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Muslim doctors and decision making in palliative care: a discourse analysis

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ABSTRACT

Muslim care providers working in a Western context have to deal with Western norms and regulations about palliative decision-making. It is known that some of them struggle with aspects of palliative care, but the way in which they argue and act when working in a Western context has not previously been studied. Therefore, this study examines the ways in which Muslim doctors frame their attitudes and practices regarding palliative decision-making. Our aim was to explore these factors through in-depth interviews, which were then analysed by means of Discourse Analysis, based on Willig's six-stage approach. For triangulation purposes, a word frequency analysis data was performed. The subjects included in the study were ten Muslim doctors with recent professional experience in palliative care in a Western setting. The analysis resulted in the identification of six discourses: the avoidance of suffering as standard medical care, mutual acceptance, paternalistic discourse, the acceptance (or non-acceptance) of dying, suffering as a religious concept, and predestination. Their interrelated dynamics demonstrated the dominance of the avoidance of suffering discourse as the standard attitude. Our sample indicates that it is the prevention of suffering as a standardised therapeutic goal, rather than as a religiously motivated course of action, guides Muslim doctors' attitudes and action orientation towards palliative decision-making.

KEYWORDS

Muslim doctors; Islam; palliative care; decision-making; discourse analysis

Introduction

Palliative care involves complex decision-making processes that may touch upon the religious views of the doctors, patients, and relatives involved (Ernecoff et al., 2015; Geros–Willfond et al., 2016; Sprung et al., 2003; Sulmasy, 2006). Ideally, decision-making in palliative care is an interactive process which reflects a patient's values (Henselmans et al., 2015a, 2015b; Shay & Lafata, 2015; Stiggelbout et al., 2015). Decision-making is implicitly or explicitly influenced by personal values (Hermann et al., 2015), hence

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questions arise concerning a doctor's religion or philosophy of life in relation to the care they provide.

Palliative care models have largely been developed in Western countries, while Muslim countries have been slow to follow suit (Al-Awamer & Downar, 2014). As a result, Islamic cultural and religious values have not yet been incorporated into palliative care models. At the same time, young Muslim doctors who have trained in the West are entering European health care systems (Muishout et al., 2018). These doctors are expected to act in accordance with a palliative model that is strongly focused on providing comfort and preventing suffering (Pastrana et al., 2008). However, they may experience difficulties with certain aspects of palliative care, such as withdrawing life support equipment, communicating the transition from curative to palliative care, and showing concern about the impact of their own actions on the course of the disease (Borhani et al., 2014; Jafari et al., 2015; Saeed et al., 2015). Furthermore, there is convincing evidence that the religious wish or hope – expressed by patients' families – to sustain life, even in the end of life phase, may result in a more 'aggressive' style of care (Ayeh et al., 2016; Bülow et al., 2012; Shinall et al., 2014). Any such approach is diametrically opposed to the Western paradigm of palliative care. Personifying both a personal Muslim identity and that of a doctor, we asked Muslim doctors for their views on these issues, both in a personal context (as Muslims) and as medical doctors. With this study we aim to contribute to research which addresses the role of religion and ethnicity in perception and attitudes towards palliative care by investigating the way in which Muslim doctors professionally position themselves in this respect (Ahaddour et al., 2018; Gatrad & Sheikh, 2002; Seale, 2010).

We studied interviews with Muslim doctors working in the Netherlands who have experience of palliative care, to provide insight into different ways of framing palliative care attitudes and practices. We focused primarily on the way in which speech is utilised. Language can hide ways of seeing the world, without the speaker necessarily being aware of it. This is why we chose discourse analysis as a tool to help in systematically scrutinising the relationship between language use and ways of seeing and being in the world. Our central question was the following: 'How does language use by Muslim doctors, who have had a Western education and who work in the West, shape their attitudes and practices regarding palliative decision-making?

Methods

Methodological approach

We used Discourse Analysis (DA) to analyse the texts of the interviews. This approach is based on the view that human speech is an instrument for shaping, rather than describing, an objective reality. In other words: talking about concepts in a certain way ('love is fate and meant to be') can shape the way people act (waiting for love, not willing to 'work' on a relationship) and feel (frustrated, disappointed when they don't find love). In DA, the main object of study is language, and the ways in which specific topics are discussed (either verbally or in writing), and how this relates to people's practices (Willig, 2015).

Corpus Linguistic (CL) analysis was used to triangulate and enrich the findings of our DA. CL is used to map and analyse the ways in which words are used in context, and it can enrich other qualitative approaches. Besides adding a quantitative dimension, it has the

potential to determine if, and how, larger blocks of language surrounding certain words confirm, elaborate, or contradict the main findings of the DA (Baker et al., 2008). The analysis was applied to data that had been used previously (as part of the same project) for the purposes of phenomenological analysis. That analysis, which was aimed at gaining an in-depth understanding of the individual professional experiences of Muslim doctors with palliative sedation, was published in 2018 (Muishout et al., 2018). Both that initial analysis and the present one are part of the same overarching research project on Islam and palliative care.

Participants

A total of fifteen participants were recruited. Each of these individuals had professional experience of the use of palliative sedation in a general medical setting. None of them were specialised palliative care doctors. Nine of these participants were recruited from our professional network (consisting of a number of Muslim doctors) in Dutch health care. A further six were recruited following a search of hospital and general practice websites, in which potential candidates were selected and subsequently contacted. All of them agreed to participate. After the inductive coding, interpretation and discussion of the first eight interviews, in terms of their mutual relationship, it was concluded that thematic saturation had been achieved. By thematic saturation, we mean that no new themes or insights emerged that were of added value with regard to the purpose of the study. Thus, the decision was taken to conduct two additional interviews, to conclude the process of data collection. Accordingly, eight men and two women ultimately took part in the present study, while the five remaining participants were not interviewed. All of the participants, who were from a Sunni background, described themselves as religiously observant. They were all practicing doctors in The Netherlands during the data collection phase (see Table 1). It is estimated that there are currently 1.2 million Muslims living in the Netherlands, which is equivalent to 7.2% of the total population (Pew Research Centre, 2017). There are no official statistics available concerning the numbers of Muslim doctors in the Netherlands. However, AMAN, the Dutch association for Moroccan doctors with an Islamic background, reported that two hundred Moroccans are active in this area. These include medical specialists, medical interns, general practitioners and medical students in 2018 (Aman, personal communication, 2019). Since Moroccans make up about 2.3% of the total Dutch population (CBS, 2019) these figures may provide a degree of insight.

Table 1. Participant characteristics.

Identifier	Birth Year	Sex	Type of Physician	Ethnic Background
1	1977	Male	Trainee general practitioner	Moroccan
2	1985	Male	General practitioner	Moroccan
3	1984	Male	Neurologist	Moroccan
4	1983	Male	Trainee internist	Turkish
5	1959	Male	Geriatrician	Afghan
6	1974	male	Anaesthetist	Moroccan
7	1980	Male	Acute medicine specialist	Moroccan
8	1977	Female	General practitioner	Moroccan
9	1970	Male	General practitioner	Turkish
10	1982	Female	Trainee internist	Moroccan

Research team

Our multidisciplinary team included individuals with expertise in the field of linguistics (AdlC), clinical oncology (HvL), religious studies (HvL, GW) and Islamic ethics (GW, GM).

Ethical issues

The Academic Medical Centre's Ethical Medical Review Committee exempted the study from the requirement for ethical consent, as The Dutch Medical Research Involving Human Subjects Act (WMO) did not apply. The participants all took part on a voluntary basis. They were guaranteed that any reverence to their names in any interview material would be coded by means of numbers. They were provided with information about the study before and after the interviews. They all consented to our use of their interview data.

Data collection

Semi-structured interviews were conducted during February and October 2016. These interviews, which took place in a quiet environment that was well-suited to in-depth interviews, lasted between forty five and one hundred minutes. At the beginning, each participant was asked to present a case involving palliative sedation in which they had personally been involved. Their personal experiences were then explored in depth, along two thematic lines. The first theme addressed the relationship between palliative sedation and a 'good death'. We posed questions such as: *What do you mean by a 'good death' … for a patient … for his/her family … for yourself?* And: *What do you feel about pain relief in the form of medication at the end of life? Would you use it yourself if you were a patient … based on what considerations?* The second theme discussed Muslim and professional identity. Here, we asked questions such as: *Do you consider yourself a Muslim? What is the current role and meaning of religion in your daily life? What is the significance of religion in your professional life? Do you think your beliefs play a role in the considerations and choices you make as a professional?*' Following on from these questions, in-depth questions were asked in which the interviewees' relationship with palliative care was further explored (see Appendix for the interview guide). All interviews were initially recorded, and then transcribed verbatim. The original Dutch quotes that are used in the results have been translated verbatim from Dutch to English.

Data analysis

The subject of palliative care as a whole was discussed intensively during the interviews. Any material obtained in this way was used for the purposes of the current study. Our participants have to relate to palliative care both as Muslims and as doctors. Accordingly, DA is a suitable strategy for investigating the way in which different discourses manifest themselves in identity construction and in the perception of a person's responsibilities as a Muslim doctor. The analysis involved a phased, cyclical process of reading, deconstructing, and reconstructing the dataset, by coding the interviews (i.e. labelling significant words and passages (GM)).

We used Willig's six stages to analyse the data (Willig, 2015). In short, these stages map various ways in which discursive objects are constructed, analyse the ways in which people position themselves in relation to these objects, and explore their significance at the level of individual experience and specific action (these stages are summarised in Box 1). Given the methodical emphasis on the relationships between thoughts, feelings, and actions, this is a suitable instrument for focusing on the process of palliative decision-making. To determine the discursive object of our analysis, we coded four interviews in which palliative care was discussed. What emerged was that medical decision-making formed a recurring pattern, one that structured the way in which the participants developed their stories. Based on this observation, palliative decision-making was taken as analytical framework to shed light on our research topic. After this, all data related to palliative decision-making was selected. From here, discursive constructions were identified, mapped and developed through Willig's stages one and two (by GM), then discussed in a plenary session (GM, HvL, AdlC, GW). The first step was to list every occurrence of statements concerning palliative decision-making ('palliative decision-making is … …') and then to cluster them into different groups, which formed the basis for the discourses ('the normal thing to do' versus 'wrong in the eyes of God' etc.). The team discussed thematic features, differences and similarities between the discursive constructions. The outcome was processed by GM, and then included in the development of the subsequent stages. The same approach was applied to stages three and four and, ultimately, five and six. In the course of several meetings, the authors further developed and refined various discursive constructions, which were finally categorised into six overarching discourses. In the complementary corpus linguistic analysis, individual, frequently used terms related to palliative care were analysed in context. AntConc (a free online software package) was used for the purposes of this word frequency analysis (Anthony, 2019).

Box 1. Willig's six-stage approach. Willig (2015, Chapter 7).

Stage	Description
1) Discursive Constructions	- Detecting and mapping the different ways in which the discursive object is discussed, either explicitly and/or implicitly.
2) Discourses	- Focusing on the differences between discursive constructions. - Framing different discursive constructions of the object within broader discourses.
3) Action Orientation	- Zooming in on the discursive contexts in which the different constructions are mobilised. - Analysing the results of constructing the object in this particular way, at this particular point within the text. - Analysing its function and relation to other constructions produced in the surrounding text.
4) Position	- Identifying subject positions within the structure of rights and duties that derives from the various constructions of the discursive object.
5) Practice	- Mapping out the way in which discursive constructions either pave the way for specific actions, or exclude them.
6) Subjectivity	- Analysing the consequences of the various subject positions taken, regarding the subjective experiences of the participants. - This is the most hypothetical stage.

Attachment: interview guide.

Main questions

1. Please describe a case in which palliative sedation took place.
2. Why was sedation initiated (in this particular case)?
3. What prompted the decision to sedate the patient? ….who was involved?. …. what was the response?
4. Can you tell me how you communicated the proposal regarding palliative sedation? Who was involved (present)?
5. How did the patient/their family respond to your proposal to switch to palliative sedation?
6. Can you describe the subsequent course of events (up until the moment of death?)
7. How did those who were closely involved with the patient (family, relatives, etc.) respond?
8. Can you tell me about your interactions with those involved, after the patient died?

*(questions 1 to 8 can be applied to several different cases)

Palliative sedation & a 'good' death

9. What do you see as the objective of palliative sedation?
10. What do you mean by a 'good death' – from the patient's viewpoint or from that of their family (or from your own viewpoint)?
11. How do you feel about pain relief (in the form of medication) around the end of life? (would you use it yourself if you were a patient and, if so, on what considerations would you base this decision?)
12. In your view, how does the use of pain management relate to a 'good death', and what are your views of palliative sedation?
13. What, in your opinion, does the use of palliative sedation at the end of life mean for the patient's 'quality' of life?

Religious background

14. In what kind of religious environment did you grow up (inside and the outside the home) ?
15. Do you consider yourself a Muslim? Can you tell me something about that?
16. May I ask if you consider yourself to be a member of a specific branch of Islam?
17. What is the current role and meaning of your religion in your daily life?
18. What is the significance of religion in your professional life (as a physician)?
19. Do you think your beliefs play a role in the considerations and choices you make as a professional?
20. What do the proclamations of imams or Islamic scholars mean to you?
21. Are you guided by any of such proclamations concerning palliative sedation?

Are there other things you would like to mention, which have not been addressed here?

Results

In the data, we were able to distinguish six discourses: *the avoidance of suffering as standard medical care, mutual acceptance, paternalistic, the acceptance (or non-acceptance) of dying, suffering as a religious concept*, and *predestination* (see Table 2).

Avoidance of suffering as standard medical care

This discourse shaped palliative decision-making as serving the ultimate goal in medicine: the avoidance of suffering. By presenting the patient's absence of pain as 'guiding principle', it made avoidance of suffering a personal mission to be achieved:

> Well, at some point you make considerations. So yes, it means …. .at such a stage you try to ensure that someone is comfortable, that someone has no pain …. And that someone has no pain …. and that breathing is calm too. Because, that's actually the **guiding principle**, right. Because it falls under the quality of life … That someone does not suffer at the very last moment of his life, while we have the possibilities to prevent that. And that someone can just say goodbye well. (**quote 1, participant 1, line 114–118**)

The obligation to fight pain was expressed by using the modality of 'must':

Table 2. Overview of discourses and quote numbers.

Discourse	Quote numbers
Avoidance of suffering as the standard medical treatment Summary: The standard aim of palliative decision-making is to avoid suffering, as far as possible. This implies that the main aim of treatment is fixed in advance and that it must be achieved.	1 to 8
Mutual acceptance Summary: The results of palliative decision-making must be fully acceptable to all of the parties involved. As a result, it becomes a shared responsibility.	9
Paternalistic Summary: In the case of palliative decision-making, the doctor should always have the final say. This stems from the premise that the doctor knows what is in the best interests of his/her patient or of the family representative in question.	10 to 13
Acceptance (or non-acceptance) of death Summary: The rejection of palliative decision-making reflects a non-acceptance of death. This is underpinned by the desire (either conscious or unconscious) to postpone a beloved individual's final farewell for as long as possible.	14 to 18
Suffering as a religious concept Summary: Palliative decision-making requires doctors to take an active approach when their patient is in pain. This can put them at odds with suffering as a religious means of doing penance for sins committed in the past.	19 & 20
Predestination Summary: Doctors must answer to God for their palliative decision-making. Accordingly, predestination can either confirm or repudiate the moral correctness of their professional action.	21 to 24

> Well, it may differ for different people … .but basically, in the Netherlands and even worldwide, I think that, as a doctor, it is your **duty** to relieve suffering. And to ensure that no-one suffers. You must use the resources you have, in consultation with the family …. and, in this case, using the medication you have. And to ensure that no-one suffers. Because if someone does not suffer …, that's also quality of life. So at the last moment you try ….that quality …… that someone is not gasping for air, screams of pain. That someone's not. …. for the family that's also …. …. You don't do that for the family alone, you do this solely for the patient. Because we have the means, … that medication, to make sure that quality of life can be achieved. So yes, I endorse that …. I think that's important. **(quote 2, participant 1, line 122–129)**

> So if patients are in pain at such a stage you **should** for example, provide them with morphine, or some other medication. **(Quote 3, participant 4, line 336–337)**

> It is for good reason we give morphine. Morphine is not a paracetamol. That we say: okay, for a knee, for pain … I won't give morphine immediately. I don't do that. But if necessary, you **have to** do something. **(quote 4, participant 5, line 402–505)**

> In the past people suffered a lot until they died. In case of suffering you didn't have the opportunity to do something about it. For lots of people this still applies, for example, in Morocco. If you have no money, you will suffer on your deathbed, unrelieved. No, or insufficient, access to painkillers is a reality over there. So, if you do have the opportunity now to do something about it in terms of pain management, then you **have to** use it. In my view, it is much more important to ensure a patient feels somewhat comfortable, so he faces death a little more comfortable. **(quote 5, participant 10, line 133–141)**

Not treating pain would be considered 'unethical':

> Because those people have not died yet, they are still with us. But . . ., they are in pain, they are hungry, they suffer from distress. And I think it's **unethical** not to treat those people, while I have something readily available. . . . . to give them a light form of morphine. While they can still talk to their loved ones, or maybe say a few more words, so they don't have to be afraid, to have the feeling of suffocating. Yes, I think that this is particularly important. **(quote 6, participant 3, line 179–184)**

A palliative trajectory was portrayed in terms of a natural process in which sedation as a final outcome was seen as being 'no different than giving someone a paracetamol tablet':

> And then I view it as **no different than giving someone a paracetamol** tablet when they are in pain. **(quote 7, participant 2, line 241–241)**

Opting for palliative sedation as standard practice was further normalised by describing it as an approach that does not 'give rise to much debate in the Netherlands':

> But I do think if you deny patients palliative sedation or morphine in their final phase, that quality of life is less than if you had done it. I'm certain of it. It doesn't seem to me that this does not **give rise to much debate in the Netherlands** either. In fact I don't know anyone who wouldn't use it in such circumstances. **(quote 8, participant 4, line 355–359)**

Mutual acceptance

The *mutual acceptance* discourse shapes palliative decision-making as the shared responsibility of all involved. This involves positioning the doctor as a mediator, someone who is prepared to construct a joint decision: 'you manoeuvre around between the wishes of your patients, what you are able to do, what you are allowed to do, and what you wish to do':

> It's not that. **You manoeuvre around between the wishes of your patients, what you are able to do, what you are allowed to do, and what you wish to do**. Therein you need to find a middle ground, so that all parties are satisfied. **(quote 9, participant 2, line 284–285)**

Paternalistic

The *paternalistic* discourse shaped palliative decision-making as an interaction between the doctor and family members representing patients who no longer had decision-making capacity, with the doctor as the final decision-maker. The principle of 'best interests' played a central role in justifying this primary orientation. Family representatives, especially those with a Muslim background, were positioned as needing protection from the burden of responsibility and from feelings of guilt. Therefore, they should not 'bear the full burden of decision-making':

> But if they **get to decide themselves fully**, they can get a sense of guilt. Like: If only we had done something else. Or: If only we had waited somewhat longer. And: If only we had done more. And if you present it as a statement, because I must be convinced there's no going back myself, then, people find it easier, in my experience. **(quote 10, participant 3, line 96–100)**

This could be achieved by presenting what was, in fact, a palliative treatment proposal as an announcement. In this way, the family representative could say: 'the doctor said so':

> If they opt for active policy, I can choose to say: no, on medical grounds. But in my experience such a thing is very difficult for the contact person, including that Muslim man. When I say: sir, how do you feel if I don't provide tube feeding? So when you do so, he feels responsible. He will say: gosh, I agreed with not providing tube feeding, not providing infusion, not sending someone to hospital. Then it will soon be my fault and then I will be criticized by others. That is why my experience is, and I tell my other colleagues too; when we say: your father is not eligible for resuscitation because of this and that . . . . In that case it is: **the doctor said so**, and he won't feel responsible. **(quote 11, participant 5, line 187–196)**

Muslim patients and relatives were framed as having 'no knowledge about palliative care', the doctor as knowing what was in the best patient's interest:

> People (of Islamic origin, GM) are totally unaware, live their lives and have **no knowledge about palliative care. (quote 12, participant 10, line 128–129)**

This *knowing* also concerned religiously motivated objections against palliative care. By describing them as 'lacking knowledge' Muslim families were positioned as in need of a guardian, i.e. the Muslim doctor:

> But some relativization … .and … .sense of reality concerning the situation. But in this case, what I have understood, I can imagine that with this Muslim family, … from faith perspective. Yes, If someone is **lacking knowledge . . . . . .** .that, this is often crucial, … treatment until the end. Because it is thought that this is the prevalent Islamic opinion, actually. Treating and continuation to the last breath. **(quote 13, participant 1, line 264–268)**

[Non] acceptance of dying

This discourse shaped people's positive and negative attitudes towards death and dying, and their relation to palliative decision-making. The *non-acceptance of dying* led to denial of a terminal patient's visible physical suffering, with family members desiring to keep a loved one alive 'as long and as much as possible':

> But you must be realistic, she is suffering. So you should not let that happen. But that man doesn't accept this. He said: no, nothing wrong. For example, he does not accept that she is in pain. But daily reporting was full of it: every touch is painful, changing her body position is painful. But that man came for example, the moment this woman was resting and said: no, she feels no pain. Yes, no, I think … I think … he seemed really at peace with it. Perhaps, other factors play a part with him: letting go of a sick demented sister afflicted by a stroke, wheelchair dependent, preoccupied, does not communicate, has recently stopped eating and drinking. But still … … … . He wanted to keep her alive, **As long and as much as possible (quote 14, participant 5, line 107–119)**

As a result, advising family members in palliative decision-making concerning their parents became synonymous with telling someone 'to let her go':

> It may be very, it sounds strange, Is still … Every time when someone asks me, I think: oh, I wish they had not asked, I find it so hard. I have also experienced it with my mother. Because it is the most dear person about whom we are talking. That person is talking about his mother, his father, his partner. Uh, uh, and then you should offer advice …, because we're actually talking about saying farewell, right. Like: how should you actually say farewell to your mother: **to let her go**, uh, drug her, we stuff her full of morphine. **(quote 15, participant 9, line 266–269)**

A task which was reported as heavily charged, because this was something 'you cannot just say':

> Yes, that's something **you cannot just say**. You know, there are all kinds of reservations. Somebody like that just wants dad and mom to stay with them for as long as possible. **(quote 16, participant 9, line 270–272)**

On the other hand, the *acceptance of dying* featured quite frequently in the data. In this accepting attitude, doctors present themselves as being much more at ease about palliative care, for example, quoting a patient as saying that 'he had lived his life' and that refraining from medical intervention was 'the natural way':

> One morning, he wanted to talk. During this talk he indicated he wanted us to discontinue his treatment. He felt that he had had enough. He was very sure about this, very convinced, **he said he had lived his life**. Well, we went along with it, and have accepted this. **(quote 17, participant 10, line 40–43)**

> And, hmm, my own view is something like this: yes, **the natural way**. If someone . . . . . He wasn't very old, but at some point you have to die of something. You shouldn't extend life endlessly. (quote 18, participant 8, line 233–235)

Suffering as a religious concept

This discourse shaped palliative decision-making as a practice that could potentially conflict with professional medical standards. The participants perceived themselves as responsible doctors with a duty to prevent suffering as being 'contrary to the steps you would normally take, as a doctor':

> Some views within Islam say: well, suffering is a kind of penance, a means by which you can expiate your sins. But this is contrary to **the steps you would normally take as a doctor**. Yes, all your life you work to make sure that your patients are not in pain but somehow, at the end, when they actually about to die, then you really musn't do anything about it. **(quote 19, participant 6, line 167–170)**

Thus, they were unable to reconcile religiously motivated suffering with their professional identity. An exception was made, however, if the patient in question deliberately chose to suffer because they 'wanted to suffer pain':

> Well, look, if someone is able to explain he wants it that way, and he tells you: **I want to suffer pain**, . . . and consciously chooses to do so. Fine, that's okay with me. **(quote 20, participant 3, line 357–358)**

Predestination

Predestination was shaped as a concept that casts doubt upon – or denies – that any actions taken by the doctor could influence the course of events. There was doubt concerning the potential effects of a doctor's choices and actions on the exact moment of death. Although they said that a Muslim ought to believe in predestination, i.e. that the moment of death 'is already known', these participants wondered whether palliative sedation interfered with God's actions:

> But all right, we as Muslims obviously believe that there is a time this is going to happen … You don't speed it up for one second, you don't extend it for one second. And this moment **is already known**. However, well, it seems to me like: well, I'm doing something of which, If I wouldn't do it, it would take a different course. We know that. **(quote 21, participant 9, line 185–189)**

Further doubt about the impact of the choices made was expressed by positioning oneself as potentially being disobedient to God, were one to refrain from treating minor diseases. In that case, the conviction that 'fate is ultimately in the hands of Allah' is inconsistent with the divine command to seek healing when effective treatment is available:

> Yeah, without an ambulance, without bells and whistles. And, uh, uh, maybe I would find it hard if they should say about this person: we won't do anything at all. Something like that seems difficult to me. With this person you mean? Uh, yeah, sorry, the patient. If they would say: we won't give antibiotics, we won't give infusion and he will die of the disease. And what would make this particularly hard for you, you think? Because I feel like I'm not a good doctor. That I am not helping this person as I should. I mean …, I want to cure someone. At the same time, however, it's true … I must not think I have that much power. As if I could someone …., you know. Eventually **fate is ultimately in the hands of Allah**, I'm certain of that. But I also believe there's a duty … .whenever there's a disease, there's the duty of searching for a cure, when available. **(quote 22, participant 8, line 397–407)**

Confidence in the correctness of the doctor's own choices and actions was the result of framing God as the sole determinant of the beginning and the end of life. Therefore, the doctors' involvement was limited to making sure that a patient 'did not suffer in her final days' before death:

> It is true that this woman has got the disease and that she is going to die. I didn't cause that, it happened to her. Well, you could say that Allah has ordained it that way. Or that it's her destiny, maktūb. And that I accidently stopped by, because she's in pain. And that I happened to come along. And … that my contribution is that she **did not suffer in her final days**. But. that I am not the doctor who gives her the last push. That's how I try to reason it through for myself. **(quote 23, participant 3, line 261–265)**

Doctors were also able to be confident about a decision by describing the patient's request to terminate the treatment and successively rapid death as being based on their feeling 'that their time had come':

> Well, actually fine. Fairly well. I especially liked it that this man, who seemed to feel **that his time had come** … That he had lived his life and therefore decided to quit with it (his medical treatment, GM). Yeah, and the extraordinary thing was, off course, that he died on the same day. Obviously his time had come. Someone else could have lived for another few weeks, so to speak. **(quote 24, participant 10, line 92–95)**

Discourses in interaction

Figure 1 depicts the dynamics and hierarchical relationships of the six identified discourses, in terms of their ability to influence the decisions taken by Muslim doctors in palliative care. The central loop in the figure moves in the direction of the arrow, yet the palliative decision-making process can move through the loop multiple times. The loop

Figure 1. Discourses and their interaction between Muslim doctors and care recipients in palliative care.

represents the dominant power of the *avoidance of suffering as standard medical care* discourse. This discourse gives direction to all action orientation, as confirmation of its dominance. The loop, which represents the route leading to it, encounters four complementary discourses: the *mutual acceptance discourse*, the *paternalistic discourse* and the *acceptance of dying* discourse. These all share a functional subordination to the realisation of the dominant discourse. If there is no *acceptance of dying* or if doctors approach *suffering as a religious concept* (which is incompatible with their professional ethics), it will be hard for the decision to gain *mutual acceptance*, and the only way to enter the central loop will be by way of the *paternalistic discourse*. In other words, when relatives do not accept that the end of a loved one's life is near and/or that steps must be taken to combat his/her pain, the attending physician will have their work cut out to get them to agree with palliative sedation. The outer area of the figure embeds one the *predestination discourse*. This, we would argue, has no direct influence on the action orientation of the doctors, but it does constitute the desired or unwanted religious side-effects that arise from the dominant discourse.

The case of 'suffering'

To better understand the language used by doctors when discursively constructing palliative care, we took a closer look at the term 'suffering', which was a central concept in the interviews. Conjugations of the verb 'to suffer' ('lijden' in Dutch) occurred 115 times in the total data set (an average of 11.5 times per interview). The way in which 'suffering' was used confirms the dominance of the *avoidance suffering as standard medical treatment* discourse. In the interviews, suffering was described as 'unnecessary', 'unbearable', 'terrible'. Many instances in which the term 'suffering' was used seem to indicate that the interviewees found this to be unacceptable. At the same time, some occurrences of 'suffering' in the data reflected the discourse of '*suffering as a religious concept*': 'suffering is penance', 'by suffering, you can lighten the burden of your sins'. The discourse *acceptance of dying* was apparent in the cases where dying was framed as something peaceful, as long as there is no suffering: 'it ended well, without suffering', 'dying in peace, without suffering'.

Discussion

Our sample in this DA- and CI based study shows that the most powerful discourse in a Muslim doctor's palliative decision-making is *avoidance of suffering as standard medical care*. A 'power game' occurred when the patients (according to several of our participants) were not able (or no longer able) to participate in palliative decision-making while they (the doctors) were being challenged by the family members' opposing views, whether or not religiously motivated (by Islam). These observations can be traced, in particular, to the *acceptance (or non-acceptance) of dying* and *suffering as religious concept*. This specific setting which arose when patients lacked decision capacity forced the doctor into a paternalistic straightjacket, in which they imposed the avoidance of suffering agenda. As a result, it seemed that any family members who disagreed were not (potentially at least) on an equal footing with the doctors, in terms of palliative decision-making. In this context, the use of the *paternalistic discourse* was of particular interest. Palliative decision-making by family members for their terminal ill loved ones is known to be linked with psychological burden (Azoulay et al., 2005; Radwany et al., 2009; Schenker et al., 2012; Wendler & Rid, 2011; Yamamoto et al., 2017). Therefore, the paternalistic tendency of some respondents (viz. to take decisions *for* family members rather than *with* them) could be regarded as being at least morally defensible, as a means of relieving them of that burden.

The resulting image of our current study provides a counterweight to the notion that religion and the end of life imply a focus on life-prolonging action, potentially involving additional suffering (Ayeh et al., 2016; Bülow et al., 2012; Shinall et al., 2014). Instead, the Muslim doctors in our sample seem to be fully committed to use palliative care in accordance with Western standards. However, some of them did indicate that they struggled with the possible relationship between the course of the disease and their own professional interventions. The primary focus on pain management, which follows from the dominant discourse, does not seem to be compliant with the modern doctor-patient relationship, as defined by highly institutionalised patient autonomy and shared decision-making (Emanuel & Emanuel, 1992; Henselmans et al., 2015a). However, a close,

integral reading of the data does suggest that as long as patients are able to express their wishes, their autonomy will be the cardinal factor in actual decision-making, even if this includes a wish to suffer.

From the perspective of Islamic law, the doctors' position as the sole and final actors in medical decision-making, in the absence of effective curative treatment, is supported by such transnational Saudi Arabia-based Islamic councils as the International Islamic Fiqh Academy and the International Fiqh Academy. Both bodies argue that any decision to terminate treatment on the grounds of futility should be based purely on a medical-technical assessment. Hence, the paternalistic way in which palliative decision-making was constructed seems to be entirely in keeping with the prevailing views in Islamic jurisprudence (International Islamic Fiqh Academy [IIFA], 2000; Islamic Fiqh Academy [IFA], 2015). Theoretically, based on these normative principles, any patients (and their loved ones) who strongly adhere to the traditions of Islam are morally obliged to accept the professional authority of physicians in the process of palliative decision-making.

We suggest that a wider discourse on *present-day dying* versus *dying in the past* might generate a useful understanding of the dynamics that we found. The central issue in constructing palliative decision-making seems to be the interplay between dying and the value placed upon suffering. *Dying in the past* denoted suffering as an inseparable and religiously meaningful part of the process of dying (Schwartz & Lutfiyya, 2012). In the Islamic tradition in particular it has been signified by the majority of Muslim scholars as a means of expiating minor sins or, in the absence thereof, as a way of acquiring a better position in paradise (Muḥammad, 1984). *Present-day dying*, which takes place in a highly medicalised context where there is greater control of pain, emphasises the absence of suffering as one of the main parameters of a good death (Schwartz & Lutfiyya, 2012). This way of dying is not without obligation, it is actually a requirement of the current medical system. Hence, the acceptance of dying within the *acceptance (or non-acceptance) of dying* discourse seems to be an imperative framework designed to fit into the framework of *present-day dying* (Zimmermann, 2012).

Implications for practice and further research

The findings may help to raise awareness of the way in which the *avoidance of suffering as standard medical care* discourse shapes the attitudes and action-orientation of Muslim doctors in the process of palliative decision-making, in interaction with the family of the patient involved. This applies in particular to the paternalistic reflex, which is evoked in confrontations with alternative discourses (represented by family members). It may be advisable to invest time and effort in engaging families (especially those with an Islamic background) in a dialogue, to explain the considerations involved in palliative decision-making (Oosterveld–Vlug et al., 2017; Pope, 2012). Equally, formal consideration should be given to the mental burden imposed on family members (Muslim or otherwise) by palliative decision-making. One finding of particular interest, concerned the appearance of different patterns in the way in which the Muslim doctors relied on their religious faith to help them cope with the burden of palliative decision-making. This finding merits further research.

Strengths and limitations

The specific composition of our research team can be considered a strength. As our type of study (discourse analysis) benefitted from linguistic expertise (AdlC), its subject (Muslim doctors and palliative decision-making) required a knowledge of clinical oncology and palliative care (HvL), a background in religious studies (HvL, GW) and a specialised knowledge of Islamic ethics (GW, GM). A limitation is that, with a single exception, the participants were all educated and trained in the Netherlands. Hence, the results may be different for Muslim doctors working in other Western countries. The study's main strength is that, by using a mixed qualitative and quantitative method, it provides insight into the role and function of religion in the power structure in discourses about palliative decision-making among Muslim doctors.

Conclusions

The prevention of suffering seems to be a decisive factor in the construction of palliative decision-making by Muslim doctors. The confrontation with alternative discourses, whether or not these are religiously tinted, which hinder its application evoke a paternalistic attitude. These findings may help to illustrate the power dynamics involved in palliative decision-making. If doctors and other care professionals can recognise and acknowledge these dynamics, this may help to improve the position of family members (surrogate decision makers) in the process of palliative decision-making, to achieve better doctor patient relations, and, ultimately, to deliver better care.

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Authorship

This study was designed by GM, AdlC, GW and HvL. GM recruited the participants and collected the data. All authors took part in the process of data analysis. GM and AdlC wrote the first draft, after which all of the authors actively participated in writing subsequent versions.

Data sharing

Details of the interview data can be obtained from the corresponding author. All of the participants gave their informed consent for coded data sharing.

Disclosure statement

We declare that we have no competing interests. This study is unfunded.

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Ethics and consent

The Medical Research Involving Human Subjects Acts (WMO) did not apply to this project.

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