

**Withholding/withdrawing life-sustaining treatment in a multi-ethnic critical care setting: an ethnographic study**

Van Keer, Rose-Lima; Deschepper, Reginald; Huyghens, Luc; Bilsen, Johan

*Published in:*  
Journal of Palliative Medicine

*DOI:*  
[10.1089/jpm.2019.0653](https://doi.org/10.1089/jpm.2019.0653)

*Publication date:*  
2021

*License:*  
Unspecified

*Document Version:*  
Accepted author manuscript

[Link to publication](#)

*Citation for published version (APA):*  
Van Keer, R-L., Deschepper, R., Huyghens, L., & Bilsen, J. (2021). Withholding/withdrawing life-sustaining treatment in a multi-ethnic critical care setting: an ethnographic study. *Journal of Palliative Medicine*, 24(3), 338-346. [32721261]. <https://doi.org/10.1089/jpm.2019.0653>

**Copyright**

No part of this publication may be reproduced or transmitted in any form, without the prior written permission of the author(s) or other rights holders to whom publication rights have been transferred, unless permitted by a license attached to the publication (a Creative Commons license or other), or unless exceptions to copyright law apply.

**Take down policy**

If you believe that this document infringes your copyright or other rights, please contact [openaccess@vub.be](mailto:openaccess@vub.be), with details of the nature of the infringement. We will investigate the claim and if justified, we will take the appropriate steps.

1

2 **Withholding/withdrawing life-sustaining treatment in a multi-ethnic critical**  
3 **care setting: An ethnographic study**

4 Rose-Lima Van Keer<sup>1</sup>, Reginald Deschepper<sup>2</sup>, Luc Huyghens<sup>3</sup>, and Johan Bilsen<sup>4</sup>

5

6 *Published in:*

7 *Journal of Palliative Medicine*

8

9 *DOI:*

10 *10.1089/jpm.2019.0653*

11

12 *Publication date:*

13 *2021*

14

15 *Document Version:*

16 *Accepted author manuscript*

17

18 1 PhD, Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Vrije  
19 Universiteit Brussel, Belgium.

20 E-mail: [Rose-Lima.Van.Keer@vub.be](mailto:Rose-Lima.Van.Keer@vub.be)

21 [Corresponding author](#)

22

23 2 PhD, Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Vrije  
24 Universiteit Brussel, Belgium.

25 E-mail: [Reginald.Deschepper@vub.be](mailto:Reginald.Deschepper@vub.be)

26

27 3 PhD, Critical Care Department, Vrije Universiteit Brussel; Service of Intensive Care Medicine,  
28 Universitair Ziekenhuis Brussel, Belgium.

29 E-mail: [Luc.Huyghens@uzbrussel.be](mailto:Luc.Huyghens@uzbrussel.be)

30

31 4 PhD, Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Vrije  
32 Universiteit Brussel, Belgium.

33 E-mail: [Johan.Bilsen@vub.be](mailto:Johan.Bilsen@vub.be)

34

35 **Abstract**

36 **Background:** Critical care physicians often have to make challenging decisions to  
37 withhold/withdraw life-sustaining treatments. As a result of society's increasingly cultural  
38 diversity such decision making often involves patients from ethnic minority groups, which  
39 might pose extra challenges.

40 **Objective:** To investigate withholding/withdrawing life-sustaining treatments with patients  
41 from ethnic minority groups and their families during critical care.

42 **Design:** Ethnographic fieldwork (observations, in-depth interviews and reading patients'  
43 medical files)

44 **Setting/Subjects:** 18 patients from ethnic minority groups, their relatives, physicians and  
45 nurses were studied in one intensive care unit of a multi-ethnic urban hospital (Belgium).

46 **Results:** During decision making physicians had a very central role. The contribution of  
47 patients and nurses was limited, while families' input was more noticeable. Decision making  
48 was hampered by communication difficulties between: (1) staff and relative(s), (2) relatives  
49 and (3) patient and relative(s). Different approaches were used by physicians to overcome  
50 difficulties, which often reflected their tendency to control decision making, e.g. stressing  
51 their central role. At times their approaches reflected their inability to align families' wishes  
52 with their own, e.g. when making decisions without explicitly informing relatives.

53 **Conclusions:** Withholding/withdrawing life-sustaining treatments in a multi-ethnic critic care  
54 context has a number of alarming difficulties, such as how to take families' input correctly  
55 into account. It is important that decision making happens in a cultural sensitive way and with  
56 involvement tailored to patients' and relatives' needs and in close consultation with  
57 interprofessional healthcare workers/other services.

58

59

60

61

62

63 **Introduction**

64 The laws regarding decisions to withhold/withdraw life-sustaining treatments (WHWD LST)  
65 vary between countries. In Belgium, the country where this study was conducted, decisions to  
66 WHWD LST may be made with or without the patient's explicit request.<sup>1</sup> Making such  
67 decisions at the request of competent patients is completely legal. Doctors who ignore such  
68 requests violate the laws which support patients' self-determination, even if doctors think that  
69 further treatment would still help the patient. Making decisions to WHWD LST without  
70 patients' explicit request is allowed when the treatment is considered medically inappropriate.  
71 The Belgian law even forbids the prolongation of medically inappropriate treatment. In such  
72 situations, physicians have major responsibility in decision making. Making decisions to  
73 WHWD LST in a situation where treatment is still possible and without patients' explicit  
74 request is considered as an omission offence. When patients are no longer competent,  
75 patients' representatives must act in the best interest of patients. Physicians have the legal  
76 right to deviate from the desires of the representatives after multi-disciplinary deliberation, if  
77 representatives insist upon medically inappropriate treatment. Belgian law regarding decisions  
78 to WHWD LST is underpinned by important medical-ethical principles, such as respect for  
79 patients' autonomy, doing good for patients, avoiding intentional harm and being truthful and  
80 faithful.<sup>2-3</sup>

81 During critical care many patients die after a decision to WHWD LST.<sup>4-5</sup> Such decisions  
82 must be discussed regularly and on time with patients and relatives, and are best made in  
83 dialogue with colleague healthcare workers.<sup>6</sup> Discussions are often time-consuming and need  
84 sufficient patient involvement.<sup>5</sup> If patients are unable to participate, and choices can only be  
85 discussed with patients' relatives, decision making can be jeopardized by relatives' difficulties  
86 in understanding information and distress.<sup>7-9</sup> Profound communication about decisions to  
87 WHWD LST with patients/families can further be impeded in acute critical situations

88 (intensive care units: ICUs) where healthcare professionals have to make decisions quickly,  
89 affected by their many job demands, medical uncertainty and curative orientation.<sup>10-13</sup>  
90 Furthermore as such decisions are influenced by culture and religion, decision making can  
91 become even more complex with ethnic minorities due to e.g. beliefs in God's sovereign  
92 power over life-death.<sup>14</sup> In this article we investigate making decisions to WHWD LST with  
93 patients from ethnic minority groups and families in the ICU, including difficulties  
94 encountered by healthcare professionals and strategies they use to deal with difficulties. Such  
95 knowledge is key for developing best practices regarding end-of-life decision making in a  
96 culturally diverse critical care context.

## 97 **Methods**

98 An ethnographic research design was used, enabling the researcher to immerse herself in the  
99 care field and explore our research topic in depth for long time on the ward itself by observing  
100 and interacting with people involved. This design is inspired by the social constructionist and  
101 interpretative approach.<sup>15</sup> Ethnographic fieldwork was done for 10 months within a 3.8-year  
102 time frame (January 2014 and October 2017).

### 103 *Setting and sampling*

104 Our research field consisted of one ICU of a multi-ethnic urban hospital in Belgium.  
105 Purposeful sampling was applied and patients and relatives were included if the birth place of  
106 patients/at least one of their legal parents was outside of Belgium, if at least one of their  
107 relatives was proficient in Dutch/ French/English, and if patients were at least 18 years old.  
108 One doctor and 3 nurses facilitated researcher's access to patients and families who met with  
109 inclusion criteria. Selected patients, relatives and all ICU's staff members were studied during  
110 patient's entire ICU stay.

111 *Participants*

112 We selected 18 patients and accompanying relatives. They were originally from Southern  
113 Europe, Turkey, North Africa and Central Africa, i.e. regions of origin of Belgium's large  
114 ethnic minority groups.<sup>16</sup> No patients and relatives refused to participate. ICU's staff members  
115 comprised 80 nurses and 12 doctors. Most of them were members of the ethnic majority  
116 group. 8 staff members (1 doctor and 7 nurses) refused to participate.

117 *Data collection*

118 Data were collected through observations on the ward,<sup>17</sup> in-depth interviews with healthcare  
119 professionals and reading patients' medical records.

120 Observations included observation of 695 interactions between research participants, 880  
121 informal conversations with research participants and attendance at 268 staff meetings. The  
122 researcher made short notes in the ICU. Afterwards, she applied a 'thick description' and  
123 emended these notes into long descriptive field notes. Private in-depth interviews were held  
124 with 27 nurses and 8 doctors who were involved in care for our included patients in the ICU,  
125 and audio-recorded (see appendix 1: topic list interviews). To not increase pressure on  
126 patients and relatives, only informal conversations were held with them.

127 *Data analysis*

128 In-depth interviews were transcribed, and thematic analysis was applied to all data, supported  
129 by NVIVO 8. This analysis encompassed (re)reading of data and assignation of themes. Core  
130 themes were detected in different data sources and within each theme, different sub-themes  
131 were identified. Themes and sub-themes were refined and linkages between different themes  
132 were studied.

133 Reliability was strengthened by the first author analysing data and two co-authors  
134 reviewing the analysis. The research process was also regularly reflected on by members of  
135 authors' academic research group. Moreover, the study was also read by a physician who is  
136 staff member of the studied team. Moreover, findings were discussed with nurses who had  
137 participated in this study during a conference.

### 138 *Ethics*

139 Study approval was received from authors' university's ethics committee (reference  
140 2013/371, date approval: 17.12.2013). Privacy of research participants and confidentiality of  
141 data were maintained. Research participants were requested to give written consent to study  
142 participation after presentation of the study. If patients lacked capacity to give consent,  
143 consent was sought from legal representatives.

### 144 **Results**

145 Patients could not express themselves or could only do so minimally. More information about  
146 patients' characteristics appear in Table 1. Patients' characteristics. 39% of ICU's staff  
147 members were men, 61% women. 42% were under 45 years.

148 Decisions to WHWD LST were made for 9 of 18 patients. Decision making was strongly  
149 influenced by physicians. The role of patients and nurses was minor, while families' input  
150 was more noticeable. Decision making was complicated by communication difficulties  
151 between: (1) staff and relative(s), (2) relatives and (3) patient and relative(s). Different  
152 solutions were used by physicians to deal with conflicts, often mirroring their status as central  
153 decision maker (e.g. convincing families to make a decision to WHWD LST) and also  
154 sometimes their inability to overcome differing viewpoints (e.g. foregoing decision making).

155 (A summary of the key findings appears in table 2: Withholding/withdrawing life-sustaining  
156 treatment in a multi-ethnic ICU)

### 157 *Decision making process*

158 Patients themselves were often not involved in decision making as they were usually  
159 unconscious. Moreover, conscious patients were easily perceived by doctors as incompetent  
160 to participate (due to e.g. illness and language barriers). Furthermore, patients often lacked an  
161 advance directive. A decision to WHWD LST was usually communicated to relatives by  
162 physicians, often depending on relatives' understanding of patient's situation. Physicians did  
163 not actively integrate nurses' views into the decision making. Moreover, nurses were not  
164 included in physicians' formal discussions with other colleagues, patients and relatives.

### 165 *Communication difficulties*

166 Firstly, decision making was often impeded by families who were against making decisions to  
167 WHWD LST. Families felt that patients should receive maximal curative therapy until death  
168 and felt it inappropriate to talk about patients' end-of-life and intervene in this domain, which  
169 was often legitimized by religious norms.

170 **Doctor:** They (ethnic minorities) aren't stupid of course, they know people die - but a lot of them struggle with the fact that, look,  
171 that patient is dying because something is happening to them. And then religion gets involved and all that kind of thing, erm, but  
172 they really struggle with the fact that, you know, if we turn off the ventilator they are going to die. Then they say yes, but 'we want  
173 him to die naturally'. (Interview with Doctor 1)

174 Secondly, it was difficult for doctors to find support for making decisions to WHWD LST  
175 from the whole family. Relatives who discussed the patient's situation with doctors more  
176 easily saw the relevance of making such decisions, whereas other relatives often remained  
177 opposed to it.



178 **Son:** Yes, but it's not really a decision you're making with us then, you're just telling us what the situation is.  
179 **Doctor:** Yes, yes, yes, yes... Why not, er, why wouldn't I ask you? Because...  
180 **Son:** Because there's nothing to find out, there's no alternative.  
181 **Doctor:** There's no alternative.  
182 **Son:** Yes I understand that.  
183 [...]  
184 **Doctor:** But I'm glad you understand that the situation is very difficult.  
185 **Son:** Yes, yes, yes, I understand, but it's difficult to get the others to understand [...]. It's also a different country, a different culture,  
186 a different thing, so we always ask if there is anything else to be done, and they always tell me 'Oh, no, because...'  
187 (Field note, Conversation between son of patient and Doctor 2, case patient 7)

188 Thirdly, decision making was challenged when staff received support from patients to  
189 withdraw therapy, against the wishes of one/more of their relatives.

190 **Nurse:** But she (the patient) had a cannula, so she couldn't really, well, she had real difficulty communicating. (...) It was a  
191 hopeless situation, she'd been here for about three months and she had already said several times that she'd had enough. She was in  
192 her eighties too. [...] But I think that it is exactly at a time like that that you, as a relative, that you really don't want it to happen [...].  
193 I think the granddaughter in particular, er, when she was trying to talk her (grand)mother round and, well, they came here to visit  
194 and the patient just kept crying and crying and crying. And, you know, she was in a lot of pain as well. (Interview with nurse 1)

### 195 *Staff's strategies to deal with communication difficulties*

196 *Trust building.* When physicians felt opposition from relatives against making decisions to  
197 *WHWD LST* some physicians tried to (re)gain their trust by holding conversations with them  
198 about patient's situation and bad prognosis. Misunderstandings were clarified and often  
199 western values (e.g. honesty) were emphasized during argumentation. Sometimes physicians  
200 directly asked relatives to put more trust in them.

201 **Doctor:** Sometimes I say so to them as well, I say 'You do need to trust me'. I say, er, 'You've got no choice.'  
202 (Interview with Doctor 1)

203 Some doctors also integrated another healthcare professional with whom relatives had a good  
204 bond. Sporadically physicians talked to influential religious figures from patient's community  
205 or sought help from hospital's chaplain.

206 *Convincing.* Conversations with families aimed at reducing disagreement were often  
207 characterized by convincing families, sometimes done in authoritarian fashion. Physicians  
208 tried to convince relatives to accept a decision to WHWD LST for specific medical reasons,  
209 because of the absence of curative options, ending of patient's suffering, preventing of a poor  
210 life quality and ensuring basic care. Physicians' efforts to fully explore patients'/families'  
211 specific perspectives were limited.

212 At the entrance to the ward, the patient's son asks the physician whether the doctors are just going to stop treating the patient, while  
213 the other relatives are standing around the patient's bed inside the ward. So they cannot hear the conversation between the son and  
214 the doctor.

215 **Doctor:** It will happen at the point when there is no treatment we can give that will work and that's when it happens, erm, it's not  
216 that I'm going to limit care or make limitations, it's simply that there's nothing more I 'can' do... And we also have to consider that  
217 there is a patient suffering in a bed, so if it really does happen, I'll phone you and say to you: 'There's nothing more I can do.'

218 **Son:** Yes, but it's not really a decision you're making with us then, you're just telling us what the situation is.

219 **Doctor:** Yes, yes, yes, yes...Why not, er, why wouldn't I ask you? Because...

220 **Son:** Because there's nothing to find out, there's no alternative.

221 **Doctor:** There's no alternative.

222 (Field note, Conversation between Doctor 2 and patient's son, case patient 7)

223 *Stressing physicians' central role in decision making.* Some doctors made their central role in  
224 decision making more clear towards relatives either in an indirect manner or through direct  
225 enforcement, e.g. by pointing to their right/duty as doctor to make a decision to WHWD LST  
226 in patient's current hopeless situation.

227 **Doctor:** We will not continue to treat him in this way.

228 **Son:** And what will you do then?

229 **Doctor:** We will take him off the machines.

230 **Son:** So if there is no improvement you will turn off the machines. (...)

231 **Doctor:** It is not up to you to decide. This is a medical decision.

232 **Son:** What about the family then? The only thing you do is talk to the family? [Doctor gives no answer to these two questions] (...)

233 **Doctor:** It doesn't mean 'kill'. Stopping the machines is not euthanasia: We are not going to give him any medication that will lead  
234 to his death. We are letting his body decide for itself. This is a medical decision. If someone has been in intensive care for three  
235 weeks and the treatment isn't helping, we have the right to stop the machines.

236 (Field note, Conversation between Doctor 2 and patient's son, case patient 7)

237 Healthcare professionals often took it for granted that doctors were prime decision makers as  
238 doctors were considered medical experts and families' socio-cultural background was often  
239 seen as impeding effective decision making.

240 Nurse: *'Sometimes it's actually best that doctors make a decision instead of the family. It's difficult for them to say goodbye to their*  
241 *loved ones.'* I ask: *'Why is it difficult for them to say goodbye?'* Another nurse replies: *'It's because of the culture. 'Muslims more*  
242 *often want to continue treatment, they can't let go... And we Belgians don't want to do that to our relatives.'* (Field note, informal  
243 conversation with nurses, case patient 8)

244 *Foregoing decision making.* Some doctors followed families' wishes not to WHWD LST,  
245 sometimes contrary to their own and patients' opinions, and temporarily delayed decision  
246 making.

247 **Nurse:** That lady didn't speak a word of French, not a word of Dutch. (...) When she was unrestrained she pulled at everything she  
248 could, and she really meant it, she'd also made it clear, meaning 'No, I don't want it anymore! (...)', and so we had that lady,  
249 because the family wouldn't let us, we couldn't stop. (...) And we couldn't communicate with the lady, unless, you know, not  
250 directly, because she didn't speak. (...) She couldn't write either. (...) Although we all knew that she had said separately to each one  
251 of us 'No, no, no, no more!' And we discussed that with the family. But the family put their foot down. It wasn't up for discussion.  
252 (...) So, yes, then we ended up restraining the lady, to stop her from pulling everything out (...).

253 **Researcher:** And you think that she was still competent to decide? That she understood what was going on?

254 **Nurse:** The lady? I think she did.

255 (Interview with nurse 2)

256 The decision to forego decision making was sometimes made in deference to families' ethno-  
257 cultural backgrounds. This was sometimes considered 'a doctor's plight', and could  
258 potentially precipitate moral distress among physicians.

259  
260 **Doctor:** (...) Sometimes you feel that you just can't bring it up.

261 **Interviewer:** Right.

262 **Doctor:** That they don't want you to. And so, erm... yes, sometimes it really is difficult. And then you keep going and that is really  
263 difficult, because the main source of depression in nurses and doctors is, is therapeutic stubbornness. With Jewish people for  
264 example, life for life. It doesn't matter how it ends. And then you have to be able to respect that. (...) It's very difficult at first, for  
265 doctors too, because then, then you have the feeling you're not doing the right thing anymore, but you do learn to, to deal with it.  
266 (Interview with Doctor 3)

267 Foregoing decision making gave doctors the opportunity to invest more in communication  
268 with families and gave relatives more time to adjust to patients' bad prognosis.

269 **Nurse:** At last she (relative) has realised the patient isn't going to get any better. We can't save her, we can't cure her. And she has  
270 had enough herself.' (...)

271 **Researcher:** Yes, but did people actually talk to the family then, or...?

272 **Nurse:** Yes.

273 **Researcher:** And then they saw how things stood...?

274 **Nurse:** Yes but it did take weeks to get to that point.

275 **Researcher:** Whereas the patient had been indicating for some time that she wanted to stop.

276 (Interview with nurse 1)

277 It also increased the chance that patients would die without having to make a decision to  
278 WHWD LST.

279 Doctor tells me: *'Next week we are going to discuss with the family whether we can stop the machines, but it's possible that his*  
280 *heart might just stop.'* Then the doctor says to the nurses: *'Next meeting is on Monday afternoon if he lasts till then, I said (to the*  
281 *family). Inflammation worsens, antibiotics change, poor lungs, poor heart. But I hope something happens to him before they have to*  
282 *decide to turn off the machines, because the woman isn't ready for it yet, is she. That saves us the conversation about turning off the*  
283 *machines. I hope his heart will fail before Monday.'* (Field note, case patient 12)

284 Furthermore, some doctors' fear of complaints and prosecution by relatives also contributed  
285 to foregoing decision making.

286 **Doctor:** (...) So you're a bit scared they'll say 'you're not doing enough'. So there's a bit of a worry that they might press charges  
287 too.

288 **Interviewer:** Has it ever happened that the family has pressed charges?

289 **Doctor:** Erm, yes, yes, yes, but not with, it was more with an, erm (she names the patient), a North African. And he had had a  
290 serious heart attack, he had had a balloon pump and we ended up taking out the balloon pump but there was no more heart function

291 after two weeks, and then we decided to stop and ultimately he died. And then there was a complaint.

292 [...]

293 **Interviewer:** And how did it end?

294 **Doctor:** (...) It hasn't been resolved yet.

295 [...]

296 **Interviewer:** Wow. And how do you yourself feel about, about legal proceedings?

297 **Doctor:** Well it's certainly no fun, because you feel like they're going to try and prove you did something wrong, when you tried to  
298 do your best for the patient.

299 (Interview with Doctor 4)

300 Sometimes continued resistance of relatives even resulted in a doctor's final decision to  
301 forego decision making.

302 **Doctor:** A Moroccan lad (...) I had said at the time, 'Look, mate, it's hopeless.' And in the end, he was breathing so we said we'd do  
303 a tracheotomy, and (...), we'll discharge him from the intensive care unit (...) We're keeping him alive but actually we know it's  
304 pointless (...) The brother, about six months later he was here for his in-laws. And afterwards he (...) (said): 'My brother was there  
305 (on another ward in hospital) for another five months, in the end. (...) You were completely right, actually.' (Interview with Doctor  
306 1).

307 Foregoing decision making contributed to stress among some nurses. They felt that this  
308 practice endangered patients' dignity, quality of life and autonomy.

309 **Nurse:** (It is) difficult to, to, how do I put it, to put the patient's culture before their comfort and humanity. I find it difficult and if  
310 the doctor does it, I have trouble accepting that decision.

311 (Interview with nurse 2)

312 **Nurse:** But I think that it is exactly at a time like that that you, as a relative, that you really don't want it to happen, that er, erm, that  
313 you have been backed into a bit of a corner, haven't you.

314 **Researcher:** So you do carry on for a while?

315 **Nurse:** Yes.

316 **Researcher:** And how do you feel about that yourself?

317 **Nurse:** I found it really difficult. Erm, yes, I felt like, well, ultimately the woman's (patient's) husband was there too, and he did  
318 agree (to stop the treatment). He is her legal representative at that point. So I think, I thought and I still think, that they should have  
319 listened to what the patient wanted more quickly! (...) It was inhuman that that lady was kept alive for several weeks longer.

320 (Interview with nurse 1)

321 Moreover, some nurses argued that foregoing decision making created false hopes of cure  
322 among relatives, was expensive and endangered care for other patients.

323 **Nurse:** The patient was really as good as dead (...) the family probably didn't realise it yet. And then you're running around doing a  
324 million things at once, and it's all a mess, everything goes from bad to worse. And we messed around for another two days. The  
325 patient already had livor mortis. But no, we kept going. Although I sometimes feel much too much effort goes into it (...) And then  
326 they come in here, they don't understand a word of what I'm saying because they only speak Berber (...) And then you set up 25  
327 machines next to them. It costs a huge amount of money (...) (Interview with nurse 2)

328 *Nurses trying to initiate decision making.* Some nurses frequently thought that decision  
329 making was postponed for too long, based on their day-to-day care for the patients as well as  
330 requests they received from patients to stop curative therapy, and consequently they tried to  
331 encourage doctors to make a decision to WHWD LST.

332 A nurse said the following about the patient to the doctor: *'He is apathetic. He doesn't want to open his eyes any more. What are we*  
333 *doing here? I feel like we're torturing him.'* (Field note, case patient 8)

334 However doctors didn't usually follow nurses' opinions as they considered themselves  
335 medical experts/prime decision makers, resulting in powerlessness and indifference among  
336 nurses.

337 **Researcher:** And suppose you say to one of the doctors, 'Look, I don't think there's much more we can do for this patient.' Do they  
338 listen to you?

339 **Nurse:** Not always, no, no.

340 **Researcher:** Yes. And how do you feel about that?

341 **Nurse:** As I get older and older, worse and worse (...) I've got more of a feeling of, er, not letting it get to you. I mean that you  
342 become more indifferent. You do say it, whatever, but well, you just keep going.

343 (Interview with nurse 3)

344 Other nurses tried to convince families of the senselessness of continuing therapy, often in  
345 vain. This sometimes increased family-staff tensions.

346 **Nurse:** (...) and the family comes, and they get annoyed with you if you dare to say 'Come on, it's enough now. Because the  
347 problem is this and this and that. And we can't fix that!'. (Interview with nurse 2)

348 Some nurses didn't interfere in decision making as they perceived themselves as lacking  
349 decision making power.

350 **Nurse:** To be honest it happens a lot, that some people thought we had gone too far.

351 **Researcher:** Nurses, you mean?

352 **Nurse:** Well, yes, that the doctor was going too far actually, but we were the ones who carried it out. (...) You see, as nurses we're  
353 never allowed to make the decision that we're going to stop. It's the doctors who, er, decide that, isn't it. So, erm, yes, we just carry  
354 out their orders. (Interview with nurse 4)

355 Consequently, these nurses minimally acknowledged or neglected patients' requests or asked  
356 patients to stop asking them to withdraw curative treatment, increasing stress among nurses.

357 **Nurse:** Sometimes the whole nursing team has just completely had it. We say, ' (...) I don't want to keep treating that patient.' (...)  
358 We had one like that once, as soon as he saw you he'd start saying 'kill me, kill me, stop it, I don't want this anymore'. (...) And  
359 then I said to him, 'Stop that. I can't decide that for you. I'm not allowed to. If I do that, I'll go to prison.' (Interview with nurse 5)

360 *Withdrawing LST without explicitly informing the patient and/or family. As a last resort,*  
361 *physicians sometimes withdrew LST without explicitly informing the patient and/or family.*  
362 Decisions were then carried out either when relatives were present through visual misleading  
363 or when relatives were absent.

364 **Nurse:** Sometimes too there are people who are on, er, powerful inotropic drugs, and they get hooked up to a drip with ordinary  
365 water. (...) With a, with the same labelling and everything, to er, well, to mislead the family a bit actually.

366 **Interviewer:** Right, so what do you mean exactly by a drip with ordinary water...?

367 **Nurse:** Well, it's purely physiological, there are no more active drugs in it. (...) So say we are giving drugs to help the patient's  
368 blood pressure, we change that drip to an ordinary one, so that they don't get any, so the family think they are still getting medicine  
369 for their blood pressure -- but in fact, er, there's nothing in the drip. (...) So in fact the patient, just, er, fades away.  
370 (Interview with nurse 3)

371 When explaining to families, patients' sudden quick decline and death was ascribed to  
372 patients themselves or 'nature'.

373 **Doctor:** I phone and I say, 'Look, he had died suddenly, and resuscitation didn't, we weren't able to resuscitate him.' Although in  
374 fact you know you are lying. You didn't even try to resuscitate him.  
375 (Interview with Doctor 1).

376 However, sometimes when physicians and patients' representative(s) had a good relationship,  
377 representative(s) were informed of the decision after it had been carried out. Non-involvement  
378 of patients in decision making was justified by physicians by their perceived unconscious  
379 state, whereas they were sometimes regarded as conscious by their relatives during decision  
380 making. Sometimes the dying process was hastened, which was done off the record.

381 **Doctor:** And if we do that (make a decision to withdraw LST) with a patient when the family isn't there (...) then, er... well then er...  
382 then you tend to use... Then you usually use euthanasia drugs.

383 **Interviewer:** Yes. And afterwards, I mean if you have been in contact with these difficult families who don't want you to stop  
384 treatment...

385 **Doctor:** And then they suddenly find out the patient has died?

386 **Interviewer:** Yes. What do you say has happened when you talk to the family?

387 **Doctor:** That the patient's heart stopped and I tried to resuscitate him. Usually you don't need to explain that very much at all (...)  
388 Because you've already gone through a whole process with these people where you insist on the same thing every time, look, it's  
389 over (...) And the strange thing is, usually, you hardly ever really get questions like 'So what actually happened, then?' (Interview  
390 with Doctor 1)

391 Although doctors didn't like to make decisions without explicitly informing the patient and/or  
392 family, it was legitimized by them by the fact that it would end intensive suffering in patients  
393 and relatives and provoke a quick death, considered by physicians as a good death.

394 **Doctor:** Erm, I absolutely hate it, when people are dying for days (...) And it doesn't help the families (...) We've all got that  
395 romantic image of, you know, taking your dad by the hand (...) and says 'I love you all' as his last words (...), and then he dies.  
396 Reality isn't like that. (Interview with Doctor 1).



397 Furthermore, this practice was done to avoid intercultural conflicts with relatives and reduce  
398 the financial costs of treatment. It was considered to be done worldwide.

399 Doctor: Far more in Muslim families or with Africans than with, er, ordinary Belgians (...) er, you will have to (resort to) tricks like  
400 that (...). And it's not nice. (...) But if they come here afterwards and they're all, you know 'phew' (sound expressing relief), you  
401 know you have made the right decision. (...) Sometimes we're shaking in our shoes, thinking 'shit, the family will be here in a  
402 moment, they're going to make a scene' and then the families say, 'Thank you for everything you have done, doctor,' etc. 'It wasn't  
403 easy, but we're glad he died by himself (...) No, then they have the feeling that he has died, that he's died naturally (...) Allah or  
404 Mohammed or whoever it is will be perfectly happy (...) And I'm certain that this practice is applied in any hospital you name  
405 anywhere in the world. (Interview with Doctor 1)

## 406 **Discussion**

### 407 *Main findings of the study*

408 In this ethnographic study we investigated making decisions to WHWD LST with patients  
409 from ethnic minority groups and relatives in a multi-ethnic ICU in Belgium. We found that  
410 these decisions were primarily made by physicians. Patients' and nurses' role in decision  
411 making was limited, while families' input was more outspoken. Decision making was often  
412 hampered by communication difficulties between staff and relative(s), between relatives, and  
413 between patient and relative(s). Different approaches were used by physicians to overcome  
414 difficulties. Generally, doctors tried to control decision making, e.g. by convincing families to  
415 make a decision to WHWD LST. Sometimes, physicians felt unable to align families' wishes  
416 regarding decision making with their own, which was reflected in e.g. physicians foregoing  
417 decision making contrary to their own opinion. In general, decision making with ethnic  
418 minorities did not go smoothly and had negative implications, e.g. carrying out ethically  
419 concerning practices and endangering patients' rights and quality palliative care.

420

421 *Strengths and limitations*

422 Although there is a body of research on end-of-life decisions in critical medical situations,  
423 studies focusing on decisions to WHWD LST are less frequent.<sup>10,18</sup> Moreover none of these  
424 studies focus on WHWD LST in relation to ethnic minorities and none use anthropological  
425 techniques. However anthropological designs allow deep knowledge of complex and sensitive  
426 themes. Our long-term observations increased trust towards the researcher and made  
427 participants often act naturally during observations. Moreover, combining observations with  
428 interviews made it possible to differentiate between participants' actual speech/behaviour and  
429 their proclaimed speech/behaviour. The researcher might have had an impact on the field and  
430 findings as she herself has a non-Belgian ethnic background which enabled her to gain a lot of  
431 trust from ethnic minorities. Moreover, the fact that the researcher has no professional  
432 background in critical care made staff communicate with her in a transparent manner about  
433 procedures. A possible limitation of this study is its single field character and small sample  
434 size, which makes it difficult to generalize our findings to other ICUs. However, findings are  
435 also of relevance for other ICUs and can foster debate about end-of-life decision making  
436 during multi-ethnic critical care.

437

438 *What this study adds*

439 Providing culturally congruent end-of-life care and collaboration between healthcare  
440 professionals, patients from ethnic minority groups and their relatives in difficult end-of-life  
441 decision making in a critical care setting is challenging. It is widely acknowledged that  
442 physicians hold central responsibility for decisions to WHWD LST and that such decisions  
443 best be made in close consultation with patients and relatives and after thorough deliberation  
444 with other healthcare workers.<sup>5-6,19-22</sup> However, our study showed that this was seldom the

445 case in our studied ICU with regard to patients and relatives from ethnic minority groups.  
446 Moreover, shared decision making, involving other healthcare workers besides physicians,  
447 e.g. nurses, was very rare. Physicians are best placed, given their expertise, to determine what  
448 is still medically effective treatment and what is not. Physicians can never be obliged to  
449 continue a therapy when they consider therapy to be ineffective according to current medical  
450 knowledge. The (Belgian) law prohibits the continuation of medically inappropriate therapy.<sup>23</sup>  
451 Probably this is the main reason why physicians want the decision to be made, preferably  
452 with, but possibly also without others' explicit consent. However, it does not relieve them of  
453 their obligation to make decisions as carefully as possible.

454 Observed decisional conflicts were also found in studies on end-of-life decision making  
455 with the ethnic majority group.<sup>24-25</sup> However, disagreement in our culturally diverse setting  
456 seemed to be more explicit and difficult to overcome due to factors related to patients' ethnic  
457 backgrounds, e.g. strict religious norms and linguistic barriers. Also, the lack of knowledge on  
458 end-of-life issues in foreign cultures among some healthcare professionals and ethno-religious  
459 discrimination and prejudice, which is quite worrying in today's multicultural society,  
460 impeded effective decision making. Discrimination and prejudices were often based on  
461 ignorance, lack of communication and structural constraints. Ethnic prejudices were  
462 sometimes used to legitimize physicians' central position in decision making. Moreover,  
463 prejudices discouraged some staff members to fully explore patients'/families' perspectives.  
464 Furthermore, adequate policy measures to deal with difficulties were lacking, e.g. no formal  
465 integration of other professionals, such as nurses or professional interpreters, in decision  
466 making.

467 Patients and relatives were not actively/explicitly involved in decision making. However,  
468 certain physicians were very concerned about relatives' viewpoints and wellbeing. Thereby,  
469 in some cases, decision making was co-shaped by relatives to a certain extent. Unfortunately,

470 this resulted in ethically and legally concerning practices, such as physicians not making a  
471 decision to WHWD LST against their own opinion, withdrawing LST without explicitly  
472 informing the family, deception and hastening the dying process. These practices highlight  
473 doctors' inability in aligning differing viewpoints.

474 It is known that patients are more likely to express their wishes to nurses who give them  
475 day-to-day care, which also came to the fore in our study, and that nurses can be effective in  
476 judging which patients would die despite continuing treatment.<sup>26-27</sup> However doctors often  
477 didn't take into account nurses' perspectives, confirming earlier studies, and nurses' efforts to  
478 convince families were often not effective.<sup>28-29</sup> This contributed to powerlessness and moral  
479 distress among nurses.

480

#### 481 *Implications for practice and research*

482 In a multi-ethnic critical care context decisions to WHWD LST should be made with cultural  
483 sensitivity and involvement tailored to patients and relatives and in close consultation with  
484 other healthcare workers and services (e.g. nurses, palliative care specialists, psychologists,  
485 intercultural mediation and interpreting services). Staff and students should receive training to  
486 develop their knowledge, skills and attitudes regarding culturally appropriate end-of-life  
487 communication and decision making (e.g. through role plays or discussions about potentially  
488 stressful real-life cases and ethnic prejudices). Furthermore, they should be trained in how to  
489 cooperate with other disciplines/services and how to take care of their own mental health.

490 Also, policy measures should be implemented allowing collaborative communication between  
491 healthcare professionals, patients and families and among healthcare professionals. They may  
492 include agreements about collaboration between the critical care team and interpreting  
493 services and involvement of nurses in end-of-life communication and decision making.

494 Moreover, educating ethnic minorities about end-of-life decision making (e.g. advanced care  
495 planning) both within and outside the ICU is valuable. Lastly, the ethically concerning  
496 practices found in this study highlight the need for debate about end-of-life decision making  
497 in a multi-ethnic critical care context. Further (evidence-based) studies are required to test the  
498 impact of these proposed measures in a multi-ethnic critical care setting.

499

## 500 **Conclusion**

501 Making decisions to WHWD LST in a multi-ethnic critic care context has a number of  
502 specific challenges, such as how to take ethnic factors into account and how to correctly deal  
503 with differing viewpoints (e.g. relatives versus staff). To effectively deal with such  
504 challenges, decision making should happen in culturally sensitive way and with involvement  
505 tailored to patients' and relatives' needs and in close consultation with other healthcare  
506 workers/services.

507

508 **Acknowledgements:** We thank the staff, patients and families for their participation in our study and the members of our project group for  
509 their support and advice

510

511 **Author Disclosure Statement:** No competing financial interests exist

512

## 513 **References**

- 514 1. Broeckaert B, The Flemish Palliative Care Federation: Treatment decisions in advanced  
515 disease - A Conceptual Framework,  
516 [www.palliatief.be/accounts/143/attachments/Research/conceptual\\_\\_framework\\_bb.pdf](http://www.palliatief.be/accounts/143/attachments/Research/conceptual__framework_bb.pdf) (2009,  
517 accessed 16 July 2018).
- 518 2. Medical Law in Belgium. Nys H. Kluwer Law International, Alphen aan den Rijn, 2015.
- 519 3. Nationale Raad van de Orde der Geneesheren: Adviezen: stopzetten en weigeren van  
520 behandelingen [National Council of the Order of Physicians: Advices: Withdrawing and  
521 withholding treatments], [https://www.ordomedic.be/nl/adviezen/advies/stopzetten-en-](https://www.ordomedic.be/nl/adviezen/advies/stopzetten-en-weigeren-van-behandelingen)  
522 [weigeren-van-behandelingen](https://www.ordomedic.be/nl/adviezen/advies/stopzetten-en-weigeren-van-behandelingen) (2015, accessed 3 April 2020)

- 523 4. Curtis JR, Vincent JL: Ethics and end-of-life care for adults in the ICU. *Lancet* 2010;376:  
524 1347–1353.
- 525 5. Cook D, Rocker G: Dying with dignity in the ICU. *N Engl J Med* 2014;370:2506–2514.
- 526 6. Vincent JL, Schetz M, De Waele JJ, et al.: "Piece" of Mind: End of Life in the Intensive  
527 Care Unit Statement of the Belgian Society of Intensive Care Medicine. *J Crit Care*  
528 2014;29:174-5.
- 529 7. Rodriguez RM, Navarrete E, Schwaber J, et al.: A prospective study of primary surrogate  
530 decision makers' knowledge of intensive care. *Crit Care Med* 2008;36:1633–1636.
- 531 8. Cunningham TV, Scheunemann LP, Arnold RM, et al.: How do clinicians prepare family  
532 members for the role of surrogate decision-maker? *J Med Ethics* 2018;44:21–26.
- 533 9. Johnson SK, Bautista CA, Hong SY, et al.: An empirical study of surrogates' preferred  
534 level of control over value-laden life support decisions in ICUs. *Am J Respir Crit Care Med*  
535 2011;183:915–921.
- 536 10. Wilson ME, Rhudy LM, Ballinger BA, et al.: Factors that contribute to physician  
537 variability in decisions to limit life support in the ICU: a qualitative study. *Intensive Care*  
538 *Med* 2013;39:1009–1018.
- 539 11. Azoulay E, Chaize M, Kentish-Barnes N: Involvement of ICU families in decisions: fine-  
540 tuning the  
541 partnership. *Ann Intensive Care* 2014;4:37.
- 542 12. Visser M, Deliens L, Houttekier D: Physician-related barriers to communication and  
543 patient- and  
544 family-centred decision-making towards the end of life in intensive care: a systematic review.  
545 *Crit Care* 2014;18:604.
- 546 13. Godfrey G, Hilton A, Bellomo R: To treat or not to treat: withholding treatment in the  
547 ICU. *Curr Opin Crit Care* 2013;19:624–629.
- 548 14. Ahaddour C, Van den Branden S, Broeckaert B: Between quality of life and hope.  
549 Attitudes and beliefs of Muslim women toward withholding and withdrawing life-sustaining  
550 treatments. *Med Health Care Philos* 2017;21:347-361.
- 551 15. Qualitative methods in social research. Esterberg KG. McGraw-Hill Humanities, Boston,  
552 2002.
- 553 16. Statbel, Directoraat-generaal Statistiek-Statistiek België: Aantal personen wonend in  
554 België, die op de dag van hun geboorte niet de Belgische nationaliteit hadden op 1-1-2017  
555 [Statbel, Directorate-general Statistics-Statistics Belgium: Amount of persons living in  
556 Belgium who didn't have the Belgian nationality on their day of birth on 1-1-2017],  
557 [www.statbel.fgov.be/nl](http://www.statbel.fgov.be/nl) (2017, accessed 10 November 2018).
- 558 17. Wind G: Negotiated interactive observation: Doing fieldwork in hospital settings.  
559 *Anthropol Med* 2008;15:79–89.

- 560 18. Sullivan DR, Slatore CG: Advance Care Planning. Does It Benefit Surrogate Decision  
561 Makers in the ICU? *Ann Am Thorac Soc* 2015;12:1432–1433.
- 562 19. Briggs D: Improving communication with families in the ICU. *Nurs Stand* 2017;32:41–  
563 48.
- 564 20. McMillen RE: End of life decisions: nurses perceptions, feelings and experiences.  
565 *Intensive Crit Care Nurs* 2008;24:251–259.
- 566 21. Mehlis K, Bierwirth EI, Laryionava K, et al.: High prevalence of moral distress reported  
567 by oncologists and oncology nurses in end of life decision making. *Psychooncology*  
568 2018;27:2733-9.
- 569 22. Hansen L, Goodell TT, Dehaven J, Smith M: Nurses' perceptions of end-of-life care after  
570 multiple interventions for improvement. *Am J Crit Care* 2009;18:263–271.
- 571 23. Nationale Raad van de Orde der Geneesheren: Code van Geneeskundige Plichtenleer  
572 1975. Art. 95-98 Het Naderende levenseinde [National Council of the Order of Physicians:  
573 Code of medical ethics. Art. 95-98 The approaching life end],  
574 [www.ordomedic.be/nl/code/hoofdstuk/het-naderende-levenseinde](http://www.ordomedic.be/nl/code/hoofdstuk/het-naderende-levenseinde) (2020, accessed 15 April  
575 2020)
- 576 24. Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB: Prior Advance Care Planning Is  
577 Associated with Less Decisional Conflict among Surrogates for Critically Ill Patients. *Ann Am*  
578 *Thorac Soc* 2015;12:1528–1533.
- 579 25. Mehter HM, McCannon JB, Clark JA, Wiener RS: Physician Approaches to Conflict with  
580 Families Surrounding End-of-Life Decision-making in the ICU. A Qualitative Study. *Ann Am*  
581 *Thorac Soc* 2018;15:241–249.
- 582 26. Kisorio LC, Langley GC: Intensive care nurses' experiences of end-of-life care. *Intensive*  
583 *Crit Care Nurs* 2016;33:30-38.
- 584 27. Calvin AO, Lindy CM, Clington SL: The cardiovascular ICU nurse's experience with end-  
585 of-life care: a qualitative descriptive study. *Intensive Crit Care Nurs* 2009;25:214–220.
- 586 28. Lind R, Lorem GF, Nortvedt P, Hevrøy O: Intensive care nurses' involvement in the end-  
587 of-life process--perspectives of relatives. *Nurs Ethics* 2012;19:666–676.
- 588 29. Latour JM, Fulbrook P, Albarran JW: EfCCNa survey: European intensive care nurses'  
589 attitudes and beliefs towards end-of-life care. *Nurs Crit Care* 2009;14:110–121.

590

591 **Table 1**

<b>Number Patient</b>	<b>Gender</b>	<b>Country of origin</b>	<b>Age</b>	<b>Religion</b>	<b>Medical condition</b> 592 593
1	F	Turkey	49	Muslim	Complicated pneumonia
2	F	Morocco	81	Muslim	Heart valve dysfunction
3	F	Morocco	61	Muslim	Complicated pneumonia
4	M	Morocco	52	Muslim	Complicated pneumonia
5	M	Morocco	82	Muslim	Chronic heartfailure and pneumonia
6	M	Algeria	51	Muslim	Kidney dysfunction
7	M	Congo	68	Christian	Brain haemorrhage
8	M	Turkey	70	Muslim	Stomach cancer
9	F	Congo	48	Christian	Brain haemorrhage
10	M	Portugal	50	Muslim	Neurotrauma
11	F	Morocco	61	Muslim	Acute pulmonary oedema and cardiac arrest
12	M	Tunesia	64	Muslim	Complicated pneumonia
13	M	Congo	41	Christian	Neurotrauma
14	F	Congo	73	Christian	Chronic obstructive pulmonary disease and heartfailure
15	M	Tunesia	66	Muslim	Heart attack and pneumonia
16	M	Morocco	45	Muslim	Neurotrauma
17	M	Greece	70	Christian	Liver cirrhosis
18	M	Turkey	52	Muslim	Brain haemorrhage



594  
595

**Table 2. Withholding/withdrawing life-sustaining treatment in a multi-ethnic ICU**

<b>ROLE OF THE DIFFERENT PARTIES</b>
<ul style="list-style-type: none"><li>➤ Physicians had a very central role in decision making</li><li>➤ Contribution of patients and nurses was limited</li><li>➤ Families' input was more noticeable</li></ul>
<b>DIFFICULTIES FOR HEALTHCARE PROFESSIONALS DURING DECISION MAKING WITH PATIENTS FROM ETHNIC MINORITY GROUPS</b>
Decision making was hampered by communication difficulties between: <ol style="list-style-type: none"><li>1) Staff and relative(s)</li><li>2) Opposing relatives</li><li>3) Patient and relative(s)</li></ol>
<b>STRATEGIES USED BY HEALTHCARE PROFESSIONALS TO DEAL WITH DIFFICULTIES</b>
<ul style="list-style-type: none"><li>➤ Physicians building trust with relatives</li><li>➤ Physicians convincing relatives to take a decision to withhold or withdraw life-sustaining treatment</li><li>➤ Physicians stressing their central role in decision making</li><li>➤ Physicians foregoing decision making</li><li>➤ Nurses trying to initiate decision making</li><li>➤ Physicians taking a decision to withdraw life-sustaining treatment without explicitly informing the patient and/or family</li></ul>

596