closely related to the previous barrier is the observation that not only in the group of PICT-negative interviewees but more remarkably also among the PICT-positive ones, the physician had never attempted to start a conversation on ACP.

"He never referred to this subject and I never started talking about it myself" (PICT-negative participant 19, 70-year-old woman)
"Have you already discussed these subjects with for example doctor R.? - We've never talked like this. No, we've never really spoken with doctor R. about this. When he comes we just talk about covid." (PICT-positive participant 9, 79-year-old man, with Moroccan GP)

Some of the interviewees indicated with varying degrees of regret that they would have wanted to have been able to have such a conversation with their respective doctors.

"Yes I feel a need [to talk about these things]. I need that, but the doctor has never started [talking about it] yet." (PICT-positive participant 6, 80-year-old man)

"My family doctor has never told me about this and actually it's up to him to speak about it. Not me. (...) For the question had never occurred to me. That I would speak with my family doctor. Normally it's my doctor who should speak with me, not I [with him]." (PICT-positive participant 8, 74-year-old man)

c. Role of the family

Another recurrent observation is that many of the participants from both groups hope for and count on their family to take care of them and to make all the necessary decisions in the future for them, once their health further deteriorates and they themselves become physically and/or mentally unfit to do so anymore.

"I'm counting on the support of my children. In our culture we keep supporting our parents. I myself also supported my mother until her death."(PICT-negative participant 19, 70-year-old woman).
"But if that time comes, I'm counting on my children. I don't think they'll abandon me."(PICT-negative participant 22, 71 year-old woman)
"If my wife goes away, I'll have my children and I have grandchildren. I have a lot. Everything I have is good. Everyone will take care of me." (PICT-positive participant 4, 87-year-old man)

Not only among PICT-negative interviewees but also among the PICT-positive patients with poorer health condition, many assumed the family would know what's best for them and how to best honor their wishes, without needing to discuss these matters explicitly with them or to resort to more formal ACP talks resulting in written documents.

"If I ever find myself in a difficult situation, then those who are close to me will have to make a decision … but me making a decision now or leaving a message, no." (PICT-negative participant 11, 72-year-old man)
"Have you spoken with your children about this? - No, without me talking to them. My children know everything. - And you're not going to talk with them about it? - No, no (...) My children are responsible for me. If a severe illness occurs (...) If I become ill and fall, then they can take me to the hospital if they want to. The hospital is an option. Without me telling them." (PICT-positive participant 4, 87-year-old man)
"I have my family. My family has to protect me. - And they know what to do? - But of course. (...) I could give her [i.e. his wife] the authorization so that she'll be the one taking decisions. If she wants to take care of me I'm ok with that, if she doesn't want to care for me, she's my wife. She's responsible for me (...) but me saying 'I want such and such' … no, I won't do that." (PICT-positive participant 7, 79 year-old man)

Another obstacle to speaking about matters pertaining to ACP, mentioned by several interviewees was a desire not to cause sorrow and suffering to loved ones.

"If I announce my wishes now to my children, I'll cause them worries and stress. They'll start crying and will ask why I've started on this." (PICT-negative participant 7, 84-year-old man)
"To have something written down on what'll happen in the future I can not do, only God is knowledgeable about that and I might, I think, cause suffering to my wife and my son, I think."(PICT-positive participant 9, 79-year-old man)

Family members also seemed to exert a more direct influence in impeding ACP, as some of the participants expressed a certain hesitancy to start conversations concerning EOL care for fear of reactions of disapproval and even ridicule from their loved ones:

"When my children will come, I'll tell them a certain mister came by and told me such and so, they'll tell me 'We have everything under control'. [So] why should I talk to them?" (PICT-positive participant 4, 87-year-old man).
"What should I say? I don't want them to laugh at me" (PICT-negative participant 5, 68-year-old woman)
"No we haven't spoken about that yet. She'll [i.e. his wife] come [after the interview] and ask me 'What did you talk about?' and if I'd explain it to her, she will say 'Okay, and me? What am I still here for?'" (PICT-positive participant 9, 79-year-old man)

At least one participant mentioned the lack of interest on the part of the family as an obstacle for talking about these matters.

"Have you spoken with your children? - They don't want to. - How's that, they don't want to? - They don't bother to know what you're saying." (PICT-positive participant 5, 76 year-old man)

d. Conviction that only God has knowledge of and control over the future

Many interviewees from both groups claimed to be rather reluctant to think or plan too much in advance, again citing the belief that only God knows what the future will bring and only He has control over what will eventually happen.

"Well of course, we are believers and we believe that God does as He pleases, so I've actually never thought about what I would do if I'd become severely ill." (PICT-negative participant 1, 69-year-old woman)
"I think that everything is in the hands of God, period. I can't limit my options in advance, the doctors and my family will have to make the decision themselves" (PICT-negative participant 11, 72-year-old man)
"We can't just presume things … we have to talk about things when they really happen, only God knows what's in store" (PICT-positive participant 4, 87-year-old man)
"For me this project is difficult. Why? Because we are Muslims. And everything is in God's hands. Death is up to God. If I perish, that's up to God. Everything is up to God. We have to be patient. Should I decide whether to go somewhere when I don't know how things will be for me? (...) No, no, no. I respect my faith. What God says." (PICT-positive participant 9, 79 year-old-man)

e. Lack of perceived current need for medical assistance

Not currently experiencing physical troubles and no present need for extensive care or treatment, was also often cited as a reason for not engaging in advance care conversations, not just within the PICT-negative group but also among the PICT-positive participants.

"I think this should be discussed at an appropriate moment. That is when one doesn't feel well or when one is severely ill. For example, someone who knows he's suffering from a terminal illness and only has a few years to live, he or she should talk about it with his children and start ACP with their family doctor. (...) I don't think it's a taboo, nor that we don't

want this [i.e. ACP], I just think the right moment hasn't come yet."(PICT-negative participant 9, 67-year-old man).
"Talking about the hospital if you're not hospitalized? Talking about something which isn't there? That's impossible. (...) What should I tell them? I'm in good health. What should I tell them?
(...) Frankly, if I become ill, I'll go to the hospital and I'll talk to my children, my daughter and my son. - At that moment? - At that moment."(PICT-positive participant 6, 80-year-old man)

"We don't talk about that, because I'm still doing fine." (PICT-positive participant 4, 87-year-old man)

3. Differences

1. Willingness to formalize

After having received a more thorough explanation of what ACP entailed and after having been given specific real life examples to illustrate it further, the majority of participants from the PICT-negative group tended to view ACP as something rather useful.

"Yes, that's a good thing. To think now. (...) It's indeed better to be prepared and not to wait until something happens." (PICT-negative participant 10, 65-year-old woman)
"I think it's a good thing. It's better to think about it when you're still fully healthy, for, when you grow old, you'll undoubtedly need help."(PICT-negative participant 20, 66-year-old woman)

The mere fact that interviews were conducted, during which people received information on the existence of advance care planning and its different aspects, appeared to trigger people and to facilitate further discussion. Most of the participants in the PICT-negative group expressed enthusiasm about ACP and confirmed they certainly wanted to carry on the conversation with family members and/or their family doctor. With most of them even intending to make an appointment with their family doctor to discuss their wishes further.

"I think it's a very good thing. We're already ill and the fact we can talk about these matters with the family doctor is a good thing. We should talk about it with the family doctor. I think this is a very good idea" (PICT-negative participant 18, 72-year-old woman)

The PICT-positive interviewees on the other hand tended to be more reticent or at least more ambiguous when asked whether they thought the existence of ACP was useful. Among the many reasons that participants cited to argue why they failed to see any use, were extensive reliance on family and/or God, the belief ACP could only cause difficult situations and the misperception that eventually everything is already taken care of by the health care system anyway.

"I don't have an opinion about it. I have my children. That's all. We don't have problems."(PICT-positive participant, 72-year-old-woman)
"No, it has no advantage. What would the advantage be? To hurt others?" (PICT-positive participant 9, 79-year-old man)

"Can't you see some benefit of making clear to others what you want? - No. - Why not? - That's how I think, I don't want to get into a discussion with others." (Participant 10, 82-year-old man)
"Registering something in advance? We have that in Islam, yes, but here … it's all arranged for by my brothers [i.e. the Belgians] and my doctor, without me having to write something down. They take care of me and give me my medication. They give me everything." (PICT-positive participant 4, 87-year-old man)

Towards the end of the interviews some of the elders in this group cautiously did admit they saw some kind of benefit in anticipatory conversations and planning.

"It is useful. Some will be happy to be able to register their wishes. - Is it good to talk about this? - Yes, it is good. So we can better understand each other." (PICT-positive participant 4, 87-year-old man).
"It is useful. It's better not to keep the family suffering." (PICT-positive participant 3, 80-year-old man, speaking in the context of registering desire not to have prolonged useless hospital admissions)
"Do you think talking about these things is useful? - Most certainly, it is useful!" (PICT-positive participant 2, 72-year-old woman)

Moreover, when asked if they would now talk to others about ACP, even among the PICT-positive participants most individuals politely expressed their readiness and even eagerness to continue the conversation with their family and/or doctor. However, when they were asked what exactly they wanted to pick up with their family doctor only a few could actually specify this.

"Now that you've been here, I have to talk to them [i.e. my children]. [Besides] they will ask me questions, because they're aware that you've come to ask me questions. -
Are you going to speak about this with your doctor? - Yes, I'll tell him. He will ask me. And if he doesn't, I will tell him, when he comes. (...) - What are you going to tell him? - The doctor [i.e. the researcher] came to visit me and told me such and so. If I become ill, I'll stay at home and die as I want, or if I become severely ill, they'll have to take me to the hospital." (PICT-positive participant 4, 87-year-old man)

"I will speak with him [i.e. the GP]. I have never spoken about this with him, but I will speak to him about this. If I become ill, I'll stay at home, with the medication he'll give me. Until our Lord decides to take my soul away. But if there's a cure, I'd desire that [i.e. going to the hospital]. But if I'm to die, I'll stay at home until I die." (PICT-positive participant 6, 80 year-old man).

However, most participants replied in a rather vague or indifferent way.

"I'll talk to him. I'll tell him. - Can you say what exactly? - No, he'll help me with his ideas. And I'll talk to him and tell him things just like you told me just now." (PICT-positive participant 3, 80-year-old man)
"Yes I want to talk to him. - About what exactly? - I'd like to talk about the things you've asked me." (PICT-positive participant 5, 76-year-old man)
"I'm prepared to speak to him. Why not? It's not bad. (...) I'll talk to him about it for sure. (...) About what exactly? - About this. - Is there an important issue for you? - No." (PICT-positive participant 9, 79-year-old man)

Moreover, it seemed that many of the PICT-positive participants had troubles grasping the ACP-concept - even when it had been reexplained to them several times. In the end, several of the participants said they were willing to talk about matters pertaining to ACP even with the doctor, but were more reluctant when asked if they would want a more formalized ACP by having for example some of their desires for the future written down.

"Maybe it's great, but for me it's difficult. To write such and so. [About] what will be. (...) No you're right, at an older age one should think. (...) But I can't say I'll write it down. I'm not going to lie to you and say 'Yes, I'm going to do it.'" (PICT-positive participant 9, 79-year-old man)
"No, I won't write something down. I won't do anything. I'm leaving it like this. Why? Because those who ask after you [know everything already]" (PICT-positive participant 3, 80 year-old man)
"If I'm severely ill, I'll go to the hospital. That's what I'm going to register. But to say I want this or that [for the future] … God only knows this, I can't do that." (PICT-positive participant 4, 87-year-old man, apparently not fully grasping ACP)

2. Marriage as a guarantee of future care

Some of the PICT-positive participants had remarried at an advanced age to wives who were considerably younger than themselves. One of the PICT-positive participants admitted that he had done this specifically in order to have someone near to care for him, after his first wife had passed away several years ago.

"[Ask for] Help? Look, I've remarried and I'm expecting to bring my wife here." (PICT-positive Participant 5, 75-year-old man)

This practice wasn't observed, nor referred to in the PICT-negative group.

3. Financial barriers

While in the PICT-negative group none of the participants mentioned the role of financial status in their take on ACP, several PICT-positive participants insinuated that financial motives played some kind of role in their lack of planning in advance and/or in their lack of enthusiasm for ACP. When one participant was asked whether he thought it would be useful to communicate his wishes for future care in advance, he replied:

"Who's going to take care of me? I don't have any money for them [i.e. elderly care professionals] to take care of me. I don't have money. Why would they care for me? … I have a wife who takes care of me. (...) If I could get all necessary medication in Morocco, I would go there, so that, when I die, I can die there … but I won't lie to you, in all honesty, I just don't have the means. " (PICT-positive participant 9, 79-year-old man)

4. Different preferences concerning future care: *Nursing homes*

While most participants in both groups said they preferred to stay at home and to be cared for by their family instead of eventually moving to a nursing home, we did observe a subtle difference in their willingness to consider moving to nursing homes if need be. Within the

PICT-negative group several participants said they found nursing homes rather useful, especially for those elderly persons who are alone and have no family members or close friends to rely on.

"I think it's necessary for someone who can't take care of himself and lives alone without somebody to help him. Why shouldn't he go to a place where there are other elderly people present and where they can support him and help him to dress?" (PICT negative participant 3, 68-year-old man)
"For someone who's all alone, this is a good thing. Praise God there is a nursing home that can put these people up." (PICT-negative participant 1, 69-year-old woman)

Some of the PICT-negative participants said they had considered and, upon taking into account their own particular situation, even prefered to voluntarily move to a nursing home, for example in order to avoid being a burden on family members or in order not to be alone.

"Otherwise I'll be at home all by myself. I will experience more stress."(PICT-negative participant 10, 65-year old woman)
"My children don't have time for this. If I become really dependent, say for going to the toilet etc., then I see moving to a nursing home as the only solution." (PICT-negative participant 8, 87-year-old man)
"If I would become needy, then I myself as well would say 'Bring me to a nursing home'." (PICT-negative participant 15, 83-year-old man)

PICT-positive participants on the other hand generally expressed more negative views, with most of the interviewees stating they didn't want to move to a nursing home and that they were quite confident that their family, in keeping with cultural traditions, would (continue to) take care of them, making such a move practically unnecessary. Moving to a nursing home was perceived as an undesirable last resort, only involuntarily imposed, with several of the participants saying they would rather die than end up there.

"You think I'll go to a nursing home, if I become ill? No, no, no. (...) It's as if you're dead. I'll stay at home until I die. But if they take me there, then I'll die. To take me there, while I have 6 children? Who are quite well off as well? No. (...) People who do not have loved ones who will take them in, go there. It's my right, but I won't go to a nursing home, God willing. I'll live with my children until I die " (PICT-positive participant 4, 87-year-old man)
"If my children can't take care of me at home, they'll have to take me there. I have no choice, I'll be forced to. But in our tradition, the children usually stay with their parents." (PICT-positive participant 6, 80 year-old man)
"No. It's a prison. I want my house. I want to keep living in my own house. I won't go to a nursing home. I prefer death." (PICT-positive participant 10, 82-year-old man)

Among PICT-negative patients around a quarter of interviewees said they had already spoken to someone about moving to a nursing home, whereas in the PICT-positive group only one admitted to have actually already talked about it with someone.

Barriers	**PICT Neg**	**PICT Pos**
Knowledge		
Lacking knowledge (explicitly mentioned as barrier)	4/22	4/10
Religion		
Future is God's/ trust in God	8/22	4/10
It's not in our (religious) traditions	3/22	3/10
ACP is against Islam	1/22	1/10
No perceived current need for ACP	10/22	6/10
Dreaming of return to home-country	6/22	1/10
Family		
Assumption that family will take care and knows what to do	13/22	6/10
Not prepared to talk/ listen/ not interested	0/22	2/10
Fear children won't take them serious	2/22	1/10
Children too busy	3/22	1/10
Desire not to hurt or cause strife	4/22	2/10
Family Doctor		
Never talked about it	7/22	6/10
Illiteracy	4/22	0/10
Financial situation	0/22	2/10
No time / opportunity	3/22	1/10
Convinced others will decide anyway	3/22	2/10

Table 2. Often mentioned barriers in ACP uptake

D. Discussion

1. Summary of the main findings

The interviews we've conducted revealed a number of similarities and differences between PICT-negative and PICT-positive elders of Moroccan origin in their knowledge, visions and attitudes concerning ACP.

Among the similarities was the observation that knowledge of the ACP concept and terminology was lacking among the interviewees from both groups and that communication concerning health concerns and future care was rather limited, despite the fact that the vast majority of participants claimed they were comfortable with talking about illness, death and EOL decisions. Nevertheless a considerable number of participants in both groups had already informally engaged in discussions (with relatives) and arrangements of matters pertaining to ACP, mainly regarding repatriation and burial after death. In both groups the discussions had almost exclusively taken place between the patient and his family members. For some participants in the PICT-positive group informally planning of care had taken the form of remarrying to a younger spouse.

Quite surprisingly not merely among PICT-negative, but even among seriously ill PICT-positive patients, more formal conversations about ACP with the family physician had never taken place. Upon receiving information about ACP, however, most participants of both groups showed a readiness to engage in conversations about ACP with their relatives and/or their GP. Furthermore, several PICT-negative interviewees expressed willingness to participate in more formal ACP. Contrastingly PICT-positive respondents voiced more doubts concerning its usefulness and were more reluctant to engage in a formalized kind of ACP, especially if it implied having preferences written down in documents.

Most commonly mentioned barriers to participation in ACP were a lack of knowledge of its existence, a lack of initiative to start talks and provide information on ACP by the family doctor and reliance by patients on family for future care and decision making. A majority of the participants stated they expected family members, especially children, to support them and to take care of them when they would become needy, even when most of them had never discussed this with them. Firmly putting their trust in cultural practices and religious values in which children are expected to care for their aging and ailing parents and if necessary even to take them in.

A considerable number of participants claimed they had full faith in God and were therefore not very concerned with the planning of care in advance, yet only two participants thought ACP went against their islamic beliefs. Also often cited as barriers were the desire not to cause sorrow to and strife among family members, and the perception of an absence of a need for medical assistance. The latter not only among PICT-negative participants, but more strikingly also among ill PICT-positive interviewees.

None of the PICT-negative interviewees mentioned financial difficulties as a reason why they were reluctant to participate. In the PICT-positive group at least one participant stated explicitly that his financial situation didn't allow for much planning.

In general PICT-negative interviewees held a more open view on eventually moving to a nursing home. PICT-positive participants tended to be against the idea of ever being admitted to a nursing home.

2. Interpretation of the results

1. Similarities

a. No previous knowledge of ACP

Our observation that both PICT-negative and PICT-positive interviewees were unfamiliar with ACP is in line with observations from previous research conducted both in the general population and among minority groups around the world. A review article by Kermel-Schiffman and Werner from 2017 that focused on knowledge of ACP among both patients and health care professionals found that in more than half of the studies it had reviewed, participants had only low to moderate levels of knowledge, with most people having only partial knowledge of certain aspects of ACP at best and this despite more and more efforts to make people more familiar with ACP.(3) Even among patients with life-limiting illnesses knowledge of ACP was still often lacking.(3, 79-81) The fact there is a near total lack of knowledge of more formal ACP among our participants is consistent with findings from other studies that show proper knowledge of ACP is even more absent or vastly insufficient among minority groups in comparison with the general population.(38) Studies in the US have demonstrated that awareness among Afro-Americans (AA), Asians and Hispanics regarding ACP and EOL decision making options was limited and that there existed a lot of misconceptions.(33, 43-47) Similar findings were reported in studies from the UK, Australia, New Zealand.(33, 40-42) Factors that play into this are lower health literacy, language barriers and a dearth of specifically tailored information for these minority groups provided by health care providers and health authorities.(33) With increasing age, education and income, awareness of ACP also increased.(38) The observation that even within the PICT-positive group none of the participants was familiar with the terminology nor the concept of ACP, should not come as a complete surprise, given the fact that even within the general population awareness is low and given the observation that migrants of Moroccan origin generally tend to have less access to the health care system and lack a thorough knowledge of the health system, due to language barriers, low levels of education, low health literacy, financial constraints and a failure to meet religious and cultural needs by Belgian elderly care services.(71)

b. Limited reflection and communication on future care

Although nearly all of the interviewees in our study claimed not to experience any difficulties reflecting about or engaging in conversations about EOL care, illness and death, and even though a good number of them had already thought about their future care, it's surprising to see that only a very limited number of them had actually talked openly with others about this topic, and if so mainly with family members. This is in line with the findings of a study conducted in Northern Ireland among members of the general public which found that some of their respondents had already thought about future care, but were majoritarily reluctant to take up the subject with their loved ones or health care providers, mainly for fear of causing upset or distress by talking about their own mortality.(82) Earlier studies have identified the natural human reluctance to explore death and dying as a reason for the lack of discussion about EOL care.(83) However, in our sample participants explicitly stated they had no problems talking about illness and dying. Not wanting to cause distress to relatives or to oneself therefore only offers a partial explanation at best. Rather, the reason such talks did not often occur might be that within Moroccan society there is a strong yet often implicit imperative of filial responsibility, based on traditions and religious beliefs about caring for

parents.(84) Children are taught and expected to help and stand by their parents once they grow old and become needy of help and they are presumed to be aware of this.(71, 84) Although this practice often becomes more and more difficult to maintain nowadays within the context and mind-set of Western society, not living up to this expectation is still experienced by both the elders as well as their children as a dishonorable failure that risks entailing gossip from the community.(84) Everyone within the community knows it's a quintessential norm within the community to care for one's parents and having to solicit external help is perceived as disgraceful.(70-71, 84) Thus it seems more plausible that for Moroccan elderly people, having to voice concerns about future care is considered to be rather superfluous, inappropriate and even shameful since children are presumed to already know what's expected of them without the need to further explicitly talk about it.

c. Informal discussions on and arrangements for ACP matters

Although none of the interviewees from either group had ever heard of the most currently used terminology for advance care planning and although we observed a total lack of engaging in ACP conversations with physicians, not to mention having completed formal ACP documents, we found that several interviewees had nevertheless already had informal discussions with family members on matters pertaining to ACP. We also noticed that most of the interviewees had already made certain arrangements concerning ACP matters. Even when minority members are aware of ACP, it's observed that they are more likely to only have had informal discussions on EOL and ACP with relatives rather than formal documentation.(46) Conceptual failure to appreciate certain cultural values and practices that grant primordial importance to the family in care and decision making, might prevent these patients from going beyond informal discussions on ACP. To counter this McDermott and Selman suggested that formal ACP processes needed to be evaluated for culture sensitivity, as some elements of formal ACP tend to be culturally unacceptable to various minority groups whereas informal, discussion-based ACP may be more acceptable in some groups.(75)

d. Barriers common to both groups

Lack of knowledge

Lack of knowledge and awareness of ACP was often cited as a reason why ACP had not been undertaken so far.(38) The fact that members of this minority group had no previous knowledge of ACP should come as no surprise as even in the general population unfamiliarity with ACP is still very common and constitutes one of the main barriers to ACP uptake.(3, 38, 85-86) Higher levels of education and health literacy have been linked with greater ACP awareness. Generally, among minorities, who most often have lower levels of health literacy, even lower degrees in uptake of ACP due to unawareness are observed.(38, 45, 55) For the Belgian context it has been described that elderly migrants are generally not very aware of the different care options as they are not familiar with existing care structures.(71) In our sample the vast majority of participants from both groups had lower education levels and many of them were even illiterate, as is the case for a great many elderly immigrants of Moroccan origin in Belgium.(71, 88) Directed culturally sensitive educational interventions have been shown to increase awareness and uptake of ACP,(38) but at present no such interventions have been specifically developed for migrants in Belgium.(17)

Role of the GP

As the main primary health care providers with usually the closest relationship with patients, general practitioners are crucial in raising awareness of ACP among patients. However, GPs often still refrain from engaging in ACP conversations with their patients, even when the latter are suffering from life-limiting chronic illnesses.(5, 17, 34) Often cited reasons by GPs are a sense of lacking the necessary skills to discuss advance care with their patients, lacking knowledge and finding it difficult to determine the right moment to initiate ACP talks.(17) In the context of diversity GPs tend to find it even more difficult and are even more reluctant to initiate talks.(87) Research has shown that certain minorities consistently experience poorer communication quality, information-giving, patient participation, and participatory decision-making.(55, 89) Doctors mainly struggle with language barriers, which makes it harder for patients to fully grasp certain medical terminology, but doctors also lack the necessary familiarity with a diversity of cultural and religious values and norms to properly connect and communicate with patients from a myriad of different backgrounds.(87) In our sample a considerable number of patients had a doctor of Moroccan origin. Yet, absence of linguistic barriers and of unfamiliarity with the culture and the religious beliefs of the interviewees did in this case not entail higher ACP uptake. None of the GPs had ever initiated talks, not even after people had become palliative, which means it remains necessary to raise awareness among GPs of the importance of ACP and to train and encourage them to engage more in ACP talks.

Central role of the family

Moroccan society is a traditional collective society centered around the family. Consequently, care responsbility, including EOL decision making, lies to a large extent in the hands of the family and/or the social network.(71, 84) As international research has shown, collectivistic family-centered values have an enormous influence on ACP engagement among ethnic minorities.(38) In our sample a majority of participants voiced hopes and often even confidence that their family would take care of them as the traditional societal imperative of filial responsibility required them to do.(84) Nevertheless some participants, mainly the PICT-negative ones, did indicate they weren't fully sure this help would eventually materialize given the fact they were now living in a different society and their children had plenty of other occupations and problems they had to attend to. The assumption that children will take good care of their parents and that what good care implies, is obvious, is deeply ingrained in Moroccan society, plausibly leading many of the participants not to bother to engage in lengthy EOL discussions with their relatives.(71, 84) Research among African Americans resulted in similar findings, with participants stating that they trusted their families to make the medical decisions and that they felt certain that their families knew what end-of-life treatments they wanted, even though they had never actually discussed their end-of-life preferences with family members.(55, 90) Against this background, it's also understandable that some of our interviewees indicated that their family members wouldn't allow ACP, claiming it would make them feel as if they had failed or would even cause them sorrow. Research has indeed demonstrated that in the majority of cases close relatives actually do take up the care for the patient, in accordance with the societal imperative of filial responsibility, but sometimes also driven by the fear of getting stigmatized by the community if they wouldn't care for their parents or even just get external professional help. (70-72)

God is in control

Several respondents from both groups indicated they were reluctant to dwell too much on the future and to plan in advance, claiming that in the end only God had control

over their future and that they disapproved of merely conjecturing. Previous research among minorities has already demonstrated that ACP uptake tends to be lower as religiosity and positive spiritual coping increases.(33, 38, 62) Within many minorities God is seen as the sole controller of physical and spiritual well-being and of life and death, affecting the extent to which and the way in which EOL decisions are made.(33, 38) As religiosity increases with age, it probably comes as no surprise that especially the on average older PICT-positive respondents were more reluctant to engage. A previous study among healthy Turkish elderly individuals in Belgium found that only a very small number of participants opposed ACP and proactive decision making, based on their belief that only God knows and controls the future.(73) However, in an earlier study among non-palliative elderly Moroccans, predominantly aged between 50 and 65 years, several respondents had also indicated they were reluctant to think, talk and plan about the future since it was beyond their control and completely in the hands of God.(84)

Lack of urgency

A great number of participants from both groups stated that they had little real interest in ACP for the time being, since they felt they weren't currently experiencing any health issues. Several studies have reported an association between health status and the completion of ACP, with being in good health constituting a major barrier to ACP uptake and with ACP discussions being more often reactive rather than pre-emptive.(39, 85-86, 91) Participants often think ACP should be undertaken when one is very ill or diagnosed with a life-limiting illness and not when one is still young or healthy and when there's still plenty of time left.(43, 85-86, 92) This was observed for the general population as well as for minority groups.(38, 73) Janssens who focused on Moroccan and Turkish migrants in Antwerp, already observed the very pragmatic *ad hoc* mentality of these migrants of solving health-related problems when they actually occur.(84) Quite remarkably in our study not just the PICT-negative individuals claimed it was too early to start such conversations, but also several ill PICT-positive participants stated that the right time had not come yet and that issues should be discussed when problems actually occur. As mentioned above, some of the PICT-positive interviewees considered themselves to be presently still in good health. Low health literacy and an incorrect diagnostic and prognostic understanding might have contributed to their failure to see the time was now. By comparison, a Canadian study focusing on seriously ill patients at high risk of dying within 6 months found that many participants, even when acknowledging their illness, had indicated the right time for ACP had not yet come and that ACP was still irrelevant to them at that point since they perceived themselves as being too healthy.(93)

2. Differences

a. Willingness to formalize

After having had ACP explained to them, most interviewees from both groups showed a willingness to engage in ACP discussions with family members and even with health care providers. Earlier research found that as age increases and as health deteriorates, patients are more likely to have engaged in ACP.(5, 28, 34) Quite surprisingly, in our sample however PICT-positive participants appeared not only to be not aware of the existence of ACP, but also more reluctant to engage in formal ACP than PICT-negative interviewees. This seemingly contradicts the findings of a recent study in the Netherlands, which found that in the general population acceptance of and engagement in formal ACP apparently increases in line with a growing perception of an approaching end of life.(94) Some of our participants mentioned that they were uncomfortable with writing down decisions for events that hadn't occurred yet, often inferring that only God knows the future. McDermott and Selman described a lower acceptability of formal ACP among seriously ill nonwhite patients in the US, with greater levels of religiosity apparently being a factor in this association.(75) Indeed, overall, patients in our PICT-positive group tended to be older than those in the PICT-negative group and religiosity has been shown to increase with age.(95) An additional explanation would be that, in fact, for many of the seriously ill PICT-positive patients arrangements had already been made, usually with the children or spouses actually already providing the needed care. Thus creating an acceptable modus vivendi in which they knew they could count on their relatives, making any further arrangements redundant or any additional formal ACP superfluous for the time being. In the PICT-negative group however many expected their children to stand by them, but all things considered, they still had to take into account the eventuality of this not happening, making it more enticing for them to also engage in formal ACP.

b. Marriage as guarantee of future care

In both groups participants had had informal discussions about funeral arrangements with family and nearly all of the participants had already taken on insurance for repatriation to the motherland. However, in the PICT-positive group we observed that some participants had resorted to additional forms of informally planned care, namely by remarrying specifically to ensure that future care for them would be guaranteed. A similar observation was reported by Berdai et al. in Moroccan elders with dementia, who in later stages of their illness, as care needs increased, sought more help, which, in order to meet the need for culture sensitivity and financial prudence, was often found by their caregivers outside the classical Belgian professional care services.(72) One of the options consisted of the so-called 'care marriages' that are used as a solution in case a needy father also happens to be widowed.(72) The new marriage enables the patient to stay in his home and relieves the other caregivers of their own care burden.(72) In our sample nearly half of the PICT-positive respondents had younger spouses with one of the participants explicitly stating that he had remarried in order to obtain care. The fact that this practice wasn't reported for PICT-negative patients, might have to do with the fact that they were generally younger and per definition still in better health and far less needy than their PICT-positive counterparts. Thus the need to resort to such desperate arrangements had not yet occurred in this group, just like it hadn't yet in patients newly diagnosed with dementia.(72)

c. Financial barriers

A few of the PICT-positive participants mentioned financial difficulties as an obstacle to ACP. As mentioned before, among minorities precarious financial situations contribute to lower ACP uptake.(50-52, 55) It might be coincidence that none of the PICT-negative patients mentioned financial difficulties as an obstacle, but it might also be due to the fact that these difficulties only become more of an issue as disease progresses and the financial burden of disease becomes bigger and more evident.(71-72)

d. Different future care preferences: Nursing homes

In general, participants of both groups prefered to stay at home if possible. This is reflected in the reality that demand for institutional elderly care by Moroccan migrants is very low. (71-72, 96) Research demonstrated that more than three quarters of elderly migrants in Brussels prefered to be cared for by their children and nearly 90% refused to reside in a retirement home.(71-72, 97) While PICT-negative participants stated that retirement homes could be useful, especially for people with no relatives, and while some of them even stated they had considered eventually moving there, PICT-positive participants held much more negative and even hostile views with some of them claiming they would rather be dead than moving there. The most fundamental reasons for low use of institutional elderly care among Moroccans are issues related to cultural and religious beliefs and practices (71, 98) Moreover, it seems that the discrepancy between what Muslim elderly people find important and what elderly care services and in particular nursing homes can offer, is considerable and increasing as the need for care becomes more intensive.(71, 98) As most of the ill PICT-positive patients in our sample could rely on at least one family member to take care of them, there did not exist a great current need for them to reflect on the eventuality of having to move to a nursing home. Since some of the PICT-negative patients however were living alone and had no one to fall back on, it was obvious that they would be more open to thinking about moving to a nursing home, even if they would actually prefer to stay home as long as possible.

3. Strengths and Limitations

One of the strengths of the present study is the fact that by focusing on a hitherto under researched minority group it offers an insight into their knowledge, visions and attitudes concerning the increasingly inevitabe topic of ACP. Moreover, the interviews were conducted face-to-face by researchers who were familiar with the native language and the cultural context of the interviewees, allowing for a direct and nuanced conversation with the participants who were, unhampered by linguistic or cultural barriers, encouraged to speak freely. The face-to-face interview format also allowed the interviewers to pick up non-verbal behavior and to be prompted by it.

However this research has some limitations as well. Although within the inclusion criteria we attempted to interview as many potential candidates as possible, from as many backgrounds as possible, we were able to only recrute a small number of PICT-positive participants (N = 10). While many potential participants had been proposed to us by their respective family physicians, 6 potential candidates could eventually not be included in our study because the family member we were asked to contact in order to make an appointment for the interview eventually declined. Most often stated reasons for declining were advanced deterioration of mental and physical health to such an extent that being interviewed was considered to be practically impossible and/or undesirable, fear of covid contamination and lack of interest. Of those PICT-positives who did accept to participate the majority (N=8) were men and with the exception of one person none of the participants had enjoyed education beyond secondary school. All of them had a good relation and regular contact with their respective family physicians, which in itself might entail a risk of selection bias leaving out people with suboptimal relationships with their physician. Moreover, for more than half of the PICT-positive participants family members were present in the room, sometimes even interrupting the interview to express their own views, which might have influenced the participants' answers. The fact that in both groups the interviews were conducted by (male) medical doctors and therefore a figure of authority might have further influenced the responses given by the interviewees.

Explaining the concept of ACP proved to be challenging in both the PICT-negative and PICT-positive group, with many of the PICT-positive interviewees not being able to fully grasp the concept, even after extensive explanation using simple language and concrete examples of ACP had been given. In nearly half of the interviews with PICT-positive respondents, either the patient or a family member indicated that the interviewee was now tired, resulting in shorter interviews. Interviewees also tended to be very sensitive to the use of certain terms and ideas such as "future" and "thinking about the future", as if it was taboo. This often resulted in the participants resorting to religious stock formulations and expressions to indicate that they preferred not to go to further into the topic.(84)

E. Conclusion and suggestions for future research

Throughout the interviews it became clear that elderly people of Moroccan origin in Belgium are generally uninformed about and unaware of the concept and terminology of ACP, even after having attained palliative status. Our findings also suggest that once clear and basic, tailored information has been provided to them, most respondents show willingness and eagerness to have ACP and EOL conversations with their family and physicians. In fact a great number of respondents have already informally engaged in talks or arrangements concerning matters of ACP with relatives or close ones. Yet, importantly, our data also seems to suggest that as disease progresses and patients become more seriously ill the willingness to engage in ACP with formal, written documents decreases.

Initiative by GPs to initiate EOL and ACP talks are pivotal in raising awareness and uptake. Our findings suggest however, that even when no linguistic or cultural barriers are present, as we've seen with the patients who had a GP of a Moroccan background, GP initiative remains absent, even when it concerns seriously ill patients. Our research also points out the high expectations elderly people have of their relatives when it comes to care and, as the older adults become more seriously ill, the increasingly central role of the family in actually providing care for them and in eventually making decisions for them. Furthermore insufficient sensitivity of the health care system to religion, culture and financial status plays a role in reluctance to take up ACP.

Therefore we conclude by recommending that more efforts be made by health authorities and care professionals to provide information that is culture and religion sensitive and tailored to the specific context of low educational levels, low health literacy and linguistic barriers within this population. This should be initiated before individuals attain palliative status, when willingness to engage in ACP is seemingly higher. GPs should not merely be more encouraged to raise awareness about ACP, but also be better trained to develop the necessary skills and capacities to be comfortable initiating EOL and ACP conversations with patients of different cultural, linguistic, religious or social backgrounds. Given the important role of the family, especially as the health of the elderly deteriorates, campaigns and interventions to raise awareness and uptake should also target close relatives of these elders and take into account the family-centered models of decision making prevalent within Moroccan tradition.

Future research should focus on exploring the knowledge and perspectives of the children and close relatives of Moroccan elderly individuals concerning ACP and EOL care options. This in order to improve communication with and involvement of close relatives in ACP decision making, and in order to eventually increase uptake among the elderly. It might also be interesting to find out their specific needs, especially in caring for the seriously ill, which might pave the way towards decreasing their care burden. Also much needed is more research that explores the specific barriers experienced by health care providers in the context of diverse populations. Particularly interesting would be to explore the barriers experienced by GPs of a Moroccan background in picking up ACP with their Moroccan patients. Finally, until now research among minorities in Belgium has focused on Turkish and Moroccan migrants. Research among both healthy and seriously ill older adults from other minorities is desirable.

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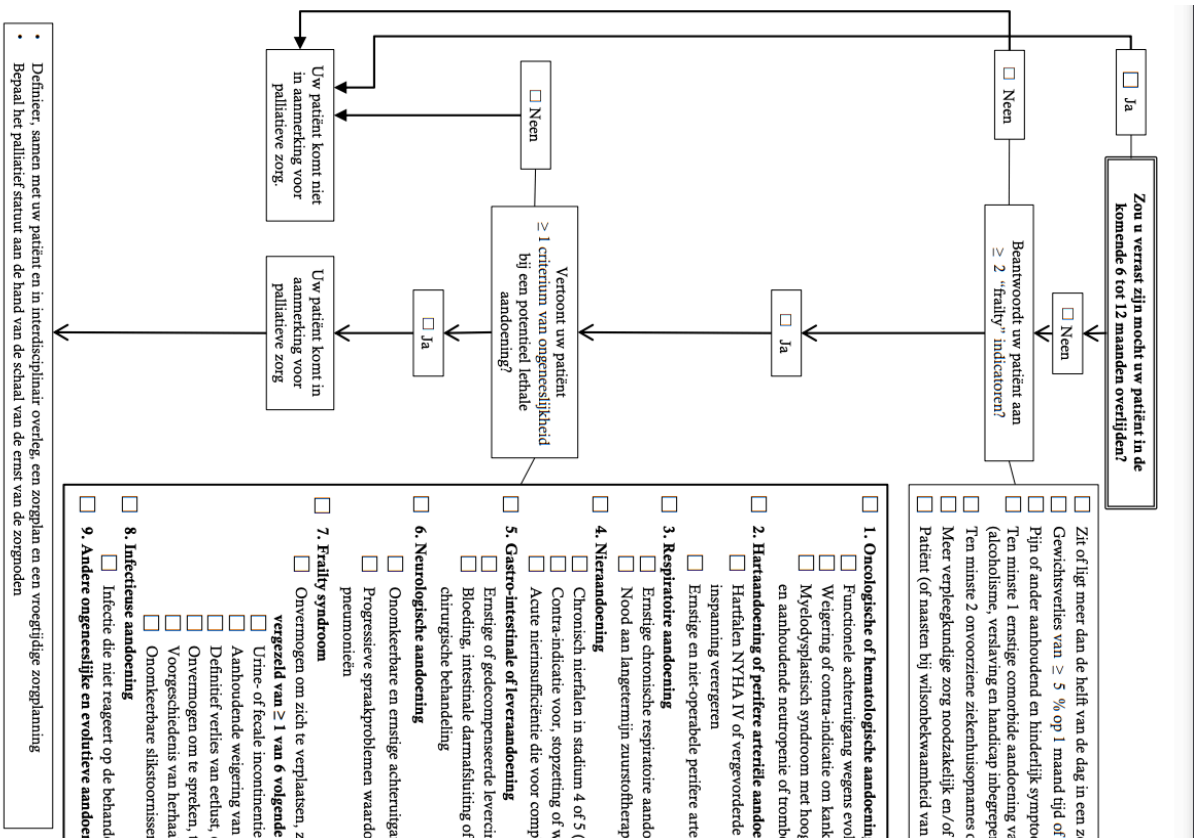
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Appendix 1. Palliative Care Indicator Tool (PICT)



Appendix 2. Study protocol for PICT-positive group

INLEIDING:
UIT INTERNATIONAAL ONDERZOEK BLIJKT DAT ETNISCHE MINDERHEDEN VAAK MINDER KENNIS HEBBEN OVER VROEGTIJDIGE ZORGPLANNING (VZP) EN IN VERGELIJKING MET DE ALGEMENE BEVOLKING HIER OOK MINDER GEBRUIK VAN MAKEN, TERWIJL IS AANGETOOND DAT VZP WEL LEIDT TOT EEN SIGNIFICANT BETERE LEVENSKWALITEIT BIJ HET LEVENSEINDE. ONDERZOEK NAAR DE TOEPASSING VAN VZP IN BELGIË BIJ PATIËNTEN VAN MAROKKAANSE ORIGINE ONTBREEKT NAGENOEG VOLLEDIG. DE VOORGESTELDE MASTERPROEF WIL DAAROM EEN KWALITATIEF ONDERZOEK AAN DE HAND VAN SEMI-GESTRUCTUREERDE INTERVIEWS UITVOEREN MET ALS DOEL DE KENNIS, ERVARINGEN, VISIE, VOORKEUREN EN ATTITUDES INZAKE VROEGTIJDIGE ZORGPLANNING (VZP) IN KAART TE BRENGEN EN DIT SPECIFIEK BIJ DIE OUDEREN VAN MAROKKAANSE ORIGINE DIE VOLGENS DE IDENTIFICATIESCHAAL VAN DE PALLIATIEVE PATIËNT (PALLIATIVE CARE INDICATOR TOOL, PICT) REEDS IN AANMERKING KOMEN VOOR PALLIATIEVE ZORG (PICT-POSITIEF). BIJ DEZE PATIËNTEN STELT DE VRAAG NAAR VZP ZICH NAMELIJK HET STERKST EN DE RICHTLIJNEN TER ZAKE ZIJN DAAROM DOORGAANS VOORAL OP DEZE GROEP GERICHT. DIT KWALITATIEF ONDERZOEK BEOOGT OP EXPLORATIEVE WIJZE STUDIE DE KENNIS, ERVARINGEN,VOORKEUREN EN HOUDINGEN TEGENOVER VROEGTIJDIGE ZORGPLANNING (VZP) TE BESTUDEREN BIJ OUDEREN VAN MAROKKAANSE ORIGINE IN BELGIË. HIERBIJ ZAL OOK GETRACHT WORDEN OM DE EVENTUEEL BELEMMERENDE EN BEVORDERENDE FACTOREN MET BETREKKING TOT HET AANWENDEN VAN VZP BINNEN DEZE POPULATIE IN KAART TE BRENGEN.

STUDIE DESIGN
KWALITATIEF ONDERZOEK AAN DE HAND VAN SEMI-GESTRUCTUREERDE INTERVIEWS IN DE MOEDERTAAL VAN DE PATIËNTEN VAN DE DOELPOPULATIE (MAROKKAANS-ARABISCH).

STUDIEOPULATIE
AANTAL DEELNEMERS
DEELNEMERS ZULLEN GERECRUTEERD WORDEN TOT DATASATURATIE BEREIKT WORDT, MAAR VERWACHT WORDT DAT ONGEVEER 25 PATIËNTEN DIE POSITIEF SCOREN AAN DE HAND VAN DE PICT-TOOL, ZULLEN GEÏNTERVIEWD WORDEN.

INCLUSIECRITERIA
PATIËNTEN:
- VAN MAROKKAANSE ORIGINE DIE OUDER ZIJN DAN 65 JAAR EN IN BELGIË WOONACHTIG ZIJN
- EN DIE BOVENDIEN HUN INFORMED CONSENT GEGEVEN HEBBEN TOT DEELNAME AAN DE STUDIE

EXCLUSIECRITERIA
- PATIËNTEN DIE TERMINAAL ZIEK ZIJN, BETEKENEND DAT ZIJ EEN LEVENSBEPERKENDE AANDOENING HEBBEN MET INGEZETTE ONOMKEERBARE ACHTERUITGANG EN LEVENSVERWACHTING VAN SLECHTS ENKELE MAANDEN OF MINDER.
- PATIËNTEN MET COGNITIEVE BEPERKINGEN (COGNITIVE IMPAIRMENT)

PROCEDURES:
DE HOOFDONDERZOEKER ZAL EERST CONTACT OPNEMEN EN UITLEG GEVEN AAN DE HUISARTSEN OVER DE STUDIE. HET GEBRUIK VAN DE PICT SCHAAL ZAL OOK UITGELEGD WORDEN. DE HUISARTSEN DIE BEREID ZIJN DEEL TE NEMEN AAN DE STUDIE ZULLEN OP HUN BEURT DE STUDIE VOORSTELLEN AAN HUN PATIËNTEN VAN MAROKKAANSE ORIGINE DIE 65-PLUSSER ZIJN. DE HUISARTS ZAL OOK DE PICT-TOOL INVULLEN VOOR DE PATIËNTEN DIE WILLEN DEELNEMEN AAN DEZE STUDIE. POSITIVITEIT VOLGENS DE PICT-TOOL IS EEN VOORWAARDE OM OPGENOMEN TE WORDEN IN DE STUDIE. INDIEN DE IN AANMERKING KOMENDE PATIËNT INTERESSE HEEFT, ZAL ER DOOR DE HUISARTS GEVRAAGD WORDEN OF DE PATIËNT ERMEE INSTEMT DAT ZIJN/HAAR CONTACTGEGEVENS DOORGEGEVEN WORDEN AAN DE ONDERZOEKER ZODAT DEZE MET HEM/ HAAR CONTACT KAN OPNEMEN. MITS TOESTEMMING VAN DE DEELNEMER ZAL DE ONDERZOEKER TELEFONISCH CONTACT MET HEM/HAAR OPNEMEN.
VOOR HET SEMI-GESTRUCTUREERD INTERVIE ZAL EEN TOPICS LIJST (IN MAROKKAANS ARABISCH) GEBRUIKT WORDEN.
DE ANALYSES EN DE PRESENTATIE VAN DE DATA ZULLEN OP EEN GEANONIMISEERDE MANIER GEBEUREN, CONFORM DE WETGEVING TER BESCHERMING VAN DE PRIVACY EN PERSOONSGEGEVENS. NA VOLTOOIING VAN DE DATACOLLECTIE ZULLEN DE GEANONIMISEERDE EN GECODEERDE DATA OPGESLAGEN WORDEN OP DE HARDE SCHIJF VAN DE HOOFDONDERZOEKER (BRAHIM CHATER) EN CO-PROMOTOR DR. DEMIRKAPU HAKKI, TOT DEWELKE ENKEL DE ONDERZOEKERS VAN DIT PROJECT TOEGANG ZULLEN HEBBEN.

STUDIE ANALYSE:

ANALYSE VAN DE INTERVIEWS:
DE INTERVIEWS ZULLEN VOLLEDIG GETRANSCRIBEERD WORDEN. DE *CONSTANT COMPARATIVE METHOD OF QUALITATIVE DATA ANALYSIS* ZAL GEBRUIKT WORDEN OM CONSISTENTE EN COMPREHENSIEVE CODERING VAN DE OPENENDED DATA TE ONTWIKKELEN EN TE IMPLEMENTEREN. HET "NVIVO 12" SOFTWAREPROGRAMMA VOOR KWALITATIEVE DATA ZAL GEBRUIKT WORDEN.

Appendix 3. Ethics Approval

Afz.: Commissie voor Medische Ethiek

Prof. dr. Stéphanie De Maesschalck
Huisartsengeneeskunde - HAG
ALHIER

contact	telefoon	e-mail	
Commissie voor medische Ethiek	+32 (0)9 332 41 81	Ethisch.comite@uzgent.be	
Ons kenmerk	**Uw kenmerk**	**datum**	**pagina**
BC-07035	2018/481	13/03/2020	1/3

Betreft : LOKALE BEVESTIGING VAN definitief CENTRAAL advies voor studie met als titel:
"Vroegtijdige zorgplanning bij palliatieve (PICT-positieve) ouderen van Marokkaanse afkomst in België: een exploratieve interviewstudie (MaNaMa Brahim"
B.U.N.: B143201838280
Fase (Phase): NVT

* Definitief enig gunstig advies centraal EC 6/2/2019 UZ Brussel 2018/481
* Adviesaanvraagformulier 19/11/2019 (volledig ontvangen dd. 20/01/2020
* Interview Topic Lijst (versie 1) dd. /1/2020
* **Patiënteninformatie- en toestemmingsformulier (versie 1) dd. 1/1/2020**
* Antwoord onderzoeker: via mail ontvangen van prof. dr. S. De Maesschalck op 12/03/2020 in antwoord op opmerkingen EC dd. 21/01/2020

Advies werd gevraagd door: prof. dr. Stéphanie De Maesschalck

BOVENVERMELDE DOCUMENTEN WERDEN DOOR HET ETHISCH COMITÉ BEOORDEELD.
ER WERD EEN ENIG POSITIEF ADVIES GEGEVEN OVER DIT PROTOCOL OP 06/02/2019 DOOR UZ Brussel.
LOKAAL WERD DIT ADVIES BEVESTIGD OP 12/03/2020.
INDIEN DE STUDIE NIET WORDT OPGESTART VOOR 12/03/2021, VERVALT HET ADVIES EN MOET HET PROJECT TERUG INGEDIEND WORDEN.

THE ABOVE MENTIONED DOCUMENTS HAVE BEEN REVIEWED BY THE ETHICS COMMITTEE.
A SINGLE POSITIVE ADVICE WAS GIVEN FOR THIS PROTOCOL ON 06/02/2019 BY THE FOLLOWING ETHICS COMMITTEE: UZ Brussel.
LOCALLY THIS ADVICE HAS BEEN UPHELD ON 12/03/2020.
IN CASE THIS STUDY IS NOT STARTED BY 12/03/2021, THIS ADVICE WILL BE NO LONGER VALID AND THE PROJECT MUST BE RESUBMITTED.

DIT ADVIES WORDT OPGENOMEN IN HET VERSLAG VAN DE VERGADERING VAN HET ETHISCH COMITE VAN 24/03/2020.
THIS ADVICE WILL APPEAR IN THE PROCEEDINGS OF THE MEETING OF THE ETHICS COMMITTEE OF 24/03/2020.

° *Het Ethisch Comité werkt volgens 'ICH Good Clinical Practice' - regels*
° *Het Ethisch Comité beklemtoont dat een gunstig advies niet betekent dat het Comité de verantwoordelijkheid voor het onderzoek op zich neemt. Bovendien dient U er over te waken dat Uw mening als betrokken onderzoeker wordt weergegeven in publicaties, rapporten voor de overheid enz., die het resultaat zijn van dit onderzoek.*
° *In het kader van 'Good Clinical Practice' moet de mogelijkheid bestaan dat het farmaceutisch bedrijf en de autoriteiten inzage krijgen van de originele data. In dit verband dienen de onderzoekers erover te waken dat dit gebeurt zonder schending van de privacy van de proefpersonen.*
° ***Het Ethisch Comité benadrukt dat het de promotor is die garant dient te staan voor de conformiteit van de anderstalige informatie- en toestemmingsformulieren met de nederlandstalige***

ALGEMENE DIRECTIE
Commissie voor Medische Ethiek

VOORZITTER:
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documenten.
- *Geen enkele onderzoeker betrokken bij deze studie is lid van het Ethisch Comité.*
- *Alle leden van het Ethisch Comité hebben dit project beoordeeld. (De ledenlijst is bijgevoegd)*

- *The Ethics Committee is organized and operates according to the 'ICH Good Clinical Practice' rules.*
- *The Ethics Committee stresses that approval of a study does not mean that the Committee accepts responsibility for it. Moreover, please keep in mind that your opinion as investigator is presented in the publications, reports to the government, etc., that are a result of this research.*
- *In the framework of 'Good Clinical Practice', the pharmaceutical company and the authorities have the right to inspect the original data. The investigators have to assure that the privacy of the subjects is respected.*
- *The Ethics Committee stresses that it is the responsibility of the promotor to guarantee the conformity of the non-dutch informed consent forms with the dutch documents.*
- *None of the investigators involved in this study is a member of the Ethics Committee.*
- *All members of the Ethics Committee have reviewed this project. (The list of the members is enclosed)*

Namens het Ethisch Comité / On behalf of the Ethics Committee

Prof. dr. P. Deron
Voorzitter / Chairman

CC: UZ Gent – HIRUZ CTU
FAGG - Research & Development; Victor Hortaplein 40, postbus 40 1060 Brussel

UZ Brussel

Appendix 4. Informed Consent

TOESTEMMINGSFORMULIER VOOR DE DEELNEMERS

Titel van de studie: VROEGTIJDIGE ZORGPLANNING BIJ PALLIATIEVE (PICT-POSITIEVE) OUDEREN VAN MAROKKAANSE AFKOMST IN BELGIË: EEN EXPLORATIEVE INTERVIEWSTUDIE

Aankruisen door de deelnemer indien akkoord

Ik heb het document "Informatiebrief voor de deelnemers" pagina 1 tot en met 3 gelezen en begrepen en ik heb er een kopij van gekregen, samen met het 'toestemmingsformulier voor deelnemers' ('geïnformeerde toestemming'). Ik heb voldoende uitleg gekregen over de aard, het doel en de duur van de studie en over wat men van mij verwacht en de implicaties van deelname.	
Ik heb voldoende tijd gehad om over deelname en de implicaties na te denken.	
Ik heb de vragen die ik wou stellen, kunnen stellen en ik heb bevredigende antwoorden gekregen op al mijn vragen.	
Ik stem ermee in om deel te nemen aan deze studie.	
Ik begrijp dat deelname aan de studie vrijwillig is en dat ik mij op elk ogenblik uit de studie mag terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op welke wijze dan ook een invloed zal hebben op mijn verdere behandeling noch op de relatie met mijn behandelende arts of met de onderzoekers.	
Ik ben me ervan bewust dat deze studie werd goedgekeurd door een onafhankelijke Commissie voor Medische Ethiek verbonden aan het UZ Gent en de Universiteit Gent en dat deze studie zal uitgevoerd worden volgens de richtlijnen voor de goede klinische praktijk (ICH/GCP) en de verklaring van Helsinki, opgesteld ter bescherming van mensen deelnemend aan experimenten. Deze goedkeuring was in geen geval de aanzet om te beslissen om deel te nemen aan deze studie.	
Men heeft mij ingelicht dat zowel persoonlijke gegevens als gegevens aangaande mijn gezondheid worden verwerkt en bewaard gedurende minstens 15 jaar. Ik stem hiermee in en ben op de hoogte dat ik recht heb op toegang en op verbetering van deze gegevens. Aangezien deze gegevens verwerkt worden in het kader van medisch-wetenschappelijke doeleinden, begrijp ik dat de toegang tot mijn gegevens kan uitgesteld worden tot na beëindiging van het onderzoek. Indien ik toegang wil tot mijn gegevens, zal ik mij richten tot de arts-onderzoeker die verantwoordelijk is voor de verwerking ervan.	
Ik geef toestemming tot het maken van geluidsopnames van de afgenomen interviews.	
Ik begrijp dat de resultaten geanonimiseerd en vertrouwelijk verwerkt en gepresenteerd zullen worden en dat mijn naam niet zal vermeld worden in het onderzoek.	

Naam en voornaam van de deelnemer	Handtekening	Datum
Naam en voornaam van de arts-onderzoeker*	Handtekening	Datum

2 kopieën dienen te worden vervolledigd. Het origineel wordt door de onderzoeker bewaard in het ziekenhuis gedurende 20 jaar, de kopie wordt aan de deelnemer gegeven.

* Aankruisen door de onderzoeker indien akkoord

Ik verklaar de benodigde informatie inzake deze studie (de aard, het doel, en de te voorziene effecten) in klaar en duidelijk verstaanbare bewoordingen mondeling te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben verstrekt.	

Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te doen toestemmen tot deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.	
Ik bevestig dat ik de verkregen informatie enkel voor het hierboven beschreven wetenschappelijk onderzoek zal gebruiken en dat ik ten alle tijden de anonimiteit van de deelnemer zal respecteren. De data zullen verzameld en verwerkt worden in overeenkomst met de Belgische wetten en grondbeginselen van vertrouwelijkheid.	

Appendix 5. Topic guide and preliminary questions (cf. Ook Hajji, 2021 (77))

Aandachtspunten:

- Bedank voor aanwezigheid
- Introduceer jezelf
- Leg het doel van onderzoek en het gesprek uit
- Wijs op vertrouwelijkheid
- Toelichting geïnformeerde toestemming en start na ondertekening: leg uit dat er "geen foute antwoorden" bestaan
- Vraag om GSM uit te schakelen
- Meld dat het gesprek opgenomen wordt

1. Gezondheidstoestand

a. Hoe zou u uw gezondheidstoestand omschrijven?
    i. Zijn er belangrijke ziekten die u heeft of heeft gehad?

b. Heeft u vragen over de zorg voor uw gezondheid in het laatste deel van uw leven?
    i. - Als het antwoord "ja" is:
        1. Waar gaat dit vooral over? Waarom?
        2. Heeft u met iemand over deze (zaken) gesproken? Waarom?
        3. Heeft u iets gedaan aan uw zorgen?
        4. Heeft u iets gepland voor de toekomst?

2. Kennis over VZP

a. Wat weet u in verband met vroegtijdige zorgplanning?
    i. Had u eerder zoiets gehoord?
        1. Ja:
            a. Wat heeft u gehoord?
            b. Wat betekent dit volgens u?
        2. Nee:
            a. Waar denkt u dat het allemaal om draait?

b. Vroegtijdige zorgplanning is vooruitdenken over de toekomst. Dit gaat over het bespreken van uw toekomstige zorgwensen met uw familieleden en uw arts. Het gaat erom uw wensen kenbaar te maken, terwijl u nog in goede gezondheid bent en uw gedachten en wensen kunt uiten. Een dergelijke planning is belangrijk om u voor te bereiden op situaties waarin u als gevolg van een toekomstige ziekte niet in staat is om te spreken of beslissingen t e nemen. Zo kunnen anderen zo veel mogelijk rekening houden met uw wensen.

c. Wist u dat u van tevoren uw wensen voor dergelijke situaties kon communiceren?

d. Hoe voelt u zich hierbij?

3. Ervaringen met VZP

a. Sommige mensen hebben misschien al momenten meegemaakt dat deze vroegtijdige zorgplanning nuttig zou zijn geweest, bijv. bij sommige van hun familieleden. Als een familielid bijvoorbeeld ernstig ziek wordt of een ongeluk krijgt en het bewustzijn verliest, is het aan de familie en de arts om namens hem beslissingen te nemen vanwege het onvermogen van de patiënt om zijn/ haar eigen wensen kenbaar te maken.

Bent u zoiets tegengekomen?
    i. Ja:
        1. Kunt u uw ervaringen toelichten?
    ii. Nee:
        1. Heeft u op televisie, in het nieuws of in uw sociale kring van een dergelijk geval gehoord?

            a. Ja:

i. Als de wensen van de patiënt vooraf bekend waren geweest, denkt u dat het een verschil zou hebben gemaakt? Gelieve hier verder op in te gaan.
ii. Heeft het horen over een dergelijke zaak u aan het denken gezet en heeft u het met anderen besproken? Waarom?

b. Heeft u zelf ooit nagedacht over uw toekomstige zorg?
i. Zo JA: Waar heeft u aan gedacht?
c. Heeft u daar zelf ooit iets over opgezocht?
d.Heeft u zelf met iemand gesproken over uw toekomstige wensen en over wat u belangrijk vindt voor uw latere zorg?
i. Ja:
1. Met wie? (Met uw familieleden, uw arts, enz.)
2. Wie begon het gesprek? Wat heeft dit tot gevolg gehad? Waar heeft u over gepraat?
3. Heeft u een volmacht gegeven aan iemand met betrekking tot uw wensen?
4. Heeft u uw wensen gedocumenteerd?
ii. Nee:
1. Zou u dit overwegen? Waarom?

4. Meningen/voorkeuren omtrent VZP

a. Nu gaan we eens bekijken wat u denkt dat nodig is voor een goed plan voor een correcte vroegtijdige zorgplanning. Met als doel de zorg zoveel mogelijk volgens uw wensen te laten lopen.
b. Voor sommige mensen is het belangrijk dat anderen weten wat hun wensen zijn voor eventuele toekomstige situaties waarin ze niet in staat zijn hun wensen te uiten en beslissingen te nemen omdat hun fysieke of mentale toestand erg slecht is.
c. Ik ga u nu drie voorbeelden hieromtrent geven.
1. Het is nu mogelijk om de levensduur van iemand die ernstig ziek is, niet bij bewustzijn is en geen hoop heeft op herstel, enigszins te verlengen, door hem te drip feeden, een beademingsapparaat te gebruiken en/of antibiotica te gebruiken.
Terwijl u in goede gezondheid verkeert, kunt u ervoor kiezen dergelijke behandelingen te weigeren, voor mocht u ooit in die toestand terechtkomen.
1. Wat vindt u ervan om dit nu voor de toekomst te bespreken?
2. U kunt nu opgeven dat u naar een rusthuis wil verhuizen als u heel oud bent en niet meer voor uzelf kunt zorgen.
1. Wat vindt u ervan om dit nu voor de toekomst te bespreken?
3. U kunt iemand machtiging (volmacht) geven om namens u te handelen.
Als u in een bepaald stadium ernstig ziek wordt en niet goed kunt nadenken over uw behandeling, kan deze persoon beslissingen voor u nemen en ervoor zorgen dat uw eerder gecommuniceerde wensen worden vervuld.
1. Wat vindt u ervan om dit nu voor de toekomst te bespreken?
d. Zelfs als u momenteel niet zo'n ernstige ziekte heeft, wat zijn de voor- en nadelen van het nu bespreken van uw wensen voor toekomstige zorgen?
e. Ik ga u nu een voorbeeld geven over het gebruik van een dergelijke "vroegtijdige zorgplanning"
i. Een 75-jarige patiënt heeft de ziekte van Alzheimer (geheugenverlies). Ze woont samen met haar dochter. Ze zegt tegen de arts: “als ik ooit een ernstige ziekte heb, waarvan ik niet zal herstellen, wil ik niet worden aangesloten op machines in het ziekenhuis, zoals mijn man. Hij had al weken pijn voordat hij stierf. Op een dag wordt deze patiënt ziek. Ze heeft een hoge temperatuur, hoest en kan niet eten of drinken. De huisarts wil haar in het ziekenhuis laten opnemen omdat ze kan herstellen door dripvoeding en antibiotica te geven. De huisarts en haar dochter besluiten dat als ze niet binnen een paar dagen verbetert, ze de behandelingen zullen stoppen en haar

ontslag uit het ziekenhuis zullen vragen opdat ze de laatste dagen thuis zou kunnen door brengen. De patiënt herstelt na drie dagen en keert terug naar huis.

Drie jaar later is haar dementie veel erger geworden. De patiënt kan niet meer uit haar bed of de fauteuil komen en is gestopt met eten. Niets geeft haar meer plezier. Ze herkent haar eigen dochter niet eens. Ze kan geen beslissingen meer nemen over haar eigen behandeling. Haar dochter zegt: "Wat dacht je van haar te voeden met een infuus?" Haar arts zegt dat hij de patiënt hier niet meer aan wil onderwerpen, omdat ze, toen ze nog gezond was, haar wens had uitgesproken om niet te worden aangesloten op machines als ze ooit zo'n slechte ziekte zou oplopen. Na twee pijnloze maanden sterft de patiënt.

1. Wat vindt u van dit verhaal?
    a. Wat vindt u ervan dat de patiënt vooraf haar wensen communiceert, terwijl ze nog gezond/ bij bewustzijn is?

f. Welke (dingen) beïnvloeden uw gedachten?

i. Hoe beïnvloedt uw cultuur uw houding ten aanzien van dit onderwerp?

ii. Hoe beïnvloedt uw cultuur uw opvattingen over het al dan niet van tevoren te plannen van welke zorgen u wil ontvangen?

iii. Bent u gelovig? Zo ja:

1. Hoe beïnvloeden uw religieuze overtuigingen uw opvattingen over dit onderwerp?
2. Hoe beïnvloeden uw religieuze overtuigingen uw opvattingen over het al dan niet doen aan vroegtijdige zorgplanning?

5. Houding t.o.v. VZP

a. Wil u net als deze patiënt, voordat u ernstig ziekte wordt, van tevoren uw toekomstige wensen met iemand bespreken? Waarom?

i. Ja:

1. Met wie (binnen de familie/ arts)? Waarom?
2. Waar wil u precies over praten?
3. Welke kwesties zijn belangrijk voor u?
4. Wanneer is volgens u de beste tijd om deze kwesties te bespreken?
   (Wanneer u in het ziekenhuis wordt opgenomen, wanneer u ontdekt dat u een ernstige ziekte heeft of wanneer u een ziekte heeft die niet kan worden genezen?)
5. Met wie wil u deze discussie aangaan?
6. Wil u dat uw arts deze vragen stelt?

ii. Nee:

1. Waarom?

b. Wat vindt u van het bespreken van ziekte en dood?

c. Met voorafgaande zorgplanning laat u in zekere zin mensen in uw omgeving weten wat uw wensen zijn met betrekking tot de toekomst. Als u niet in staat bent om goed te denken, of beslissingen te nemen over uw behandeling, omdat u ernstig ziek bent, zal die persoon die u autoriteit gaf, beslissingen nemen voor u met gemoedsrust en ervoor zorgen dat uw eerder gecommuniceerde wensen worden uitgevoerd.

i. Wilt u iemand autoriteit geven namens u? Waarom?

6. Barrières t.o.v. VZP

a. Wat maakt het volgens u gemakkelijker of wat zou het gemakkelijker maken om over deze onderwerpen te praten?

i. Wat kan er worden gedaan om de discussie over deze onderwerpen aan te moedigen (binnen het gezin of met artsen)?

ii. Wat zou u ertoe brengen om over deze onderwerpen te praten en deel te nemen aan vroegtijdige zorgplanning?

iii. Heeft u suggesties voor ons?

iv. Hoe kunnen we u in dit opzicht beter van dienst zijn?

v. Wie moet wat doen? (Arts, verpleegkundige, associaties/ verenigingen, gemeenteraad, enz.)
vi. Waarom worden ze niet besproken?

b. Wat maakt het volgens u moeilijker om over deze onderwerpen te praten?
i. Is het omdat het concept van vroegtijdige zorgplanning niet bekend is?
ii. Omdat mensen nu geen ernstige ziekten hebben?
iii. Taboes rond de discussie over de dood
iv. Zijn ze moeilijk te besprek vanwege je religie?
v. Zijn ze moeilijk te bespreken vanwege je cultuur?
vi. Is het omdat het bespreken van deze onderwerpen pijnlijk kan zijn voor familieleden?

7. **Afronding**
   a. Denkt u dat wat we hier hebben besproken nuttig zou kunnen zijn voor de Marokkaanse gemeenschap in België? Waarom?
      i. Indien ja -> in welke situaties
   b. Is er nog iets wat u zou willen toevoegen?
   c. Van wat we vandaag hebben gesproken, wat was het belangrijkste voor u?
   d. Ik ga deze informatie niet doorgeven aan uw arts of uw familieleden. Dat wil zeggen, als u met hen wil praten over dergelijke zaken, moet u zelf contact met hen opnemen. Bedankt voor uw interesse en uw tijd.

Vragenlijst socio-demografische factoren

1. Geslacht?
2. Je leeftijd?
3. Waar bent u geboren en opgegroeid? (Dorp, stad, ...)
4. Waren uw ouders eerder in België dan u? (Eerste/ tweede generatie?)
5. Hoeveel jaar bent u in België?
6. Bent u getrouwd?
7. Heeft u kinderen? Hoeveel?
8. Met wie woont u samen? Alleen, met uw echtgenoot/ partner of met anderen?
9. Wat is uw opleidingsniveau? Kunt u lezen en schrijven?
10. Wat was uw beroep? Waar heeft u gewerkt?