



Care and decision-making at the end of life for migrants living in the Netherlands: An intersectional analysis

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ABSTRACT

As migrant populations age, the care system is confronted with the question how to respond to care needs of an increasingly diverse population of older adults. We used qualitative intersectional analysis to examine differential preferences and experiences with care at the end of life of twenty-five patients and their relatives from Suriname, Morocco and Turkey living in The Netherlands. Our analysis focused on the question how – in light of impairment – ethnicity, religion and gender intersect to create differences in social position that shape preferences and experiences related to three main themes: place of care at the end of life; discussing prognosis, advance care, and end-of-life care; and, end-of-life decision-making.

Our findings show that belonging to an ethnic or religious minority brings forth concerns about responsive care. In the nursing home, patients' minority position and the interplay thereof with gender make it difficult for female patients to request and receive responsive care. Patients with a strong religious affiliation prefer to discuss diagnosis but not prognosis. These preferences are at interplay with factors related to socioeconomic status. The oversight of this variance hampers responsive care for patients and relatives. Preferences for discussion of medical aspects of care are subject to functional impairment and faith. Personal values and goals often remain unexpressed. Lastly, preferences regarding medical end-of-life decisions are foremost subject to religious affiliation and associated moral values. Respondents' impairment and limited Dutch language proficiency requires their children to be involved in decision-making. Intersecting gendered care roles determine that mostly daughters are involved.

Considering the interplay of aspects of social identity and their effect on social positioning, and pro-active enquiry into values, goals and preferences for end-of-life care of patients and their relatives are paramount to achieve person centred and family-oriented care responsive to the needs of diverse communities.

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1. Introduction

As migrant populations age, the care system is confronted with the question how to respond to care needs of an increasingly diverse population of older adults. Older migrants on their part are confronted with end of life care that may not be responsive to their needs. In the Netherlands, migrants make up 10 % of the population of adults aged 55 and older. Children of migrants make up an additional 5,5 % of the population of adults aged 55 and older. They predominantly migrated from Suriname, Turkey or Morocco, prompted by the former colonial presence of The Netherlands in Suriname and as labor migration followed by family reunification (De Regt et al., 2022).

The participants in this study are migrants and their children from Suriname, Turkey, and Morocco. Previous research on care at the end of life showed they, compared to Dutch patients, were more likely to be admitted to, and die in the hospital; less likely to receive morphine or morphine-like medication and continuous deep sedation; and, more likely to receive care that, according to physicians, is directed at curative care too long; end-of-life decisions (ELD) were made less frequently (Torensma et al., 2020). These differences resemble findings from research comparing migrant and ethnic minority populations to majority populations elsewhere, and inequities in access to palliative care are documented across countries (Shabnam et al., 2022; Evans et al., 2012; Johnson, 2013).

Comparing across countries, however, runs the risk of conflating terms such as migration, ethnicity and race, and research into the intersection of ethnicity and old age has been criticised for an essentialist understanding of ethnicity – assuming that ethnic groups are homogenous and fixed (Koehn et al., 2013; Berdai Chaouni et al., 2021; Helberg-Proctor et al., 2016). Rather, migrants' needs and preferences for care at the end of life are diverse and dynamic; subject to the intersection of various aspects of social identity and individual experience in relation to one's social position (Klokgetiers et al., 2022). There is a paucity of research that does justice to this variation in the context of palliative care. In this study we will examine how preferences and experiences with care and decision-making at the end of life of Surinamese, Turkish and Moroccan migrants living in the Netherlands vary with the intersection of various aspects of social identity; taking into account how differential social positions that come with a certain amount of privilege or disadvantage shape the allocation of power and organize everyday relationships in the context of palliative care.

Palliative care is an approach aimed at improving the quality of life of patients facing life-limiting illness through the prevention and relief of suffering (World Health Organization 2020). Palliative care in The Netherlands is not a separate discipline. It is integrated in existing care structures (hospital, nursing home, home care, general practice) and delivered by generalists, who are supported by care professionals specialized in palliative care (from palliative care units, consultation teams, hospices) when required (Boddaert et al., 2017). It follows a comprehensive, person-centred approach in which moral action centres on interpersonal and long-term care relationships, yet shares medical ethical notions underpinning general care (e.g. autonomy, beneficence) that at times give rise to moral debate on what constitutes 'good care' (Hermesen, 2005). The Netherlands is one of the few countries in the world with a legal system that regulates the practice of euthanasia and assisted suicide in case of unbearable suffering (Emanuel et al., 2016).

To ensure good care at the end of life, quality indicators, such as proportion of home deaths on population level or documentation of treatment preferences, have been established (De Roo et al., 2013). Increasingly, research findings accentuate variation in perspectives on 'good care' at the end of life among migrants and their children (Ahaddour et al., 2018a,b; van Eechoud et al., 2017; de Graaff, 2016; Paal and JJPo, 2017). Van Eechoud et al. report that among Turkish, Moroccan, Tunisian and Algerian migrants in Belgium, relatives variably base decisions on truth-telling on patient's emotional strength, personal preference, and understanding of the Belgian care context (van Eechoud

et al., 2017). Paal and Bukki (2017) report migrant and non-migrant patients in Germany base preference for hospital admission on feelings of safety and obligation to consult specialist care (Paal and JJPo, 2017). And, Ahaddour et al. (2018a,b) found that tolerant, yet varying attitudes toward withholding and withdrawing treatment and an absolute rejection of physician assisted suicide and euthanasia among Moroccan women in Belgium were strongly rooted in theological arguments, but diverged based on age and differing ideas of what constitutes 'a good death' (Ahaddour et al., 2018a,b).

These studies shed light on the multiplicity of preferences for care at the end of life but do not consider the impact of intersecting aspects of identity on social position and individual experience. In this study, we will further examine differential perspectives, preferences and experiences using an intersectional lens (Crenshaw, 1991); paying attention to social contexts and structural factors (e.g. institutional racism) that impact experiences of migrants and their children, to help foreground issues of social justice and situate health disparities (Hunting, 2014; Warner and Brown, 2011). By broadening the evidence on the complexity of experience across diverse populations and creating nuanced understanding of care preferences and experiences, we hope to rise above essentialist thinking and offer insights and suggestions for responsive person-centered care at the end of life.

2. Methods

2.1. Design

For this study we conducted an intersectional analysis of twenty-five interview transcripts obtained in 2017 – 2018 as part of a research project on dignity at the end of life for migrants and their children (de Voogd et al., 2020). We followed the *practical guidelines for secondary intersectional analysis in qualitative health research* (Stuij et al., 2020). The original research had a qualitative design, using semi-structured interviews, and was led by XdV.

2.2. Data collection

Respondents were recruited via palliative teams, and the oncology, lung diseases and neurology departments of two hospitals; various nursing homes; a general practitioner; and migrant organizations. Identification of palliative patients was done according to Murray's illness trajectories, i.e. on the basis of having an incurable disease and/or being in the last 3 months to 8 years of life (Murray et al., 2005). Purposive sampling was used to ensure variety in country of origin, sex, age and disease type, permitting representation as much as possible with respect to the population of interest.

Interviews were carried out in different constellations, i.e. patient only, (surviving) relative only, patient-relative collective interview, patient-relative separate interview. Relatives acted as a support or proxy for impaired or deceased patients. A semi-structured interview guide was used for all interviews (de Voogd et al., 2020). The guide included questions on dignity, as well as questions on preferences and experiences with palliative care included for the purpose of this study (i.e. There may come a time at which there are no more treatments that can cure you. What do you want to happen then and why?). Interviews were conducted according to respondents' language preferences. XdV conducted the interviews in Dutch and two bilingual interviewers conducted interviews in Turkish, Berber and Arabic. All interviews were audio recorded and transcribed verbatim. Transcription of the interviews in Turkish, Berber and Arabic included translation to Dutch. All personal identifiers were deleted from transcripts to ensure anonymity. In addition to the interviews we collected data on age, sex, country of birth, self-identified ethnicity, educational level, occupation, religion, disease type, care context and place of residence.

2.3. Data analysis

We conducted a qualitative intersectional analysis, whereby intersectional analysis followed inductive thematic analysis (Braun and Clarke, 2006). We selected place of care at the end of life; discussing prognosis, advance care, and end of life care; and, end-of-life decision-making as themes for the intersectional analysis as these best captured respondents' expressed preferences and experiences (Braun and Clarke, 2006). According to Stuij et al. (2020) intersectional analysis requires zooming in on individual experiences in relation to respondents' social position, which is done by familiarization with the data and analyzing identified themes from selected aspects of social identity. And zooming out to relate individual experience to a broader social historical context, which requires exploring, selecting and interpreting intersections (Stuij et al., 2020). For example, a respondent (#10) in our sample shared feeling neglected and disrespected by the, in particular female, staff in the nursing home; he expressed feeling discriminated against. Zooming in we may relate his experience to his gender and ethnic identity, and ethnic minority status within the context of the nursing home; zooming out we may place his experience in a broader social historical context and the (subjective) social position of older male Moroccan migrants in the Netherlands who experience a lack of acceptance and discrimination (Klokgieters et al., 2022).

Familiarization with data started with MT reading all 25 transcripts. Subsequently, MT, RO, IvV, JS and BOP collectively read and discussed two transcripts, and MT read and discussed two additional transcripts with RO, IvV, JS and BOP individually. The individual discussions were followed by collective discussion to reflect on emerging intersections and observed power dynamics. We selected ethnicity, religion, and gender as the aspects of social identity to focus on in relation to the selected themes. When aspects of SES were addressed by respondents, we also included them. Lastly, the impact of functional impairment resulting from incurable disease or old age on respondents' social identity and position in society was broadly apparent. Although we understand this impairment to be inherent to the last stage of life rather than a social identity, we do consider it in intersection with other aspects of social identity. See textbox 1 for further specification of selected aspects of identity.

Analysis continued with MT developing a coding tree based on the selected themes and social identities (e.g., code for ethnicity with subcodes culture, migration, experiences of racism), and coding and analyzing all data accordingly. Exploring, selecting, and interpreting intersections happened in discussion with all authors. MT wrote a summary of results with accompanying quotes per selected theme and discussed the results with all authors, critically reflecting on intersections and power dynamics, and relating them to the socio-historical context. Finally, as the lead researcher of the primary study XdV helped bridge between the stages of data collection and secondary data analysis by providing context on respondents and data collection dynamics.

2.3.1. Textbox 1

We understand ethnicity to signify shared language, culture (i.e., customs with regard to food and drink; cultural references such as songs; traditions such as burial rites) and country of birth. The operationalization of ethnic identity also includes shared experience of migration (Cornell and Hartmann, 2006) and ethnic minority position, e.g. being considered a 'foreigner'. We understand religion to signify a shared set of religious attitudes, beliefs, moral frameworks, and practices, e.g. the belief in a supernatural power (God) with control over life and death. We understand gender to refer to sociocultural norms, identities, and relations that are different for men and women and influence the way people perceive and present themselves, their attitudes, behaviors, and experiences (Stanford University). We define SES as a combination of one's financial income, level of education and occupation (Mackenbach et al., 2008). Lastly, functional impairment in the context of this study is

the loss of function, both cognitive and physical, as a result of incurable disease or old age.

2.4. Reflection on social position

Reflexivity is a fundamental part of intersectional analysis. As part of the analytic process we reflected on the frames of reference within our research team. In the first discussions we actively engaged with questions such as 'Who am I and with what lens do I look at the data?'; 'Which assumptions do I have about the identity and context of the participants?'.

Positioning ourselves in this research our team consists of cis-gender women, and (one) cis-man; with a Dutch, and Dutch and Tunisian background. Several of us relate to the experiences of partners and children with a migration background. We had no (current) religious affiliation, but some had Christian or Catholic religious upbringing, Muslim religious affiliation, or spiritual affiliations with Buddhism. Our scholarly backgrounds are in medical anthropology and sociology, psychology, public health, health sciences, epidemiology, medicine (general practice) philosophy, medical ethics, Arabic language and culture, and religious studies. Although certainly not exhaustive, the diversity of perspectives in our team allowed for rich discussion of our data.

2.5. Ethics approval and consent to participate

The medical ethical committee of the Amsterdam University Medical Centers/University of Amsterdam declared this study did not require ethics approval, according to the Dutch Medical Research Involving Human Subjects Act (World Medical Association 2013). Respondents were informed about the aims and methods of the study, and their legal rights. We obtained written informed consent before or directly after the interviews.

3. Results

Our results show how – in light of impairment – aspects of our participants' ethnicity, religion and gender intersect to create differential preferences and experiences related to three main themes: place of care at the end of life; discussing prognosis, advance care, and end of life care; and, end-of-life decision-making. Participants were patients and their (surviving) relatives from Suriname, Morocco and Turkey. Interviews pertained to twenty-five patients. Fourteen patients were female, eleven male. Patients were mostly 65 years or older and suffered various health conditions, the majority resided in nursing homes. See textbox 2 for context on nursing home care in The Netherlands. Patients reported varying but predominantly lower educational and occupational levels. The majority of patients had an Islamic religious background. See table 1. for a description of the sample.

3.1. Textbox 2

In The Netherlands approximately one-fifth of migrant patients is known to experience the end of life in a care home or nursing home, compared to one-third of the majority population (Torensma et al., 2020). Various 'culturally specific' nursing homes exist, providing a home for patients based on their religious affiliation or specific ethnic minority background (Netwerk van Organisaties van Oudere Migranten 2021). Admission to a nursing home is based on an indicated care need and end of life care in the nursing home is covered by healthcare insurance. Subject to one's financial circumstances, residents pay a personal contribution (PZNL 2023).

3.1.1. Place of care at the end of life

Due to functional impairment the majority of our respondents resided in nursing homes, but many indicated this was not their

Table 1
Description of the sample (patients).

	#
Interview constellation	
Patient only	12
Patient-relative collective	8
Patient-relative separate	1
Surviving relative only	4
Care context	
Home	6
Nursing home	17
Hospice	1
Residential community	1
Sex	
Female	14
Male	11
Age group	
>65	4
66 – 70	2
71 – 75	4
76 – 80	4
81 – 85	8
86 – 90	3
Country of Birth	
Suriname	10
Morocco	8
Turkey	7
Religion	
Islam	17
Evangelical Brotherhood Church	4
Hinduism	2
None	2
Educational level	
None	5
Primary education	5
Secondary education	4
Vocational school	1
College	2
University	–
Unknown	8
Occupational level	
NA	4
Elementary	9
Lower	6
Intermediate	2
Higher	2
Academic	–
Unknown	2
Condition*	
Dementia	6
CVA / ICH	3
Heart disease	4
Lung disease	3
Kidney disease	2
Musculoskeletal disease	2
Cancer	5
Diabetes	4
Arthritis	2

*Whereby several patients suffered multiple conditions.

preferred place of care. Aspects related to respondents' gender, ethnicity and religion influenced preferences and experiences with the nursing home as place of care (see §1.1). The intersection of ethnicity and ethnic minority position with gender determined preference for care in the country of origin (see §1.2).

3.1.1.1. Preferences for care at home and in the nursing home. Generally, respondents preferred their home over the nursing home as place of care at the end of life. The stigma associated with nursing homes and the incongruence thereof with how our respondents identified (see #28), the perceived impact on social position – “falling between the cracks” (#07) – and the need to maintain ethnic and religious identity (see #30 below) determined this preference. Ultimately, however, functional impairment dictated the move to the nursing home which, in turn,

became the place of death.

Relative: “There are people with mental problems in that nursing home. That is hard. Not everyone has the same illness, mentally my mother was fine ... But because she was ill, she could not stay without help. ... I really did not want to leave her there.” (#28)

More specifically, functional impairment intersected with gender. The loss of the ability to do gendered tasks such as cooking and cleaning influenced female respondents' preference for the nursing home – “in a care home you know you'll eat on time” (#01). The nursing home provided options for support in activities of daily living (ADL) that were not available in the home context. When support in ADL was available, care at home was preferred as it enabled preservation of both gender identity and ethnic identity in light of functional impairment (see #30).

Relative: At some point she literally said: ‘you don't appreciate me anymore. ... She used to cook for us. She lost that. With that she lost her love, her value as a mother caring for her children. ... And then the diagnosis came – Alzheimer. And we asked ourselves what do we do? ... My mother would never survive in a regular institution, because she was so culturally bound. She had her own norms and values with regard to food, drink, but also her daily rituals. Well, we said as long as we can take care of you we will ... Also doing the cooking.’ (#30)

3.1.1.2. Experiences with care in the nursing home. The intersection of impairment with gender also determined experiences of care in the nursing home. It was generally male respondents who expressed entitlement to care, emphatically in light of severe functional impairment (see #04). Female respondents expressed more discomfort in asking for care (see #31); they emphasized interdependence and relational aspects of care.

Patient: Sometimes they are busy with someone. ... But I think I should always be the first, because I cannot walk. I cannot go to the bathroom myself. ... It is dangerous. If I fall than I cannot get up. I need to have a nurse. The only thing I can do is to have someone. Someone needs to cook for you. Someone needs to bathe you. Someone needs to dress you. Someone needs to undress you. ... You need someone.” (#04)

Relative: If I helped her in the shower she could easily tell me: ‘I want it like this’. But a nurse, less so. ... She would have held back ... If it would go wrong ... She'd dare not say so. Because she'd think maybe next time the nurse will be even less nice to me.” (#31)

Respondents' position as an ethnic and religious minority inhibited them to ask for and receive care responsive to culturally and religiously determined needs (e.g. food, daily rituals, prayer). We saw an intersection with gender, whereby female respondents had more difficulty than male respondents to express needs and receive care responsive to their needs. In a few cases respondents explicitly related feelings of neglect in institutions (nursing homes as well as hospitals) to discrimination and racism. E.g. respondent #28 shared an example of an unmet request for a room in which her friend could lie, pray and die in the direction of Mecca, as well as the experience of her and her mother being treated ‘differently’ from other patients:

Relative: “I also have an example of my friend who recently passed away. Why won't you let this woman pass away in [facing] the right direction? ‘I would like to face that direction ... I always pray facing that direction. That is how I would like to die.’ ... It is a simple thing which for us is very important.”

Later in the interview: “Every day when I am with my mother I ask if I can have an orange juice and she [nurse] will not give it to me... Simple things but they hurt. When other people have guests they ask: ‘Would you like soup? Would you like something to drink?’ You feel a difference between my mom and other patients. ... [Interviewer: did you feel discriminated?] Yes, something like that. With some things. Not with all staff, with some...” (#28)

3.1.1.3. Preference for care in the country of origin. Experience of migration, related to ethnic identity and ethnic minority position, influenced respondents' preference for place of care. Several respondents expressed wanting to return to and die in their country of

origin – a return to “the land, my [mother]land” (#11), where their family can visit them, and they “are not a foreigner” (#16). Others preferred to remain in the Netherlands, female respondents more often expressing a preference to remain in the Netherlands because their children are ‘here’; or had no preference as long as their family was present.

Patient: My children are here ... I will stay here with my children. With my family. I do not have a mother or father. I have an aunt and uncle, they are there [country of origin]. My children are here. I want to stay with my children.” (#03)

3.1.2. Discussing prognosis, advance care, and end of life care

Discussing and planning for care at the end of life relies heavily on the interaction between patient, relative, and care professional. Intersection of aspects related to functional impairment, religion, ethnicity and SES influenced respondents’ preferences for discussion of prognosis, advance care and end of life care. We did not observe intersection of aspects related to gender. Variance in social position furthermore impacted the relation to care professionals and subsequent experiences with discussion of care. Personal values and goals for end of life care often remained implicit, and were not actively discussed, while a few respondents did explicitly discuss medical end of life decisions with care professionals.

3.1.2.4. Discussing prognosis and diagnosis. Most respondents expressed a preference for open discussion of the end of life, albeit responsive to culturally or religiously determined needs. Several respondents wanted to discuss diagnosis but not prognosis and related this preference to aspects of their religious identity – the belief in a higher power. Care professionals do not have the authority to make prognosis about the end of life and respondents experienced conflict when they did.

Patient: “I didn’t know. The only part of the doctor’s story I understood was that he said I would die in three months. I looked him in the eye and asked: ‘who are you? ... You cannot know. Only God [Allah] knows.’ And he said he did know. Upon which I said: ‘Don’t lie! You cannot know.’ Yes, I really said it like that... So they admitted me here, because I would supposedly die in three months.”

Later in the interview, when asked about wanting to be informed about infaust diagnosis: “Yes, yes I definitely would want that. Let them inform me. I have to be prepared. Why would he hide my illness? Let him tell me and let him tell my children. ... No I never experienced conflict, only that time in the hospital when they told me I would die.” (#11)

Communication preferences differed between respondents, including between relatives and patients holding different social locations. E.g. influenced by previous experience (see #18 below) and occupation as part of SES (see #17 below). At times, responsive communication was obstructed by essentializing practices of care professionals who made assumptions regarding preferences based on respondents’ ethnic identity (“culture”) thereby reducing them to one aspect of their identity. Informed by her occupational background, respondent #17 observed healthcare professionals communicated differently, indirectly, with her partner and her and felt this was based on an ethnicized view of their identity that overlooked her differential preferences.

Relative: “In fact, I never posed the critical questions I am teaching my mother to ask now. ... I want to know exactly what I can expect and that is what I mean with taking me serious. And that can be an unpleasant story, but I’d rather hear an unpleasant story than no story. [Interviewer: was that the case for your mother and grandmother too?] “I believe so, Because when my mother came to the Netherlands, she [her mother’s mother] died within two days. So she died before my mother could be adequately informed. ... It is always hard to lose your mother, but my mother felt very powerless in it.” (#18)

Relative: “I do not know if they take cultural background into account. I do notice that they are careful towards us. ... I also have a medical

background and what I know is that you are direct and you do not beat around the bush. And I notice that does happen with us. ... [instead] tell us what we can expect, tell us what awaits us. Tell us! That is what I experience, but he [patient] may not [prefer that]. ... You hear ... it is prolongation, it is palliative. But... I’m missing information. What kind of cancer is it? What can I expect? ... I have to dig every time. I find it difficult sometimes. ... I don’t know if that has something to do with religion or [cultural] background... That they [doctors] think: ‘Most of them...that they don’t want to know. Let them see what fate brings. ‘I don’t know if the doctors ... [Interviewer: That they already think you don’t want to know?] Yes.” (#17)

3.1.2.5. Discussing advance care and end of life care. Subsequent discussion of advance care was impeded by functional impairment, both as a pragmatic barrier and under the influence of the impact on respondents’ social positioning. E.g. when impairment affected the view of one’s own identity and actions – “If you don’t have good health, why would you think about the future?” (#07). When accepting impairment and old age, aspects of religious identity could still affect discussion of advance care.

Although respondents deflected direct questions - wanting to “[leave] the future to my creator” (#18) – they continued to implicitly express values, goals and preferences with regard to the last phase – “I pray for my independence” (#18), as well as the end of life - “I would like to face that direction ... That is how I would like to die.” (#28). However, these were not discussed with care professionals.

Patient “We cannot know the future. I do not know. [But] I know every human wears out and declines, both inside and outside. I experience that too. But I can’t complain. I am eighty-one and I manage. I try my best. ... [Interviewer: Did the doctor tell you about the possible consequences of your health complaints?] No, I leave my future to my creator. ... I don’t know my future and I cannot anticipate a future I do not know. I pray for my independence. ... And I pray for a long life. Because I want to see my granddaughter, that cheeky one there, I want to see her become a woman. Firmly rooted in society.” (#18)

When asked about discussion of medical aspects of advance and end of life care, preferences again differed between relatives and patients holding different social locations. Respondent 31 shared the difficulty of discussing pain medication with her mother, caused by a combination of her religiously informed preference with her lower educational level. Only a few respondents shared having discussed their preferences with care professionals. These respondents were more proficient in the Dutch language and preferred direct communication. This seemingly shaped their social position in relation to- and subsequent interaction with care providers e.g. for “the only woman of color living in the neighborhood” (see #30 below).

Relative: “I cannot explain it to my mother. When I explain to my mother that there is a small pill for it. And you won’t have any pain, but there also is a chance that you will die. Within her faith that is not allowed, those pills ... It’s a kind of euthanasia what you’re doing, isn’t it. ... She might think so, but- Yes. Well, then she [is] not fully educated. I don’t see it that way. But yes, she could see it that way.” (#31)

Relative: “So she was about seventy-five ... And she notice it wasn’t going well ... And so she had close contact with her GP. Mother spoke perfect Dutch, was well integrated, lived in a neighborhood as the only woman of color. ... When she was seventy-five ... around that time she started to feel she needed to talk to her GP. She told het GP: ‘Gee, doctor, can you arrange for me that I can get euthanasia when I get so sick that I no longer... that I am in pain... or have lost my mind. Can we agree that you will help me with that?’ And the GP said yes. They would do it and my mother then wrote a letter documenting her wish not to suffer.” (#30)

Lastly, it was more common for respondents to have discussed and documented their preferences concerning funeral care and rites, for which honoring cultural and religious traditions was important.

Relative: “For the funeral, the ceremony ... a ‘bazuin’ choir. Which are musicians, and that was distinctively ... So, Suriname is a melting pot,

ethnically. He [father] had a different mix of ethnic origin than my mother. ... In Suriname we call that Creole. Otherwise, you can be Hindustani, or Chinese, or more Javanese. But we are Creole. And the Creole, the mixed people, have a 'bazuin' choir. That is really Creole, it is not for Hindustani people, it is also not for Chinese people. It is a certain type of music with wind players and drummers, there were five or six musicians. They played before, during and after the ceremony. And that was really, in that sense, the cultural aspect of the ceremony." (Hunting, 2014)

3.1.3. End-of-life decision-making

Preferences with regard to end-of-life decisions (ELD) on administration of pain medication and euthanasia were influenced by aspects related to SES and religion. Loss of social identity following functional impairment influenced ELD to forego or withdraw treatment (see §3.1). Respondents' preferences and experiences with regard to decision-making were influenced by intersection of impairment and aspects related to ethnicity and gender (see §3.2).

3.1.3.6. End of life decisions (ELD). Respondents spoke about ELD to refrain from hospital admission, to forego treatment, to cease artificial nutrition or hydration, and shared examples of patients ceasing to take in food or drink. Respondents elaborately discussed the topic of pain medication, emphasizing the wish to prevent or minimize suffering. The preference not to administer pain medication often resulted from the wish to 'stay awake' to recite the Shahada (the declaration of faith) among Islamic respondents. We furthermore encountered variation in knowledge and understanding of potential side effects and purposes of pain medication that may be resultant from varying educational level. And, when understood as "a way to end it" (#07), administration of pain medication gave rise to moral debate on euthanasia, informed by religious identity. Acceptability of euthanasia was furthermore embedded in context and time and influenced by respondents' previous experience with the end of life, either privately or professionally. I.e. this experience enabled respondents to anticipate ELD (#19).

Relative: "With my grandma it never occurred to us, to talk about euthanasia. Also because it was the 70 s, 80s. But now we are years ahead. And say my father is bedridden and there is nothing... well then I would bring it up. Euthanasia I mean, to talk about it. ... They should not resuscitate my father ... I also work in the hospital. I know what I am talking about. Then we have a man in bed. Who may decline even further. And then I come in and he doesn't even recognise me ... I have never discussed this with my father but I know the kind of man he is. I know my father very well. ... He was the one who did everything for his mother and he also didn't like that. To see his mother that way. How she deteriorated. That was terrible." (#19)

3.1.3.7. Preferred role in end-of-life decision-making. When asked about decision-making very few respondents preferred a central role in decision-making. Rather, respondents' social position as older, first generation, migrants determined their preference for prominence of others, often children. I.e. the intersection of impairment, age "they [children] decide, I don't know anything, I am old" (#15, f), and limited Dutch language proficiency effectively required prominence of children in decision-making. Intersecting gendered care roles determined that daughters were involved in decision-making, as they were primary caregivers and/or had a professional care background (care being a female dominated sector) (see #19, §3.1 last quote).

Relative: "But then you can get an interpreter. That would have been useful. ... Yes, that would have helped my mother. Then she would have resigned [to it] a bit. ... And she would [have been able to] tell that man [the doctor] in her own language. And then maybe she would have had a different kind of painkillers, maybe she would have had that hospice treatment at home earlier." (#31)

Several respondents clearly preferred care professionals take a central role in decision-making as "she is the doctor, she knows" (#02). Care professionals' attempts at shared decision-making at times undermined

their requested role of the authority of knowledge and caused distrust among patients (see #17). Lack of clarity on decision-making roles created a decision-making void and, in a few instances, inappropriate end of life care (see #30). Previous experiences of maltreatment, disrespect, and discrimination that respondents related to their ethnic minority position added to distrust, leaving them in an intricate position where they both depend on and distrust care professionals in palliative care.

Patient: "And then he sent me to the hospital straight away. ... they scanned everything. And then it turned out to indeed be colorectal cancer. Then they were talking about what to do. To do a surgery for a stoma, or this, or that... Two doctors [discussing] with each other, and to discuss with us what they would do exactly. But they disagreed between the two of them. One said this and the other said that. And then I thought: 'well, something is wrong. If you don't agree between the two of you, why did you call us? You have to decide first, so that we can hear what their advice is.' Well then I had my doubts. I thought I won't stay here, in this hospital. I will go to another hospital." (#17)

Relative: "But why I got so angry: why isn't there anyone who says 'it will only go down from here. You won't find her character. You won't find her appearance.' She changed so much that my mother was not my mother anymore. I regret that so much. That there isn't a point at which a... I understand no one can do it for us. But she could no longer decide. And we could no longer decide for her. [A point at which] someone said 'Stop. You cannot do this anymore. This is no longer your mother. What you are doing now is holding onto something that she never would have wanted.' But maybe he [the GP] was leaning on me too much. On my will to keep going." (#30)

4. Discussion

The objective of this study was to explore the complex interplay of factors that impact perspectives, preferences, and experiences with care and decision-making at the end of life for migrants living in The Netherlands. By means of intersectional analysis we have sought to explicate how – in light of impairment – ethnicity, religion and gender intersect to create differences in social position that inform use of and access to responsive care at the end of life. At times, we also identified an interplay with aspects related to SES, such as educational level. Our analysis was centered around three themes related to care at the end of life: place of care; discussing and planning for care; and end-of-life decision-making.

4.1. Summary of findings

With regard to place of care, our findings show that belonging to an ethnic or religious minority brought forth concerns about the opportunity to receive care that caters towards culturally or religiously determined needs. Respondents therefore preferred the home context over a residential care context. Functional impairment ultimately dictated the move to a nursing home, whereby female respondents specifically related this to the loss of the ability to do gendered tasks such as cooking or cleaning. In the nursing home, respondents' ethnic and religious minority position and the interplay thereof with gender put female respondents more than male respondents in a position from which it was difficult to request for and receive care responsive to their needs. It contributed to some respondents experiencing the lack of responsive care as (institutional) racism. The intersection of ethnic identity (migration) and ethnic minority position with male gender determined preference for care in the country of origin.

With regard to end of life communication, the belief in a higher power determined the preference to discuss diagnosis but not prognosis for respondents with a strong religious affiliation. Preferences varied, however, upon interplay with factors related to SES and the oversight of this variance thwarted responsive care for both patients and relatives. Preference for not discussing and planning advance care was subject to functional impairment – no need to plan when you do not have a future;

and faith – leaving the future in the hands of a higher power. Consequently, expression of values, goals and preferences for advance care remained implicit. Some respondents expressed explicit preferences for medical aspects of advance and end of life care, and shared having discussed these with healthcare professionals. The need to honor traditions related to religious and ethnic identity motivated respondents to plan funeral care.

Lastly, perspectives and preferences with regard to ELD on administration of pain medication and euthanasia were affected by educational level as part of SES, but were foremost subject to religious identity and associated moral values and perspectives on the end of life. Respondents' impairment and limited Dutch language proficiency required prominence of children in end-of-life decision-making. Intersecting gendered care roles often determined daughters who were primary caregivers and/or had a professional care background were involved in decision-making.

In this study we provide various examples of the intersection of social identities in older migrants' care preferences and experience. Our findings show intersection of ethnicity, religion, and gender uniquely affects end-of-life care preferences and experience, for example, by the effect of female older migrants' social position on their place of care. Care at home was preferred as it enabled preservation of ethnic and religious identity, but the ability to do gendered tasks such as cooking or cleaning dictated the move to a nursing home.

4.2. Strengths and limitations

In the Netherlands, research on the intersection of ethnicity and old age is sparse (Hoogendijk et al., 2022; Ahmad et al., 2022); our study is the first to look at the intersection of various aspects of social identity and their impact on social position in the context of palliative care. Conducting a secondary analysis of data allowed us to enrich our understanding of migrant patients' palliative care experiences while minimizing the burden of research for participants (Ruggiano and Perry, 2019).

When interpreting our findings some limitations also need to be considered. Firstly, we adopted intersectionality as a framework for our analysis. However, the set-up of the original research was not intersectional. Consequently, the operation of certain axes of power in shaping lived experience may have remained obscured (Hunting, 2014; Cole, 2009). E.g. sampling was based predominantly on ethnic group membership and did not include majority Dutch; as a result we do not know if values and goals for advance care would similarly have remained implicit if religious patients held an ethnic majority position; how it would have affected social position in relation to health care professionals. To reach in-depth understanding of the workings of social position in end-of-life care we recommend future research to adopt an intersectional approach throughout the entire design.

Secondly, the variation in interviewers - matching respondents with an interviewer primarily based on language but in the case of most Turkish and Moroccan respondents subsequently also based on ethnicity and religion – may have caused respondents to express themselves differentially. We observed prominent religious discourse in certain interviews and were inclined to relate preferences expressed in these interviews to aspects of religious identity. However, upon reflection, we related the difference in discourse to the variation in interviewers. The team of researchers engaged in our data analysis and our elaborate discussion of findings, necessary for the interpretive task of situating intersectionality-relevant qualitative data, aided our understanding and enhanced credibility of our findings (Nowell et al., 2017).

4.3. Comparison with other studies

Impairment is inherently a social process, stemming from a mismatch between personal physical abilities and the demands of one's environment. Our findings shed light on the social context of gender

differences in impairment and old age, i.e. the perpetuating influence of gender norms that construct women as caregivers and how these effect place of care and ultimately place of death. Similar to our findings, Sutherland et al. show that female patients receiving palliative home care felt distress when having to rely on others, following loss of their ability to carry out feminine domestic 'duties' (Sutherland et al., 2018). For some female participants in our study this impelled the move to a nursing home; an 'enabling environment' (Verbrugge and Jette, 1994). Conkova et al., further differentiating between places of care, report that while older Turkish men showed readiness to move to a nursing home if necessary, Turkish women preferred a co-living arrangement in which people care for each other (Conkova and Lindenberg, 2020), emphasizing the importance of caregiving in maintaining gender identity for female older migrants. In an intersectional study, Ahmad et al. show that gender intersects with ethnic identity: informal caregivers with a more fluid, multifaceted ethnic identity experienced less "oppressive, gendered care norms" allowing them to seek formal care for their relatives, including care in a nursing home (Ahmad et al., 2022). These findings show how the organization of social relations shapes how resources are sought by – and allocated to – people requiring care at the end of life. Research furthermore shows inequity persists in the nursing home. Shabnam et al. report limited language proficiency prohibits older migrants from expressing their needs in the nursing home (Shabnam et al., 2022); in addition, our findings suggest this pertains in particular to older migrant women.

With regard to discussion of advance and end of life care, our and previous findings show that resorting to faith is a helpful coping strategy but *can* shut down conversations about care (van Eecheoud et al., 2017; Ahmad et al., 2022). We found this particularly befell conversations about medical end of life decisions (ELD); values and goals that may contribute to the 'quality of dying' (e.g. to lie, pray and die in the direction of Mecca) are in fact expressed. However, the experience of our respondents suggests these values and goals are not discussed or organized between patients, relatives, and care professionals. Actively engaging older migrants in advance care planning (ACP) conversations – a process by which patients establish goals and preferences for future care, across the physical, psychological, social and spiritual domain, together with relatives and care professionals – therefore, may benefit the organization of responsive care at the end of life (Wicks et al., 2018). In general, such ACP conversations are not yet common practice and are found to need active encouragement by care professionals (Glaudemans et al., 2015; Demirkapu et al., 2021). And findings by Ahmad et al. suggest this may particularly be the case for older migrants of lower SES; migrants who migrated later in life from an environment where educational opportunities were limited were found less assertive in organizing care (Ahmad et al., 2022).

Furthermore, differences in social position shape communication preferences, the interaction between patients and care professionals, and the opportunity to build trusting relationships (Shabnam et al., 2022). Addressing differences in social position and awareness of the resultant allocation of power may benefit ACP conversations. For example, our findings show religion and language concordance affected discussion of medical ELD. This suggests the need for increased effort to engage in discussion of advance care when providers are not fluent in the patient's preferred language. Indeed, Demirkapu et al. show that upon receiving comprehensible information Turkish older adults in Belgium find ACP useful and 'compatible' with their religious beliefs (Demirkapu et al., 2021). How the intersection of gender affects social positioning and interaction in ACP conversations is not apparent from our findings. Previous research, however, suggests attitudes towards ACP are shaped by gendered role expectations; women who are often caregivers for others at the end of life more often feel restricted in their own choices and goals (Williams et al., 2015; Ullrich et al., 2021).

Lastly, our intersectional analysis shows that preferences for medical ELD and discussion thereof are influenced by an interplay of diverse views and understanding of what is morally accepted by one's faith, by

knowledge of workings of ELD and by previous experience with end of life care. Based on these findings we recommend that ACP discussions explore differing perspectives on what constitutes a 'good death', and the medical interventions that facilitate such a death. For migrant patients with a strong faith it is advisable to involve spiritual caregivers with palliative care experience to guide in these discussions. Moreover, the decision-making is seldom a matter of one-to-one communication but involves relatives, whose values and preferences may differ. It has been found that frames of references for what constitutes a 'good death' shape interactions on an implicit level and are more often than not, not shared by all the actors involved in care at the end of life (Soom Ammann et al., 2016). Conflict may arise in the absence of adequate, ongoing negotiation of differing needs and expectations between all actors and a subsequent lack of joint decision-making (Soom Ammann et al., 2016; de Graaff et al., 2012). In our study, relatives experienced dissatisfaction with communication that was based on stereotypical notions and a lack of clarity on decision-making roles. Feeling heard is an important prerequisite to feeling safe (Shabnam et al., 2022) and our findings suggest not feeling heard results in distrust and the perception of (institutional) racism. ACP conversations have been found to contribute to trust and can be beneficial for the care relationship when care professionals recognize the role of families in end of life communication and decision-making (Wicks et al., 2018; van der Plas et al., 2022).

4.4. Conclusion & implications

Our findings show how – in light of impairment brought forth by incurable disease or old age – ethnicity, religion and gender intersect to create differential preferences for and experiences with care at the end of life for migrants and their children living in The Netherlands. The intersectional lens helps us understand how intersecting aspects of social identity and the social context shape relations between patients, relatives and care professionals affecting access to responsive care at the end of life. To provide end-of-life care responsive to the needs of diverse communities in practice, considering the interplay of said factors is paramount. Advance care planning (ACP) conversations can benefit the organization of responsive care through pro-active enquiry into values, goals and preferences for end-of-life care. Our findings suggest that ACP conversations responsive to the needs of older migrants require active engagement, with a focus on comprehensible information. And for migrant patients with a strong religious affiliation, an understanding of religion as a framework within which treatment decisions are planned for and made. With regards to the latter, it may be advisable to involve spiritual caregivers with palliative care experience. To do justice to the diverse and dynamic preferences of older migrants and their relatives as shown in our study, ACP conversations should allow for adequate, ongoing negotiation of differing needs and expectations between all actors, while addressing intersection of patients' social identities and differences in social position.

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CRedit authorship contribution statement

Marieke Torensma: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Xanthe de Voogd:** Data curation, Methodology, Project administration, Writing – review & editing. **Roukayya Oueslati:** Formal analysis, Writing – review & editing. **Irene G.M. van Valkengoed:** Formal analysis, Writing – review & editing. **Dick L. Willems:** Funding acquisition, Supervision, Writing – review & editing. **Bregje D. Onwuteaka-Philipsen:** Formal analysis, Funding acquisition,

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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