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MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: AN ETHNOGRAPHIC STUDY

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3 1 **MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: AN**
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5 2 **ETHNOGRAPHIC STUDY**
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53 25 **Word count:** 3560 words
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56 26 **Key words:** intensive care units, patients, cultural diversity, communication, mental health
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1
2
3 **Abstract**
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5 **Objectives:** To investigate the state of the mental wellbeing of patients from ethnic minority groups
6
7 and possible related risk factors for the development of mental health problems among these
8
9 patients during critical medical situations in hospital.
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13 **Design:** Qualitative ethnographic design.
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15
16 **Setting:** 1 intensive care unit (ICU) of a multi-ethnic urban hospital in Belgium.
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18
19 **Participants:** All doctors and nurses at the ICU, 10 patients from ethnic-minority groups, and their
20
21 visiting family members.
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23
24 **Results:** The mental wellbeing of critically ill patients from ethnic minority groups is basically
25
26 characterized by 'extreme emotional loneliness'. Patients had several human basic needs for which
27
28 they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their
29
30 relatives, nor to other patients. These needs included the need for social contact, the need to
31
32 increase comfort and alleviate pain, the need to express desperation and participate in end-of-life
33
34 decision making. Three interrelated risk factors for the development of mental health problems
35
36 among the patients included were identified: Firstly, healthcare professionals' mainly biomedical
37
38 care approach (e.g. focus on curing the patient, limited psychosocial support), secondly, the ICU
39
40 context (e.g. time pressure, uncertainty, regulatory frameworks) and thirdly, patients' different
41
42 ethno-cultural background (e.g. religious and phenotypical differences).
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44

45
46 **Conclusions:** The mental state of patients from ethnic minority groups during critical care is alarming,
47
48 and is characterized by extreme emotional loneliness. It is important that staff should identify and
49
50 meet patients' unique basic needs in good time with regard to their mental wellbeing, taking into
51
52 account important threats related to their own mainly biomedical approach to care, the ICU's
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54 structural context as well as the patients' different ethno-cultural background.
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51 **Article summary**52 **Strengths and limitations of this study**

- 53 • As far as we know, this is the first study where the mental wellbeing of patients from ethnic
54 minority groups is profoundly investigated by means of an ethnographic research design.
55
- 56 • By studying the mental wellbeing of these patients as is 'genuinely expressed', from multiple
57 perspectives and in a contextual manner, through ethnographic fieldwork in an intensive
58 care unit of a multi-ethnic urban hospital in Belgium, we have tried to develop a nuanced,
59 non-stereotypical and rich insight into such patients' mental wellbeing.
60
- 61 • A limitation of this research could be the fact that the fieldwork was done in only one ICU.
62 Therefore transferability to other situations must be done with caution. However, by
63 spending a lot of time in a variety of situations (with 10 patients and their families, and all
64 their healthcare professionals) it was possible to gain a rich insight into our sensitive research
65 topic.
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70 INTRODUCTION

71 During critical care, patients' mental wellbeing comes under threat in several ways.[1-2] Hallucinations, fear,
72 and depression frequently occur among patients admitted to the intensive care unit (ICU).[3-6] Several risk
73 factors are identified, including dependency and poor communication.[2,3,7,8] Although disturbances in
74 critically ill patients' mental health negatively affect their whole care process, healthcare professionals working
75 in a critical care setting lack adequate strategies to improve patients' mental health.[7,9]

76 Additionally, healthcare professionals have to communicate increasingly with patients from ethnic minority
77 groups [10] as a result of societies' increased ethno-cultural diversity. We might assume that critically ill
78 patients from ethnic minority groups are at an even higher risk of mental health problems. Inattention by
79 healthcare professionals to specific ethno-cultural habits (e.g. gender segregation) can contribute to traumatic
80 experiences for such patients.[11,12] Furthermore, language differences and ethno-cultural norms prescribing
81 acceptance of physical suffering can lead to less adequate communication and pain relief[13,14], which can
82 endanger such patients' psychological state.[5,11,15] Yet, although we increasingly live in a multi-ethnic
83 society, in-depth research about the mental wellbeing of patients from ethnic minority groups is rather scarce.

84 In this study we therefore aim to investigate 'the state of the mental wellbeing of patients from ethnic
85 minority groups and possible related risk factors for the development of mental health problems among these
86 patients in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among
87 patients from ethnic minority groups can contribute to the development of recommendations to prevent such
88 problems for these patients.

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90 METHODS

91 Patients' mental wellbeing in a multi-ethnic critical care setting is a sensitive, complex, and novel topic of
92 research. Therefore an ethnographic research design has been used.[16-18]

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60**94 Participants & setting**

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96 Ethnographic fieldwork was done in one ICU of a multi-ethnic urban hospital in Belgium over 6 months (January
97 2014-June 2014). Staff's, patients', and relatives' behaviour, interactions, and experiences were studied for 360
98 hours. The selected patients and the family members who accompanied them, as well as their healthcare
99 professionals, were followed for the whole critical period. Patients and their family members were purposefully
100 selected. They were only eligible for inclusion in the study if the patient or at least one of his/her legal parents
101 was born abroad, if at least one of the family members was able to speak Dutch, French, or English, and if the
102 patient was at least 18 years old. In total we selected 10 patients and their visiting family members, who were
103 originally from North Africa, Turkey, Central Africa, and Southern Europe, i.e. regions of origin of large ethnic
104 minority groups in Belgium.[19]The patients were between 40 and 82 years old and consisted of 6 males and 4
105 females. The critical care team consisted of 80 nurses and 12 doctors, who were almost all white Caucasians
106 from the dominant ethnic group.

107

108 Data collection

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110 Data were collected through triangulation of several data collection strategies, namely negotiated interactive
111 observation,[16] in-depth- interviews with healthcare professionals,[17] and the reading of patients' medical
112 records. The researcher engaged in 'negotiated interactive observation', which gave her the opportunity to
113 have 480 informal conversations with healthcare professionals, family members, and patients, attend 144 staff
114 meetings, and witness 375 interactions between healthcare professionals, relatives, and patients during visiting
115 hours.

116 When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she
117 transformed these notes into comprehensive descriptive field notes containing observations of participants'
118 discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on
119 her behaviour and feelings in the field.[17] Formal in-depth- interviews were held with nine healthcare

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3 120 professionals. These interviews were recorded. All data were collected by the first author (RVK), a trained
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5 121 ethnographer and sociologist.
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10 123 **Data analysis**
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14
15 125 The analysis started with a 'thick description' [20] of participants' discourse, behaviour, and interaction and
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17 126 was followed by a grounded theory analysis.[21] In depth-interviews were transcribed, and data were
18
19 127 conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This
20
21 128 process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly,
22
23 129 an open coding phase was performed, involving the reading and rereading of the data. This resulted in the
24
25 130 formation of different codes, for instance 'physical contact', 'proximity', and 'fighting'. To find similarities and
26
27 131 differences between these codes, new codes were constantly compared with already existing codes. Secondly,
28
29 132 axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example
30
31 133 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance
32
33 134 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category
34
35 135 ('emotional loneliness') around which the related categories are clustered.[21,22]

36
37 136 Data collection and analysis were stopped when the point of saturation was reached.[21,23] Reliability was
38
39 137 strengthened by the first author (RVK) doing the data analysis and two co-authors (RD & JB) doing a peer-
40
41 138 revision of the analysis. The process of data collection and data analysis was also regularly discussed by
42
43 139 members of the multidisciplinary academic research group in which these authors participate, consisting of a
44
45 140 health scientist, a psychiatric nurse, 2 anthropologists, and 1 sociologist. To improve the reliability and accuracy
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47 141 of the study, the results were also read by an intensive care specialist who is part of the intensive care team at
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49 142 the hospital in which the researcher did her fieldwork.
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55 144 **Ethics**
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3 145 The research protocol (reference 2013/371) was approved by the university ethics committee of the XXX. The
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5 146 privacy of the research participants and confidentiality of the data were respected, e.g. by using pseudonyms.
6
7 147 Written consent to participation in the study was sought from healthcare professionals, family members, and
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9 148 patients who were still able to communicate. If the patient lacked the capacity to give consent, consent was
10
11 149 sought from his/her legal representative.
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16 151 **RESULTS**

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18
19 152 The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
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21 153 (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among
22
23 154 patients. Patients had several basic needs for which they could not sufficiently turn to anybody, neither to their
24
25 155 healthcare professionals, nor to their relatives, nor to other patients. These needs comprised 'the need for
26
27 156 social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to
28
29 157 express desperation, and to participate in end-of-life decision making'.
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34 159 **1) Need for social contact**35
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40 161 Patients longed for social contact with relatives, healthcare professionals and other patients, and not only
41
42 162 verbally but also non-verbally. This need became even more significant when patients were unable to
43
44 163 communicate verbally as a result of their medical state and/or language differences. More specifically, patients
45
46 164 longed for proximity of others, physical contact, and chatting.

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49 165 Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and
50
51 166 talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting
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53 167 time, to come more often, or to take them back home (see appendix table 1). Some patients also wanted to
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55 168 phone home to request visits from relatives (see appendix table 2). Furthermore, patients wanted healthcare
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57 169 professionals to communicate more often with them. However, the rules concerning visits, the infrastructure/
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3 170 accommodation (e.g. no telephone) and healthcare professionals' focus on the patients' disease made it
4
5 171 difficult for staff to fully satisfy patients' need for social contact. Moreover, pressure of work and time made it
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7 172 tough to communicate with patients. Furthermore language differences and misconceptions of healthcare
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9 173 professionals towards patients' ability to communicate in the language of the host country, sometimes based
10
11 174 on patients' different skin colour, endangered the meeting of patients' social needs. (see appendix table 3 and
12
13 175 4). Some patients also felt the urge to connect with other patients. This became indirectly apparent when
14
15 176 patients stared at other beds and/or asked questions about other patients' conditions. Nonetheless,
16
17 177 infrastructural constraints (e.g. remote beds) and language differences made communication between patients
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19 178 impossible. (see appendix table 5)

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27 181 **2) Need for non-medical information exchange with healthcare professionals**

28
29 182 The information exchange between doctors and patients was primarily of a medical nature. When patients
30
31 183 were conscious, doctors explained to patients their medical situation, which medical actions they had
32
33 184 undertaken as well those they would undertake in the future, and which medical decisions had been taken.
34
35 185 However, patients not only felt the need to get medical information regarding their physical state from
36
37 186 healthcare professionals, but equally to exchange information with them on matters that were not strictly
38
39 187 medical, e.g. practical issues, visual aspects (e.g. activities going on around them) and their family (see
40
41 188 appendix table 6 and 7). Furthermore, nurses regularly did not communicate with patients or only
42
43 189 communicated with them in a task-related manner (see appendix table 8).

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46 190 Despite healthcare professionals' good intentions, they often perceived it as impossible to communicate
47
48 191 with patients about non-medical issues due to their prime task of safeguarding the patients' clinical state, time
49
50 192 pressure, and their workload (see appendix table 9). Also language differences made communication between
51
52 193 patients and healthcare professionals about non-medical matters more difficult (see appendix table 10). In
53
54 194 addition, communication with relatives about non-medical issues was limited as well. Relatives often focused
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56 195 on their search for exhaustive medical information from doctors during the restricted visiting hours.

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3 196 **3) Need to increase comfort and alleviate pain**

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5 197 Patients wanted to increase their comfort and be free from pain. This need was often expressed through verbal
6
7 198 and non-verbal communication. Patients verbally requested acts of care to increase comfort in the language of
8
9 199 the host society or in their own mother tongue. They also often indirectly requested comfort-increasing care by
10
11 200 expressing their suffering through non-verbal signs, e.g. pointing with their heads. However, sometimes these
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13 201 expressions of patients' hardship were not noticed, minimally acknowledged, not apprehended or
14
15 202 misunderstood, even neglected, normalized or temporarily medically suppressed by giving tranquilizers, by
16
17 203 healthcare professionals. Inadequately meeting patients' need for comfort and pain alleviation was related to
18
19 204 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely
20
21 205 perceived language differences. Consequently, comfort and pain was often addressed based on healthcare
22
23 206 professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients.

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25
26 207 Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals
27
28 208 because they were too occupied with medical care tasks (see appendix table 11). Apprehension by healthcare
29
30 209 professionals of patients' verbal messages was sometimes hampered by language differences (see appendix
31
32 210 table 12). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with
33
34 211 patients sometimes unfolded inadequately or no communication occurred, in both cases sometimes grounded
35
36 212 in healthcare professionals' misconceptions of patients' language proficiency (see appendix table 13 and 14).

37
38 213 On the other hand, some patients who were at moments totally unable to communicate as a result of
39
40 214 medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless
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42 215 (see appendix table 15). When patients experienced discomfort for a longer time some of them did not want to
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44 216 ask healthcare professionals for help anymore and wanted to leave the ICU (see appendix table 16).

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50 218 **4) Need to express desperation**

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53 219 Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the
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55 220 hospital, others wanted to completely give up treatment (see appendix table 17).
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3 221 Patients felt the need to express and share these feelings with others. However, patients regularly felt obliged
4
5 222 to suppress their hopelessness during critical care in front of healthcare professionals and relatives, resulting in
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7 223 frustration and sadness.

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10 224 Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients
11
12 225 with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for
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14 226 patients to express their negative feelings. And even when patients did express their hopelessness, healthcare
15
16 227 professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless,
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18 228 tranquilizers/antidepressants were given (see appendix table 18).

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20 229 Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients
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22 230 (see appendix table 19). Relatives' religious beliefs and high expectations for cure in western hospitals
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24 231 functioned as sources of hope. Furthermore, negative information was hidden for some family members by
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26 232 other relatives so as to not create unrest within their large transnational families, which affected relatives'
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28 233 positive outlook on the patients' situation (see appendix table 20). Additionally, families' considerable size led
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30 234 to group pressure among its members to remain hopeful. Moreover, patients themselves presented their
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32 235 situation in a more positive manner towards visiting relatives coming from the home country so as to not worry
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34 236 their relatives there (see appendix table 21).

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41 239 **5) Need to participate in end-of-life decision making**

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44 240 Enduring physical and mental suffering triggered a need for some patients to participate in a decision to
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46 241 withdraw therapy. This need was verbally and non-verbally expressed at several points (see appendix table 22).

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49 242 However healthcare professionals regularly acknowledged these patients' communication only minimally,
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51 243 neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central
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53 244 decision makers and wanted to continue treatment, when they believed that patients still had a chance to
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55 245 survive within the context of their specific pathology. Patients were seen as lacking the required expertise to
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57 246 make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as

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3 247 they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or
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5 248 after taking anti-depressants (see appendix table 23). Further, healthcare professionals saw it as their mission
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7 249 to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient
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9 250 who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by
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11 251 some healthcare professionals as a personal failure. (see appendix table 24 and 25)
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13 252

14 15 253 **DISCUSSION**

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20 255 This ethnographic study investigates the state of the mental wellbeing of patients from ethnic minority groups
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22 256 and possible related risk factors for the development of mental health problems among these patients in a
23
24 257 multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups
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26 258 is basically characterized by an 'extreme emotional loneliness'. Patients had several human basic needs for
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28 259 which they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their
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30 260 relatives, nor to other patients. It concerned the need for social contact, for non-medical information
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32 261 exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in
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34 262 end-of-life decision making. Three interrelated risk factors for the development of mental health problems
35
36 263 among the included patients were identified: firstly healthcare professionals' mainly biomedical approach to
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38 264 care, secondly the ICU context, and thirdly the patients' different ethno-cultural background.

39
40 265 The mental wellbeing of patients from ethnic minority groups in a critical care setting is an under-
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42 266 researched topic. Although a body of research has recently begun to grow that focuses on the lifeworld of
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44 267 patients in a critical care context [see for example:2,3,7,9], still very few of these studies focus on specific
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46 268 vulnerable patient groups, e.g. patients from ethnic minority groups. As far as we know, this is the first study
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48 269 where the mental wellbeing of these patients is investigated in depth by means of an ethnographic research
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50 270 design. A study design of this kind is the most appropriate way to gain nuanced/deep insight into complex
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52 271 themes e.g. mental wellbeing of patients from ethnic minority groups in a critical care setting. Ethnographic
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54 272 day-by-day observations on the ward allow the study of patients' mental wellbeing as it is 'genuinely
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56 273 expressed' and from the perspective of the different people involved, from a non-prejudiced perspective. A
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3 274 weakness of this research could be the fact that the fieldwork was done in only one ICU. Therefore
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5 275 transferability to other situations must be done with caution. However, by spending a lot of time in a variety of
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7 276 situations (with 10 patients and their families, and all their healthcare professionals) it was possible to gain a
8
9 277 rich insight into our sensitive research topic. There is no specific reason to believe our findings are not valuable
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11 278 for other similar settings.

12
13 279 Our study shows that the patients included felt extremely emotionally lonely because several of their basic
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15 280 needs were insufficiently met. This seems to confirm previous research showing that ICU patients favour a
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17 281 holistic care approach and thus value attention from healthcare professionals not only to their bio-physiological
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19 282 needs but also to other general psycho-social and existential human needs, e.g. the need for social contact, for
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21 283 non-medical information exchange, religious needs and participation in decision making.[7,11,12,24]

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24 284 Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this
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26 285 model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems,
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28 286 caused by biological processes and expressed in signs and symptoms.[25] Care is orchestrated by healthcare
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30 287 professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine,
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32 288 although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory
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34 289 frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central
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36 290 responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced
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38 291 with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care
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40 292 strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks,
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42 293 making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure
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44 294 (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and
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46 295 professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly
47
48 296 prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[5,7] On the
49
50 297 other hand, taking into account patients' emotions becomes even more complex and challenging when
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52 298 patients have a different ethno-cultural background. The included patients' different ethno-cultural
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54 299 backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and
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56 300 collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care

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3 301 and suffering , communication forms and families' history of migration), and the level of patient-staff
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5 302 interaction (e.g. phenotypical features, language).
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7 303 Staff, occupied with urgent lifesaving care tasks, were frequently unable to react effectively to patients'
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9 304 verbal and non-verbal communications, often expressed by patients who completely lacked knowledge of the
10
11 305 language of the host country. However, adequately decoding ethno-culturally diverse patients' non-verbal
12
13 306 communication is crucial for optimal pain management and shared medical decision making.[26,27]
14
15 307 Furthermore, pressured healthcare professionals had little time to gain in-depth-knowledge of patients' level of
16
17 308 skill in the language of the host society. Therefore the staff easily developed misconceptions of patients'
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19 309 language proficiency based, for example, on their general knowledge of the patient's country of origin or
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21 310 specific phenotypical features, which led to inadequate communication or a complete absence of
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23 311 communication with patients about their needs. Moreover, insufficiently satisfying specific needs which were
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25 312 ethno-culturally inspired led to high emotional loneliness among patients. For example, a failure to meet
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27 313 patients' needs for multiple types of social contact (e.g. proximity of others) strengthened by the collectivistic
28
29 314 orientation of their minority cultures, led to high emotional suffering among patients. Moreover, because
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31 315 relatives shared ethno-cultural expectations towards patients to remain stoic and hopeful in difficult times,
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33 316 they did not pay enough attention to patients' specific unique basic needs, i.e. their need to express
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35 317 desperation and participate in end of life decisions, which made patients feel left behind. In line with this
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37 318 finding, previous research has shown that overt communication about pain and sorrow between patients from
38
39 319 certain ethnic minority groups and their relatives is limited.[28] Additionally, relatives' high levels of hope
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41 320 triggered healthcare professionals, caring for patients with an uncertain prognosis, to continue life-saving
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43 321 treatments and reinforced their belief in their core responsibility to save patients' lives, while these patients'
44
45 322 voices were largely unheard. Likewise, previous research demonstrates that more aggressive interventions
46
47 323 occur at the end of the lives of patients from ethnic minority groups.[29] Relatives shared high levels of hope,
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49 324 which were associated with an ethno-cultural non-disclosure of negative information by some relatives
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51 325 towards other relatives, ethno-religious beliefs,[30] migration-related expectations towards an unlimited field
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53 326 of medical possibilities in western hospitals, and group pressure among the many relatives to remain hopeful.
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3 328 **CONCLUSION**

4
5 329 This study shows that the mental state of patients from ethnic minority groups during critical care is alarming.
6
7 330 These patients had specific basic needs for which they could not sufficiently turn to anybody, leaving them in a
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9 331 state of extreme emotional loneliness. Three interrelated risk factors for the development of mental health
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11 332 problems among these patients were identified: firstly, healthcare professionals' mainly biomedical care
12
13 333 approach, secondly the ICU work context and thirdly the patients' different ethno-cultural background.
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16 334 Mental health problems among patients, irrespective of their ethno-cultural background, can primarily be
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18 335 reduced by investing in patient-centred care, which requires the implementation of intervention measures
19
20 336 stimulating the coexistence of biomedical and more holistic views on health and care among staff, on the level
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22 337 of daily work, training and education, and ICU policy/organization. Such structural measures include staff
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24 338 training in mental health, flexible visiting policies, the presence of a social worker on the ward, questioning the
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26 339 division of labour and working hours, close cooperation with a psychologist/psychiatrist, etc. Additionally, in a
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28 340 multi-ethnic ICU context, extra measures are urgently required, e.g. cultural sensitivity training for staff and
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30 341 students, language facilitation, and the presence of religious figures on the ward. Further (evidence-based)
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32 342 research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical
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34 343 care setting.
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38 345 **Abbreviations**

39 346 ICU, intensive care unit

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44 348 **Contributors:** All authors have met the four authorship criteria as stated in the International Committee of
45
46 349 Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly
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53 353 the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the
54
55 354 manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research
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57 355 design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of
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3 356 the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and
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5 357 applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB
6
7 358 applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to
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APPENDIX

Table 1

Patient: I've had enough... I've gone mad.

(..)

Researcher: But when your children are here, does that lift your spirits?

Patient: Yes, at the time...

Researcher: And at other times?

Patient: When they've gone? I'd like them to stay here longer.

[Field note, Norah]

Table 2

Patient: 'Telephone'.

Researcher: 'Do you want to use the telephone?'

Patient: 'Yes'.

Researcher: Who do you want to call?

(...)

Patient: 'Home'.

Researcher: 'Why?'

Patient: 'To say they have to come.'

[Field note, Zacharia]

Table 3

When I come in the patient is writing, along with his daughter Barbara. I notice that he is already able to write better than in the previous days. He points to me and writes 'NAME' on the paper. So he is asking my name. Then he points to his daughter and writes 'Barbara' on the paper. I say my name and then write my name on the paper.

[...]

During the change of nursing shift, the following is said about the patient:

'The patient wants to write all the time'. A nurse remarks: '*But he writes in Arabic!*' (...). Annoyed, the nurse continues, saying: '*I'm not going to learn Arabic so that I can understand him! We can never get anything right*'. (...) The nurse storms angrily out of the meeting. Some of the other nurses look shocked but they continue with the meeting. Another nurse asks: '*How can he write? He can't even hold a glass, talk ...*'. However the patient does not know any Arabic and speaks languages including French.

[field note, Quintus]

Table 4

Researcher: So there aren't many people you can talk to?

Patient: Here in hospital?

Researcher: Nods, uh huh...

Patient: No... They don't answer you...

Researcher: Who?

Patient: The nurses [...] They came when I had almost gone mad.

Researcher: And why?

Patient: I don't know.

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3 **Researcher:** And what do you think about that?
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5 **Patient:** Leave the hospital.
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8 [Field note, Norah]
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12 **Table 5**
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15 **Patient:** *Is there a sick person over there?*
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18 The patient lifts her head a little and looks curiously at the bed in the distance that is diagonally opposite her
19 bed. She can only catch a glimpse of that bed ...
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22 **Patient:** *She has been ill for a week ...*
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25 **Researcher:** *There are six beds here ...*
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28 [...]
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31 **Patient:** *Six in intensive care... Is it serious?*
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34 **Researcher:** *Some are more seriously ill than others...*
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36 [Field note, Norah]
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41 **Table 6**
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44 The doctor gives a medical explanation to the patient. (...) During the doctor's explanation, the patient looks
45 questioningly at the doctor. She asks the doctor: *'When can I go to the room?'* (Meaning: The patient asks the
46 doctor when she can leave the ICU and go to a room in another ward). The doctor says: *'today'*.
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49 [Field note, Norah]
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Table 7

I try to talk about his medical situation with him (patient) a bit and say: '*Your cannula has gone*' and point to his throat. He says bluntly: '*I'm not interested in that*'. I'm shocked by what he says. I ask what does interest him.

He says: '*My wife*'.

[Field note, Zacharia]

Table 8

The patient is lying with his eyes open. He has to gasp for air the whole time, is looking around which makes him seem very frightened (...). A nurse comes to aspirate the phlegm. He simply carries out his task and does not speak to the patient.

[Field note, Zacharia]

Table 9

Researcher: Erm, how did you experience your care for the patient? (..)

Nurse: Very difficult! Erm, not always easy. Erm. He wasn't always easy to deal with himself. The patient.

Which is sometimes understandable, of course, if you are that ill. Erm, but because of the, the pressure of work we're actually under, sometimes you can erm, with him, not as much, I mean sometimes we couldn't give him as much time as we would like to. Erm and sometimes I find that the most difficult part of your job, that you do want to stay in a room longer sometimes to, well, to be able to talk to your patient a bit more, or take your time a bit more with everything, but that sometimes that's not possible because you've got other things to do and you have to say "No, I have to go!" and, erm, yes, that's pretty much that. If I just look at the patient themselves, I mean.

[Interview with nurse Vanessa]

Table 10

The nurse comes into quarantine without saying anything to the patient. She looks at the medication and does several things on the PC. The patient looks at the nurse and says: *'tranquil'*, relax. I deduce from this that the patient wants to talk to the nurse. The nurse doesn't react to the patient's words. Then she pours the patient's urine into a plastic bottle. The patient asks me: 'What is she doing?' I say to her: 'He's asking what you're doing'. She replies in Dutch, a language the patient doesn't understand: *'I'm pouring his pee into a bottle'*. Then she leaves quarantine.

[Field note, Zacharia]

Table 11

10 minutes later, the patient is shivering with cold. He points to the blanket. He wants an extra blanket, but there are no nurses nearby. I leave quarantine again and go and ask the nurses for a blanket. One of them says: *'Now he's messing us around. I was with him just a moment ago.'* There was no response to his request.

[Field note, Abdallah]

Table 12

I sit down at the nurses' table. The patient sees us and calls out to us in Arabic. The nurses stay where they are and say: *'It is annoying, though, that we don't understand them'* (...). Apparently these carers feel powerless. The patient continues to call out and complain, and waves her arms in the air. She also bangs her arms against her head. Clearly she is trying to tell us something. None of the carers go over to her.

[Field note, Fadila]

Table 13

I ask the nurses who are checking the parameters shown on the monitor by the patient's bed: *'Does he speak French?'* One nurse answers: 'Yes, because French is an official language in Algeria, isn't it.' However the visitor

1
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3 told me that the patient only speaks Arabic. The patient is very distressed. 2 nurses stand around his bed after
4 visiting hour and ask him in French: *'Can you breathe properly? Are you comfortable? Bilal, Bilal, are you*
5 *comfortable?'* The patient is still very distressed and every time the nurses say something to him, he moves his
6 head from left to right. (...) The carers therefore assume that this patient understands them on the basis of
7 their presuppositions.
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11 [Field note, Bilal]
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19 **Table 14**

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21 The patient clearly looks around when the nurse comes into the unit. The nurse notices but does not stop and
22 consider the patient's conspicuous head movements. I ask the nurse: *'Do you think the patient can understand*
23 *us?'* He says: *'He's conscious, he's reacting because he is looking at me but I don't think he understands me (...) I*
24 *think he only speaks Moroccan, he lives with his son and the family speak Moroccan with him.'* However the
25 patient does speak French.
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31 [Field note, Zacharia]
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38 **Table 15**

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40 During the nurses' meeting in the unit, the patient's situation was discussed. Among other things, he is said not
41 to be a difficult patient: *'He doesn't cause trouble, he's not in pain and he doesn't complain'*. It strikes me that
42 the patient has little opportunity to 'complain' given that he had a cannula that rendered him unable to speak.
43 Besides, according to the visitor, he does not speak Dutch, French or English, so he cannot speak to the nurses.
44 It is also strange that the nurses decide he has no pain purely on the basis of the absence of verbal
45 communication between the patient and the carers.
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51 [field note, Bilal]
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Table 16

Patient: I'm not going to stay in intensive care, this place is death.

Researcher: Why?

Patient: I don't like it...Nobody comes, nobody listens... Even the nurses, one in ten glances your way for a moment, that's all ...(...) *'I can't manage yet, when I'm done'*...Anyway, I don't like it.

[...]

The patient looks sad and dejected. She says to her daughter that she wants to be moved because her back hurts. She says the nurses aren't friendly to her and that they don't often come when she asks them to.

Suddenly she starts to cry.

[Field note, Norah]

Table 17

Patient: Nothing has changed...

Researcher: How does that feel?

(Silence; she's thinking)

Patient: It doesn't change anything.

Researcher: You don't think it changes anything? And why do you think that?

Patient: I'm disgusted with life.

Researcher: You're...?

Patient: Disgusted with life.

Researcher: Disgusted with life ... And that means?

Patient: I've no more hope.....I want to leave the hospital...

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3 [Field note, Norah]
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9 **Table 18**

10 The nurse says that the patient is nervous and that that is why she is giving her a Xanax. The nurse speaks to
11 the patient in Dutch, asking: *'Why are you nervous?!, You have to do your best, you know!!'*. I have the
12 impression that the patient doesn't understand the nurse. (...) The patient says in French: *'Don't understand.'*

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18 [Field note, Norah]
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23 **Table 19**

24 I hear from the nurses that the patient gets panic attacks, hyperventilates and that his heart rhythm has
25 increased (...) During visiting hour the patient says to his wife: *'it's fucked,'* to which the wife replies hopefully:
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'You'll get through it, you'll get better. The infection has gone down'. The patient rolls his eyes at this.

[Field note, Abdallah]

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Table 20

In the meantime, the patient's daughter tells me her brother talked to another doctor the previous evening
and that it was a 'good' conversation. The patient was apparently a bit better and they would see how he was
later in the week. This has clearly given the daughter more hope today. However I witnessed the conversation
the day before between the doctor and the patient's son from a distance and the news the doctor brought was
not good news. I deduce from this that the patient's son is hiding the confronting information the doctor gave
him from his sister and giving her a rosier picture of the patient's situation so that she would continue to hope.

[Field note, Onur]

Table 21

Then the uncle says: *'Will you fight for your children?'* The patient nods. The uncle continues: *'You came out of the coma, that's a sign that you want to continue, that you want to fight. Your face looks better.'* Then the patient shakes his head and lowers his eyes. (...) Then the patient's brother comes into quarantine. He flew over yesterday from Morocco. When he asks the patient how he is, the tone is more cheerful. The patient lifts his hand into the air and makes small, successive striking motions in the air, with which he means to indicate that his medical situation is improving. The brother laughs and says he saw him a while ago in a coma and that he is pleased he is now awake and eating. So he says to the patient that he sees clear progress. It is striking that the patient says to his brother who has flown over from Morocco that he is better, whereas he tells his wife and uncle that he is not doing well.

[field note, Abdallah (died in the ICU)]

Table 22

I ask him (the patient) if he is okay. He shakes his head, indicating *'no'*, then breathes in and out loudly. He looks like a fish gasping for air. He means by this that he has difficulty breathing, even with the machines. He points to the machines. He looks angry and very sad at the same time. (...) He strikes the air with his hand, a gesture that I believe means he wants to give up. He points to the machines again and says *'that's useless'*. (...) The patient sighs and looks really contorted. I ask in French if he is in pain. *'Vous avez mal?'* He nods and points to his chest.

[Field note, Abdallah]

Table 23

I see the doctor walking into the unit. I go over to him for a moment and tell him about the patient's panic attacks. He says: *'That is normal, because he has already been in here for three months... We can hardly tell his body it has to stop... And even if the patient or family wanted us to stop treatment, we couldn't comply with*

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that....I ask him: 'Why not?' He replies: 'The patient and his family are not competent to decide because they are in a phase of pain and emotion... If we say we are going to continue, we will continue...

[Field note, Abdallah]

Table 24

Nurse: And I think he had indicated a couple of times himself that he had had enough.

Researcher: How did he indicate that?

Nurse: Yes, by actually, erm by saying, and by saying "It doesn't help, does it! Don't do that, it doesn't help!" He said that very often at the end.

Researcher: And who did he say that to then?

Nurse: He said it to me a couple of times. (...) He definitely said to me: "Just leave it like this, it's not going to, you know..." Erm, but even helping to decide "We're going to stop!" I don't think he did that. (..)

[..]

Researcher: Erm, and did you talk about that to other people, about the fact that the man told you he would prefer the treatment to stop?

Nurse: Yes. Yes. We do tell each other that. Yes, I did say it to my colleagues, and to the doctor as well, that he wanted, that those words had been said and that that... Well it's heartbreaking, isn't it, because, well, somehow you know he's right but, you still do it, don't you.

Researcher: Yes. And how did the doctors react to this?

Nurse: It wasn't easy. Because the doctor also had real difficulty with it, to take the decision to let him go. Yes. I think, well, at times like that, still not being able to admit it and saying anyway "We're going to keep going".

[Interview Nurse Vanessa]

Table 25

Nurse: I think the doctor, well, sometimes she gets really involved in the family's emotions too.

Researcher: She does?

Nurse: (...) With the gentleman too, I think she found it really difficult. As well as that, I think, well, it's different, isn't it, it's anonymous, I'm going to say it, "I think that she sometimes sees it as a personal failure!"

Researcher:

Uhuh.

Nurse: "I, I couldn't save the patient."

[interview nurse Conny]

Research checklist

No research checklist was used as no appropriate checklist exists for ethnographic studies.

For peer review only

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MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A QUALITATIVE ETHNOGRAPHIC STUDY

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3 1 **MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A**
4
5 2 **QUALITATIVE ETHNOGRAPHIC STUDY**
6

7
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52
53 25 **Word count:** 3560 words

54
55
56 26 **Key words:** intensive care units, patients, cultural diversity, communication, mental health
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1
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3 27 **Abstract**

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5 28 **Objectives:** To investigate the state of the mental wellbeing of patients from ethnic minority groups
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7 and possible related risk factors for the development of mental health problems among these
8
9 patients during critical medical situations in hospital.
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13 31 **Design:** Qualitative ethnographic design.

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16 32 **Setting:** 1 intensive care unit (ICU) of a multi-ethnic urban hospital in Belgium.

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19 33 **Participants:** 84 ICU staff members, 10 patients from ethnic-minority groups, and their visiting family
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21 34 members.

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24 35 **Results:** Patients had several human basic needs for which they could not sufficiently turn to
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26 anybody, neither to their healthcare professionals, nor to their relatives, nor to other patients. These
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28 37 needs included the need for social contact, the need to inpatientease comfort and alleviate pain,
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30 38 the need to express desperation and participate in end-of-life decision making. Three interrelated
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32 39 risk factors for the development of mental health problems among the patients included were
33
34 40 identified: Firstly, healthcare professionals' mainly biomedical care approach (e.g. focus on curing the
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36 41 patient, limited psychosocial support), secondly, the ICU context (e.g. time pressure, uncertainty,
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38 42 regulatory frameworks) and thirdly, patients' different ethno-cultural background (e.g. religious and
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40 43 phenotypical differences).

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44 44 **Conclusions:** The mental state of patients from ethnic minority groups during critical care is
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46 45 characterized by extreme emotional loneliness. It is important that staff should identify and meet
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48 46 patients' unique basic needs in good time with regard to their mental wellbeing, taking into account
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50 47 important threats related to their own mainly biomedical approach to care, the ICU's structural
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52 48 context as well as the patients' different ethno-cultural background.

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50 **Article summary**

51 **Strengths and limitations of this study**

- 52 • As far as we know, this is the first study where the mental wellbeing of patients from ethnic
53 minority groups is profoundly investigated by means of an ethnographic research design.
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- 55 • By studying the mental wellbeing of these patients as is ‘genuinely expressed’, from multiple
56 perspectives and in a contextual manner, through ethnographic fieldwork in an intensive
57 care unit of a multi-ethnic urban hospital in Belgium, we have tried to develop a nuanced,
58 non-stereotypical and rich insight into such patients’ mental wellbeing.
59
- 60 • One limitation of this research could be the fact that the fieldwork was done in only one ICU.
61 Therefore transferability to other situations must be done with caution. However, by
62 spending a lot of time in a variety of situations (with 10 patients and their families, and all
63 their healthcare professionals) it was possible to gain a rich insight into our sensitive research
64 topic.

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69 INTRODUCTION

70 Having a good mental health/wellbeing means more than not having a mental disorder. The WHO defines
71 mental wellbeing as *'a state of well-being in which an individual realizes his or her own abilities, can cope with
72 the normal stresses of life, can work productively and is able to make a contribution to his or her community'*. It
73 is perceived as crucial to our capacity as people to think, communicate with others, earn money and enjoy life.
74 Risk factors include individual factors on e.g. the socio-economical level (e.g. being poor, having a low
75 educational level), cultural level (e.g. belonging to an ethnic minority group) and behavioural level (e.g. having
76 an unhealthy life style, having little sleep), contextual/structural factors (e.g. facing adverse work conditions,
77 discrimination) and biological/genetical factors (e.g. being physically ill) [1,2]. It is then no surprise that during
78 critical care patients' mental wellbeing comes under threat, and especially when other risk factors are involved,
79 e.g. when patients have a different ethno-cultural background [3,4].

80 Hallucinations, fear, and depression frequently occur among patients admitted to the intensive care unit
81 (ICU).[5-8] Several risk factors are identified, including invasive treatments, separation from family, physical
82 pain, immobility, dependency, lack of control, lack of privacy and poor communication.[4,5,9,10, 11] Although
83 disturbances in critically ill patients' mental health negatively affect their whole care process, healthcare
84 professionals working in a critical care setting lack adequate strategies to improve patients' mental health.
85 They are often not aware of patients' mental health problems as they mainly focus on the technological care
86 aspects and lack training in mental care. Many critical care nurses for example do not have enough insight in
87 the elements that might affect their patients' psychological state. [9,12] Furthermore in society at large,
88 mental health problems remain a sensitive issue as such problems are often difficult acknowledged and talked
89 about.

90 Additionally, healthcare professionals have to communicate increasingly with patients from ethnic minority
91 groups, i.e. persons of a different origin who share certain cultural characteristics to some extent [13], as a
92 result of societies' increased ethno-cultural diversity. In Belgium, healthcare for migrants is basically organized
93 in the same manner as for people from the ethnic majority group. However it is known that during the care for
94 migrants problems regularly arise which are situated on mainly 2 levels, namely firstly health differences
95 (ethnic minorities have less chance on a healthy life than people from the ethnic majority group) and secondly

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3 96 problems regarding the accessibility and use of healthcare services (ethnic minorities have lower access to
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5 97 healthcare services and receive less quality care than members of the ethnic majority group). Problems are
6
7 98 often very complex and related to different factors, such as linguistic and cultural differences. [14] We might
8
9 99 assume that critically ill patients from ethnic minority groups are at an even higher risk of mental health
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11 100 problems and that ethno-cultural differences render mental health problems more complex and multifaceted.
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13 101 Inattention by healthcare professionals to specific ethno-cultural habits (e.g. gender segregation),
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15 102 discrimination, unfamiliarity with the western healthcare system and different foodways can contribute to
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17 103 traumatic experiences for ethnic minorities.[15,16, 17, 18] Furthermore, language differences and ethno-
18
19 104 cultural norms prescribing acceptance of physical suffering can lead to less adequate communication and pain
20
21 105 relief[19,20], which can endanger such patients' psychological state.[7,15,21] Yet, although we increasingly live
22
23 106 in a multi-ethnic society, research about the mental wellbeing of patients from ethnic minority groups during
24
25 107 critical care is rather scarce and there are very few in-depth studies which try to understand this topic in its
26
27 108 specific context and from different angles.

28
29 109 In this study we therefore aim to investigate 'the state of the mental wellbeing of patients from ethnic
30
31 110 minority groups and possible related risk factors for the development of mental health problems among these
32
33 111 patients in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among
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35 112 patients from ethnic minority groups can contribute to the development of recommendations to prevent such
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37 113 problems for these patients.

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41 42 115 **METHODS**

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45 116 Patients' mental wellbeing in a multi-ethnic critical care setting is a sensitive, complex, and novel topic of
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47 117 research. Therefore an ethnographic research design has been used, which gave the researcher the
48
49 118 opportunity to immerse herself into her study field and study the research topic for a long period on the
50
51 119 workforce itself. By getting a feel of the lifeworld of the ICU, observing and interacting with different parties,
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53 120 the researcher was able to grasp the research topic in all its different facets and from different angles.

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3 122 **Participants & setting**
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8 124 Ethnographic fieldwork was done in one ICU of a multi-ethnic urban hospital in Belgium over 6 months (January
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10 125 2014-June 2014). 40 % of the ICU patients are estimated to belong to an ethnic minority group. Staff's,
11
12 126 patients', and relatives' behaviour, interactions, and experiences were studied for 360 hours. The selected
13
14 127 patients and the family members who accompanied them, as well as their healthcare professionals, were
15
16 128 followed for the whole critical period. No relationship was established with the research participants prior to
17
18 129 the beginning of the study. Patients and their family members were purposefully selected and approached
19
20 130 face-to-face. They were only eligible for inclusion in the study if the patient or at least one of his/her legal
21
22 131 parents was born abroad, if at least one of the family members (patient/his or her relatives) was able to speak
23
24 132 Dutch, French, or English, and if the patient was at least 18 years old. In total we selected 10 patients and their
25
26 133 visiting family members, who were originally from Morocco, Algeria, Turkey, Congo and Portugal. No patients
27
28 134 and relatives refused to participate. The patients were between 40 and 82 years old and consisted of 6 males
29
30 135 and 4 females. They were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
31
32 136 (2), brain haemorrhage (2), cancer (1), and a severe accident (1). All patients were sedated for some time, and
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34 137 as a result were unable to communicate or only had limited ability to communicate, depending on the level of
35
36 138 sedation. The critical care team consisted of 80 nurses and 12 doctors, who were almost all white Caucasians
37
38 139 from the dominant ethnic group. 8 staff members refused to participate in the study. Of course also other
39
40 140 people were present during the ethnographic fieldwork, e.g. doctors who mostly work in other wards.
41
42 141 Research participants were aware of the researcher's reason for doing the research (improving intercultural
43
44 142 communication in the ICU). (For further information about patients' characteristics: see table)
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48 144 **Data collection**
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53 146 Data were collected through triangulation of several data collection strategies, namely negotiated interactive
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55 147 observation,[22] in-depth- interviews with healthcare professionals,[23] and the reading of patients' medical
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57 148 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care
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3 149 tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward.
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5 150 Therefore 'negotiated interactive observation' was chosen, meaning that before starting the observations the
6
7 151 researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique
8
9 152 enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation
10
11 153 gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family
12
13 154 members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare
14
15 155 professionals, relatives, and patients during visiting hours.

16
17 156 When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she
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19 157 transformed these notes into comprehensive descriptive field notes containing observations of participants'
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21 158 discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on
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23 159 her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare
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25 160 professionals in two meeting rooms in the hospital. The interview questions were based on an interview guide,
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27 161 which was discussed among experts before the actual data collection started and pilot tested among a limited
28
29 162 number of persons. The interviews lasted between 50 minutes and 1h30 and were audio recorded. Interview
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31 163 transcripts were not returned to the research participants for comments or corrections. All data were collected
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33 164 by the first author (RVK), a trained ethnographer and sociologist (MSc) who was doing academic scientific
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35 165 research at university at the time of the study. She is extensively trained in qualitative research.

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39 40 167 **Data analysis**

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45 169 The analysis started with a 'thick description' [25] of participants' discourse, behaviour, and interaction and
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47 170 was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were
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49 171 conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This
50
51 172 process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly,
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53 173 an open coding phase was performed, involving the reading and rereading of the data. This resulted in the
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55 174 formation of different codes, for instance 'physical contact', 'proximity', and 'fighting'. To find similarities and
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57 175 differences between these codes, new codes were constantly compared with already existing codes. Secondly,

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3 176 axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example
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5 177 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance
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7 178 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category
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9 179 ('emotional loneliness') around which the related categories are clustered.[26,27]

10
11 180 Data collection and analysis were stopped when the point of saturation was reached.[26,28] Reliability was
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13 181 strengthened by the first author (RVK) doing the data analysis and two co-authors (RD & JB) doing a peer-
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15 182 revision of the analysis. The process of data collection and data analysis was also regularly discussed by
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17 183 members of the multidisciplinary academic research group in which these authors participate, consisting of a
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19 184 health scientist, a psychiatric nurse, 2 anthropologists, and 1 sociologist. To improve the reliability and accuracy
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21 185 of the study, the results were also read by an intensive care specialist who is part of the intensive care team at
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23 186 the hospital in which the researcher did her fieldwork. Furthermore the study results were presented to and
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25 187 discussed with the nurses who had participated in this study during a conference.
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30 189 **Ethics**

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33 190 The research protocol (reference 2013/371) was approved by the university ethics committee of the Vrije
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35 191 Universiteit Brussel. The privacy of the research participants and confidentiality of the data were respected,
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37 192 e.g. by using pseudonyms. Written consent to participation in the study was sought from healthcare
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39 193 professionals, family members, and patients who were still able to communicate. If the patient lacked the
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41 194 capacity to give consent, consent was sought from his/her legal representative.
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46 196 **RESULTS**

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49 197 The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
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51 198 (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among
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53 199 patients. Patients had several basic needs for which they could not sufficiently turn to anybody, neither to their
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55 200 healthcare professionals, nor to their relatives, nor to other patients. These needs comprised 'the need for
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3 201 social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to
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5 202 express desperation, and to participate in end-of-life decision making’.

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10 204 **1) Need for social contact**

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16 206 Patients longed for social contact with relatives, healthcare professionals and other patients, and not only
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18 207 verbally but also non-verbally. This need became even more significant when patients were unable to
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20 208 communicate verbally as a result of their medical state and/or language differences. More specifically, patients
21
22 209 longed for proximity of others, physical contact, and chatting.

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25 210 Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and
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27 211 talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting
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29 212 time, to come more often, or to take them back home (see appendix table 1a). Some patients also wanted to
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31 213 phone home to request visits from relatives (see appendix table 1b). Furthermore, patients wanted healthcare
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33 214 professionals to communicate more often with them (see appendix table 1c). However, the rules concerning
34
35 215 visits, the infrastructure/ accommodation (e.g. no telephone) and healthcare professionals’ focus on the
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37 216 patients’ disease made it difficult for staff to fully satisfy patients’ need for social contact. Moreover, pressure
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39 217 of work and time made it tough to communicate with patients. Furthermore language differences and
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41 218 misconceptions of healthcare professionals towards patients’ ability to communicate in the language of the
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43 219 host country, sometimes based on patients’ different skin colour, endangered the meeting of patients’ social
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45 220 needs. (see appendix table 1d). Some patients also felt the urge to connect with other patients. This became
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47 221 indirectly apparent when patients stared at other beds and/or asked questions about other patients’
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49 222 conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made
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51 223 communication between patients impossible. (see appendix table 1e)

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226 **2) Need for non-medical information exchange with healthcare professionals**

227 The information exchange between doctors and patients was primarily of a medical nature. When patients
228 were conscious, doctors explained to patients their medical situation, which medical actions they had
229 undertaken as well those they would undertake in the future, and which medical decisions had been taken.
230 However, patients not only felt the need to get medical information regarding their physical state from
231 healthcare professionals, but equally to exchange information with them on matters that were not strictly
232 medical, e.g. practical issues, visual aspects (e.g. activities going on around them) and their family (see
233 appendix table 2a and 2b). Furthermore, nurses regularly did not communicate with patients or only
234 communicated with them in a task-related manner (see appendix table 2c).

235 Despite healthcare professionals' good intentions, they often perceived it as impossible to communicate
236 with patients about non-medical issues due to their prime task of safeguarding the patients' clinical state, time
237 pressure, and their workload (see appendix table 2d). Also language differences made communication between
238 patients and healthcare professionals about non-medical matters more difficult (see appendix table 2e). In
239 addition, communication with relatives about non-medical issues was limited as well. Relatives often focused
240 on their search for exhaustive medical information from doctors, which was reinforced by group pressure
241 within their families, during the restricted visiting hours.

242 **3) Need to increase comfort and alleviate pain**

243 Patients wanted to increase their comfort and be free from pain. This need was often expressed through verbal
244 and non-verbal communication. Patients verbally requested acts of care to increase comfort in the language of
245 the host society or in their own mother tongue. They also often indirectly requested comfort-increasing care by
246 expressing their suffering through non-verbal signs, e.g. pointing with their heads. However, sometimes these
247 expressions of patients' hardship were not noticed, minimally acknowledged, not apprehended or
248 misunderstood, even neglected, normalized or temporarily medically suppressed by giving tranquilizers, by
249 healthcare professionals. Inadequately meeting patients' need for comfort and pain alleviation was related to
250 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely
251 perceived language differences. Consequently, comfort and pain was often addressed based on healthcare

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3 252 professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and
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5 253 irritation and insecurity occurred on both sides (see appendix table 3a).
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7 254 Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals
8
9 255 because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients'
10
11 256 verbal messages was sometimes hampered by language differences (see appendix table 3b). Moreover, when
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13 257 patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded
14
15 258 inadequately or no communication occurred. This was sometimes related to healthcare professionals'
16
17 259 misconceptions of patients' language proficiency, based on the very quick and minimal moments of interaction
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19 260 they had with patients and relatives and patients' different skin colour. Also staff's general knowledge of
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21 261 patients' country of origin which they sometimes easily applied to all patients from that country contributed to
22
23 262 these misconceptions (see appendix table 3c).
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25
26 263 On the other hand, some patients who were at moments totally unable to communicate as a result of
27
28 264 medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless
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30 265 (see appendix table 3d). When patients experienced discomfort for a longer time some of them did not want to
31
32 266 ask healthcare professionals for help anymore and wanted to leave the ICU (see appendix table 3e).
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36 37 268 **4) Need to express desperation**

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40 269 Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the
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42 270 hospital, others wanted to completely give up treatment (see appendix table 4a). Patients felt the need to
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44 271 express and share these feelings with others. However, patients regularly felt obliged to suppress their
45
46 272 hopelessness during critical care in front of healthcare professionals and relatives, resulting in frustration and
47
48 273 sadness.
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51 274 Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients
52
53 275 with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for
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55 276 patients to express their negative feelings. And even when patients did express their hopelessness, healthcare
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3 277 professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless,
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5 278 tranquilizers/antidepressants were given (see appendix table 4b).
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7
8 279 Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients
9
10 280 (see appendix table 4c). Relatives' religious beliefs and high expectations for cure in western hospitals
11
12 281 functioned as sources of hope. Furthermore, negative information was hidden for some family members by
13
14 282 other relatives so as to not create unrest within their large transnational families, which affected relatives'
15
16 283 positive outlook on the patients' situation (see appendix table 4d). Additionally, families' considerable size led
17
18 284 to group pressure among its members to remain hopeful. Moreover, patients themselves presented their
19
20 285 situation in a more positive manner towards visiting relatives coming from the home country so as to not worry
21
22 286 their relatives there (see appendix table 4e).
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27 28 29 289 **5) Need to participate in end-of-life decision making**

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31 290 Enduring physical and mental suffering triggered a need for some patients to participate in a decision to
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33 291 withdraw therapy. This need was verbally and non-verbally expressed at several points (see appendix table 5a).
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36 292 However healthcare professionals regularly acknowledged these patients' communication only minimally,
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38 293 neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central
39
40 294 decision makers and wanted to continue treatment, when they believed that patients still had a chance to
41
42 295 survive within the context of their specific pathology. Patients were seen as lacking the required expertise to
43
44 296 make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as
45
46 297 they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or
47
48 298 after taking anti-depressants (see appendix table 5b). Further, healthcare professionals saw it as their mission
49
50 299 to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient
51
52 300 who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by
53
54 301 some healthcare professionals as a personal failure. (see appendix table 5c)
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303 **DISCUSSION**

304 Health has

305 This ethnographic study investigates the state of the mental wellbeing of patients from ethnic minority groups
306 and possible related risk factors for the development of mental health problems among these patients in a
307 multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups
308 is basically characterized by an 'extreme emotional loneliness'. Patients had several human basic needs for
309 which they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their
310 relatives, nor to other patients. It concerned the need for social contact, for non-medical information
311 exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in
312 end-of-life decision making. Three interrelated risk factors for the development of mental health problems
313 among the included patients were identified: firstly healthcare professionals' mainly biomedical approach to
314 care, secondly the ICU context, and thirdly the patients' different ethno-cultural background.

315 The mental wellbeing of patients from ethnic minority groups in a critical care setting is an under-
316 researched topic. Although a body of research has recently begun to grow that focuses on the lifeworld of
317 patients in a critical care context [see for example:4,5,9,12], still very few of these studies focus on specific
318 vulnerable patient groups, e.g. patients from ethnic minority groups, and mental health issues. Furthermore
319 some researchers that do focus on critically ill patients from ethnic minority groups study their experiences
320 mainly through interviews with patients, their relatives or staff [see for example: 15, 29]. So as far as we know,
321 this is the first study where specifically the mental wellbeing of patients from ethnic minority groups is
322 investigated in one particular context, namely the critical care context, by means of an ethnographic research
323 design. A study design of this kind is the most appropriate way to gain nuanced/deep insight into complex
324 themes e.g. mental wellbeing of patients from ethnic minority groups in a critical care setting. Ethnographic
325 day-by-day observations on the ward allow the study of patients' mental wellbeing as it is 'genuinely
326 expressed' and from the perspective of the different people involved, from a non-prejudiced perspective.

327 The researcher might have had an impact on the field and the research findings as she herself has a non-
328 Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from
329 patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic

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3 330 feature of qualitative ethnographic research [23]. A weakness of this research could be the fact that the
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5 331 fieldwork was done in only one ICU. Therefore transferability to other situations must be done with caution.
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7 332 However, by spending a lot of time in a variety of situations (with 10 patients and their families, and all their
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9 333 healthcare professionals) it was possible to gain a rich insight into our sensitive research topic. There is no
10
11 334 specific reason to believe our findings are not valuable for other similar settings. Another weakness of this
12
13 335 study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-
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15 336 depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can
16
17 337 be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't
18
19 338 allow other techniques, such as video recording and full participant observation, for ethical reasons.

20
21 339 Our study shows that the patients included felt extremely emotionally lonely because several of their basic
22
23 340 needs were insufficiently met. This seems to confirm previous research showing that ICU patients favour a
24
25 341 holistic care approach and thus value attention from healthcare professionals not only to their bio-
26
27 342 physiological needs but also to other general psycho-social and existential human needs, e.g. the need for
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29 343 social contact, for non-medical information exchange, religious needs and participation in decision
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31 344 making.[9,15,16,30]

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34 345 Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this
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36 346 model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems,
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38 347 caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare
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40 348 professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine,
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42 349 although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory
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44 350 frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central
45
46 351 responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced
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48 352 with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care
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50 353 strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks,
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52 354 making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure
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54 355 (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and
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56 356 professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly
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58 357 prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the

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3 358 other hand, taking into account patients' emotions becomes even more complex and challenging when
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5 359 patients have a different ethno-cultural background. The included patients' different ethno-cultural
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7 360 backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and
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9 361 collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care
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11 362 and suffering , communication forms and families' history of migration), and the level of patient-staff
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13 363 interaction (e.g. phenotypical features, language).

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15 364 Staff, occupied with urgent lifesaving care tasks, were frequently unable to react effectively to patients'
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17 365 verbal and non-verbal communications, often expressed by patients who completely lacked knowledge of the
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19 366 language of the host country. However, adequately decoding ethno-culturally diverse patients' non-verbal
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21 367 communication is crucial for optimal pain management and shared medical decision making.[32,33]
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23 368 Furthermore, pressured healthcare professionals had little time to gain in-depth-knowledge of patients' level of
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25 369 skill in the language of the host society. Therefore the staff easily developed misconceptions of patients'
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27 370 language proficiency based, for example, on their general knowledge of the patient's country of origin or
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29 371 specific phenotypical features, which led to inadequate communication or a complete absence of
30
31 372 communication with patients about their needs. Moreover, insufficiently satisfying specific needs which were
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33 373 ethno-culturally inspired led to high emotional loneliness among patients. For example, a failure to meet
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35 374 patients' needs for multiple types of social contact (e.g. proximity of others) strengthened for some patients by
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37 375 the collectivistic orientation of their minority cultures, led to high emotional suffering among particular
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39 376 patients. Moreover, because relatives shared ethno-cultural expectations towards patients to remain stoic and
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41 377 hopeful in difficult times, they did not pay enough attention to patients' specific unique basic needs, i.e. their
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43 378 need to express desperation and participate in end of life decisions, which made patients feel left behind. In
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45 379 line with this finding, previous research has shown that overt communication about pain and sorrow between
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47 380 patients from certain ethnic minority groups and their relatives is limited.[34] Additionally, relatives' high levels
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49 381 of hope triggered healthcare professionals, caring for patients with an uncertain prognosis, to continue life-
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51 382 saving treatments and reinforced their belief in their core responsibility to save patients' lives, while these
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53 383 patients' voices were largely unheard. Likewise, previous research demonstrates that more aggressive
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55 384 interventions occur at the end of the lives of patients from ethnic minority groups.[35] Relatives shared high
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57 385 levels of hope, which were associated with an ethno-cultural non-disclosure of negative information by some
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3 386 relatives towards other relatives, ethno-religious beliefs,[29] migration-related expectations towards an
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5 387 unlimited field of medical possibilities in western hospitals, and group pressure among the many relatives to
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7 388 remain hopeful.

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9 389 Finally, another striking observation is that not only patients' mental health but also the mental state of
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11 390 healthcare professionals working in such interethnic critical medical situations can become severely threatened
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13 391 due to their experiences of powerlessness towards meeting some of their patients' human basic needs. This
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15 392 can further negatively affect patients' mental state.

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17 393 Our study results are certainly also of relevance to patients from majority ethnic backgrounds because we
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19 394 found that the ICU context and staff's biomedical approach, factors to which all patients are exposed, hindered
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21 395 the satisfaction of several human basic needs which are shared by all patients irrespective of their ethno-
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23 396 cultural background. Patients from ethnic minority groups their different ethno-cultural background forms an
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25 397 extra important risk factor for not meeting their basic needs. Of course the relative importance of this risk
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27 398 factor is different for each patient.

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29 399 Mental health problems among patients, irrespective of their ethno-cultural background, can primarily be
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31 400 reduced by investing in patient-centred care, which requires the implementation of intervention measures
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33 401 stimulating the coexistence of biomedical and more holistic views on health and care among staff, on the level
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35 402 of daily work, training and education, and ICU policy/organization. Such structural measures include staff
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37 403 training in mental health, flexible visiting policies, the presence of a social worker on the ward, questioning the
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39 404 division of labour and working hours, close cooperation with a psychologist/psychiatrist, etc. Additionally, in a
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41 405 multi-ethnic ICU context, extra measures are urgently required, e.g. cultural sensitivity training for staff and
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43 406 students, language facilitation, and the presence of religious figures on the ward. Further (evidence-based)
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45 407 research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical
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47 408 care setting.

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54 411 **CONCLUSION**

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3 412 The followed patients had specific basic needs for which they could not sufficiently turn to anybody, leaving
4 413 them in a state of extreme emotional loneliness. Three interrelated risk factors for the development of mental
5 414 health problems among these patients were identified: firstly, healthcare professionals' mainly biomedical care
6 415 approach, secondly the ICU work context and thirdly the patients' different ethno-cultural background.
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13 417 **Abbreviations**14
15 418 ICU, intensive care unit
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19 420 **Contributors:** All authors have met the four authorship criteria as stated in the International Committee of
20 421 Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly
21 422 Work in Medical Journals.
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26
27 424 **Authors' contributions:** RVK contributed to the research design, applied for the ethical approval, completed
28 425 the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the
29 426 manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research
30 427 design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of
31 428 the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and
32 429 applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB
33 430 applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to
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38 433

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3 4404
5 441 **Competing interests:** The authors declare that they have no competing interests.6
7 4428
9 443 **Data sharing:** Extra data is available by emailing RVK.

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For peer review only

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3 **1 APPENDIX**
4
5 **2 (Note: all the names are pseudonyms)**

6 **TABLE 1. NEED FOR SOCIAL CONTACT**

7
8 **a) Longer visits**

9
10 **Patient:** I've had enough... I've gone mad.

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12 (..)

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14 **Researcher:** But when your children are here, does that lift your spirits?

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16 **Patient:** Yes, at the time...

17
18 **Researcher:** And at other times?

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20 **Patient:** When they've gone? I'd like them to stay here longer.

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22 [Field note, Norah]

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27 **b) Phone home**

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29 **Patient:** 'Telephone'.

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31 **Researcher:** 'Do you want to use the telephone?'

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33 **Patient:** 'Yes'.

34
35 **Researcher:** Who do you want to call?

36
37 (...)

38
39 **Patient:** 'Home'.

40
41 **Researcher:** 'Why?'

42
43 **Patient:** 'To say they have to come.'

44
45 [Field note, Zacharia]

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49 **c) More communication with staff**

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51 **Researcher:** So there aren't many people you can talk to?

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53 **Patient:** Here in hospital?

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55 **Researcher:** Nods, uh huh...

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57 **Patient:** No... They don't answer you...

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59 **Researcher:** Who?
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Patient: The nurses [...] They came when I had almost gone mad.

Researcher: And why?

Patient: I don't know.

Researcher: And what do you think about that?

Patient: Leave the hospital.

[Field note, Norah]

d) Misconceptions of staff towards patients' language proficiency

When I come in the patient, a dark-skinned man, is writing, along with his daughter Barbara. I notice that he is already able to write better than in the previous days during which he wrote a lot of indecipherable signs on the paper. He points to me and writes 'NAME' on the paper. So he is asking my name. Then he points to his daughter and writes 'Barbara' on the paper. I say my name and then write my name on the paper.

[...]

During the change of nursing shift, the following is said about the patient:

'The patient wants to write all the time'. A nurse remarks: '*But he writes in Arabic!*' (...). Annoyed, the nurse continues, saying: '*I'm not going to learn Arabic so that I can understand him! We can never get anything right*'. (...) The nurse storms angrily out of the meeting. Some of the other nurses look shocked but they continue with the meeting. Another nurse asks: '*How can he write? He can't even hold a glass, talk ...*'

However the patient does not know any Arabic and can talk French, an official language in Belgium.

Apparently the nurse wrongfully believed that the patient could only talk a foreign language because he has a different skin colour and has been writing a lot of unreadable signs lately.

[field note, Quintus]

e) Infrastructural constraints

Patient: *Is there a sick person over there?*

The patient lifts her head a little and looks curiously at the bed in the distance that is diagonally opposite her bed. She can only catch a glimpse of that bed ...

Patient: *She has been ill for a week ...*

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Researcher: *There are six beds here ...*

[...]

Patient: *Six in intensive care... Is it serious?*

Researcher: *Some are more seriously ill than others...*

[Field note, Norah]

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TABLE 2. NEED FOR NON-MEDICAL INFORMATION EXCHANGE WITH HEALTHCARE PROFESSIONALS

a) Practicalities

The doctor gives a medical explanation to the patient. (...) During the doctor's explanation, the patient looks questioningly at the doctor. She asks the doctor: *'When can I go to the room?'* (Meaning: The patient asks the doctor when she can leave the ICU and go to a room in another ward). The doctor says: *'today'*.

[Field note, Norah]

b) Family

I try to talk about his medical situation with him (patient) a bit and say: *'Your cannula has gone'* and point to his throat. He says bluntly: *'I'm not interested in that'*. I'm shocked by what he says. I ask what does interest him. He says: *'My wife'*.

[Field note, Zacharia]

c) No communication from staff

The patient is lying with his eyes open. He has to gasp for air the whole time, is looking around which makes him seem very frightened (...) A nurse comes to aspirate the phlegm. He simply carries out his task and does not speak to the patient.

[Field note, Zacharia]

d) Time pressure and workload

Researcher: Erm, how did you experience your care for the patient? (..)

Nurse: Very difficult! Erm, not always easy. Erm. He wasn't always easy to deal with himself. The patient. Which is sometimes understandable, of course, if you are that ill. Erm, but because of the, the pressure of work we're actually under, sometimes you can erm, with him, not as much, I mean sometimes we couldn't give him as much time as we would like to. Erm and sometimes I find that the most difficult part of your job, that you do want to stay in a room longer sometimes to, well, to be able to talk to your patient a bit more, or take your time a bit more with everything, but that sometimes that's not possible because you've got other things to do and you have to say "No, I have to go!" and, erm, yes, that's pretty much that. If I just look at the patient themselves, I mean.

[Interview with nurse Vanessa]

e) Language differences

The nurse comes into quarantine without saying anything to the patient. She looks at the medication and does several things on the PC. The patient looks at the nurse and says: '*tranquil*', relax. I deduce from this that the patient wants to talk to the nurse. The nurse doesn't react to the patient's words. Then she pours the patient's urine into a plastic bottle. The patient asks me: '*What is she doing?*' I say to her: '*He's asking what you're doing*'. She replies in Dutch, a language the patient doesn't understand: '*I'm pouring his pee into a bottle*'. Then she leaves quarantine.

[Field note, Zacharia]

TABLE 3. NEED TO INCREASE COMFORT AND ALLEVIATE PAIN

a) Mistrust and irritation

10 minutes later, the patient is shivering with cold. He points to the blanket. He wants an extra blanket, but there are no nurses nearby. I leave quarantine again and go and ask the nurses for a blanket. One of them says: '*Now he's messing us around. I was with him just a moment ago.*' There was no response to his request.

[Field note, Abdallah]

b) Language differences

I sit down at the nurses' table. The patient sees us and calls out to us in Arabic. The nurses stay where they are and say: *'It is annoying, though, that we don't understand them'* (...). Apparently these carers feel powerless. The patient continues to call out and complain, and waves her arms in the air. She also bangs her arms against her head. Clearly she is trying to tell us something. None of the carers go over to her.

[Field note, Fadila]

c) Misconceptions of staff towards patients' language proficiency

I ask the nurses who are checking the parameters shown on the monitor by the patient's bed: *'Does he speak French?'* One nurse answers: *'Yes, because French is an official language in Algeria, isn't it.'* However the visitor told me that the patient only speaks Arabic. The patient is very distressed. 2 nurses stand around his bed after visiting hour and ask him in French: *'Can you breathe properly? Are you comfortable? Bilal, Bilal, are you comfortable?'* The patient is still very distressed and every time the nurses say something to him, he moves his head from left to right. (...) The carers therefore assume that this patient understands them on the basis of their presuppositions.

[Field note, Bilal]

d) Quiet comfortable patient

During the nurses' meeting in the unit, the patient's situation was discussed. Among other things, he is said not to be a difficult patient: *'He doesn't cause trouble, he's not in pain and he doesn't complain'*. It strikes me that the patient has little opportunity to 'complain' given that he had a cannula that rendered him unable to speak. Besides, according to the visitor, he does not speak Dutch, French or English, so he cannot speak to the nurses. It is also strange that the nurses decide he has no pain purely on the basis of the absence of verbal communication between the patient and the carers.

[field note, Bilal]

e) Wish to leave the ICU

Patient: I'm not going to stay in intensive care, this place is death.

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Researcher: Why?

Patient: I don't like it...Nobody comes, nobody listens... Even the nurses, one in ten glances your way for a moment, that's all ...(...) *'I can't manage yet, when I'm done'*...Anyway, I don't like it.

[...]

The patient looks sad and dejected. She says to her daughter that she wants to be moved because her back hurts. She says the nurses aren't friendly to her and that they don't often come when she asks them to.

Suddenly she starts to cry.

[Field note, Norah]

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TABLE 4. NEED TO EXPRESS DESPERATION

a) Wish to give up treatment and leave the hospital

Patient: Nothing has changed...

Researcher: How does that feel?

(Silence; she's thinking)

Patient: It doesn't change anything.

Researcher: You don't think it changes anything? And why do you think that?

Patient: I'm disgusted with life.

Researcher: You're...?

Patient: Disgusted with life.

Researcher: Disgusted with life ... And that means?

Patient: I've no more hope.....I want to leave the hospital...

[Field note, Norah]

b) Tranquilizers

The nurse says that the patient is nervous and that that is why she is giving her a Xanax. The nurse speaks to the patient in Dutch, asking: *'Why are you nervous?!, You have to do your best, you know!!'*. I have the impression that the patient doesn't understand the nurse. (...) The patient says in French: *'Don't understand.'*

[Field note, Norah]

c) Hopeful relatives

I hear from the nurses that the patient gets panic attacks, hyperventilates and that his heart rhythm has increased (...). During visiting hour the patient says to his wife: *'it's fucked,'* to which the wife replies hopefully: *'You'll get through it, you'll get better. The infection has gone down'*. The patient rolls his eyes at this.

[Field note, Abdallah]

d) Relatives hiding negative medical information for each other

In the meantime, the patient's daughter tells me her brother talked to another doctor the previous evening and that it was a 'good' conversation. The patient was apparently a bit better and they would see how he was later in the week. This has clearly given the daughter more hope today. However I witnessed the conversation the day before between the doctor and the patient's son from a distance and the news the doctor brought was not good news. I deduce from this that the patient's son is hiding the confronting information the doctor gave him from his sister and giving her a rosier picture of the patient's situation so that she would continue to hope.

[Field note, Onur]

e) Patient more positive towards relatives from his home country

Then the uncle says: *'Will you fight for your children?'* The patient nods. The uncle continues: *'You came out of the coma, that's a sign that you want to continue, that you want to fight. Your face looks better.'* Then the patient shakes his head and lowers his eyes. (...) Then the patient's brother comes into quarantine. He flew over yesterday from Morocco. When he asks the patient how he is, the tone is more cheerful. The patient lifts his hand into the air and makes small, successive striking motions in the air, with which he means to indicate that his medical situation is improving. The brother laughs and says he saw him a while ago in a coma and that he is pleased he is now awake and eating. So he says to the patient that he sees clear progress. It is striking that the patient says to his brother who has flown over from Morocco that he is better, whereas he tells his wife and uncle that he is not doing well. [field note, Abdallah (died in the ICU)]

TABLE 5. NEED TO PARTICIPATE IN END-OF-LIFE DECISION MAKING

a) Verbal and non-verbal communication by patient

I ask him (the patient) if he is okay. He shakes his head, indicating 'no', then breathes in and out loudly. He looks like a fish gasping for air. He means by this that he has difficulty breathing, even with the machines. He points to the machines. He looks angry and very sad at the same time. (...) He strikes the air with his hand, a gesture that I believe means he wants to give up. He points to the machines again and says 'that's useless'.

(...) The patient sighs and looks really contorted. I ask in French if he is in pain. 'Vous avez mal'? He nods and points to his chest.

[Field note, Abdallah]

b) Patient seen as incompetent by staff

I see the doctor walking into the unit. I go over to him for a moment and tell him about the patient's panic attacks. He says: 'That is normal, because he has already been in here for three months... We can hardly tell his body it has to stop... And even if the patient or family wanted us to stop treatment, we couldn't comply with that....' I ask him: 'Why not?' He replies: 'The patient and his family are not competent to decide because they are in a phase of pain and emotion... If we say we are going to continue, we will continue...'

[Field note, Abdallah]

c) Saving the patient as doctors' mission

Nurse: And I think he had indicated a couple of times himself that he had had enough.

Researcher: How did he indicate that?

Nurse: Yes, by actually, erm by saying, and by saying "It doesn't help, does it! Don't do that, it doesn't help!"

He said that very often at the end.

Researcher: And who did he say that to then?

Nurse: He said it to me a couple of times. (...) He definitely said to me: "Just leave it like this, it's not going to, you know..." Erm, but even helping to decide "We're going to stop!" I don't think he did that. (..)

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Researcher: Erm, and did you talk about that to other people, about the fact that the man told you he would prefer the treatment to stop?

Nurse: Yes. Yes. We do tell each other that. Yes, I did say it to my colleagues, and to the doctor as well, that he wanted, that those words had been said and that that... Well it's heartbreaking, isn't it, because, well, somehow you know he's right but, you still do it, don't you.

Researcher: Yes. And how did the doctors react to this?

Nurse: It wasn't easy. Because the doctor also had real difficulty with it, to take the decision to let him go. Yes. I think, well, at times like that, still not being able to admit it and saying anyway "We're going to keep going".

[Interview Nurse Vanessa]

8

Patients' characteristics

Number	Pseudonym	Country of origin	Medical condition
1	Amrani	Turkey	Complicated pneumonia
2	Fadila	Morocco	Heart problems
3	Norah	Morocco	Complicated pneumonia
4	Abdallah	Morocco	Complicated pneumonia
5	Zacharia	Morocco	Heart problems
6	Bilal	Algeria	Abdominal problems
7	Quintus	Congo	Brain haemorrhage
8	Onur	Turkey	cancer
9	Kabibe	Congo	Brain haemorrhage
10	Ali	Portugal	Severe accident

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Answer (including page number where the item can be found)
Domain 1: Research team and reflexivity			
Personal characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	RVK conducted the entire data collection (including interviews): see p. 7 line 163-165.
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	The researcher is MSc in sociology and MSc in social and cultural anthropology. She is extensively trained in qualitative research. Researcher's credentials were added in the revised manuscript: see p. 7, line 163-165
3	Occupation	What was their occupation at the time of the study?	The researcher was doing academic scientific research at university as sociologist and anthropologist: see p. 7, line 163-165
4	Gender	Was the researcher male or female?	The researcher is female. In the section 'data collection' we refer to the researcher with 'she', e.g. see p. 7, line 156
5	Experience and training	What experience or training did the researcher have?	The researcher is trained in sociology and anthropology. She is extensively trained in quantitative and qualitative research techniques, which is added in the revised manuscript. See p. 7, line 163-165
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	No relationship was established with the research participants prior to study commencement. This was added in the revised manuscript: see p. 6, line 128-129
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Participants were aware of the researcher's reason for doing the research (improving intercultural communication in the ICU). This was mentioned by the researcher verbally and written in the forms on

			informed consent which the study participants had to sign. This information was added in the revised manuscript: See p. 6, line 141-142
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. <i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? e.g. <i>purposive, convenience, consecutive, snowball</i>	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.g. <i>face-to-face, telephone, mail, email</i>	Participants were approached face-to-face. This was added to the revised manuscript: See p. 6, line 129-130
12	Sample size	How many participants were in the study?	Our sample consisted of staff members (nurses and doctors), patients and their relatives. In total 144 participants were included in the study (observations and interviews). See p. 6, line 132-133 and line 138-139.
13	Non-participation	How many people refused to participate or dropped out? Reasons?	No patients and relatives refused to participate. 8 healthcare professionals refused to participate because they were not interested in the study topic. This was added to the revised manuscript, p. 6, line 133-134 and line 139.
Setting			
14	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>	The data was collected in the clinic (ICU). See p. 6, line 124-125
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	As common in ethnographic studies sometimes also non-participants were present during the data collection, e.g. doctors who mostly work in other wards, relatives of patients who were not included in the study. This was added in

			the revised manuscript: See p. 6, line 139-140
16	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>	Following important characteristics of the sample has been mentioned: ethno-cultural background (p. 6, line 131-132 and line 137-138), age (see p. 6, line 133), gender (see p. 6, line 133-134), medical condition (see p. 6, line 134-137). See also our included table on patients' characteristics.
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Interview questions were based on an interview guide, which was discussed among experts before the actual data collection started and pilot tested among a limited number of persons. This was added in the revised manuscript (see p. 7, line 160-162)
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	We don't know what is meant with the word repeat interviews.
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	The researcher used audio recording to collect the data (Interviews were audio recorded). This was added in the revised manuscript. See p. 7, line 162.
20	Field notes	Were field notes made during and/or after the interview or focus group?	Fieldnotes were made in 2 stages: firstly, in the field during the data collection (by making short notes in a logbook during observations and after interviews); secondly, after the researcher had left the field (by transforming the short notes in longer comprehensive descriptive field notes): see p. 7, line 156-159
21	Duration	What was the duration of the interviews or focus group?	The interviews lasted between 50 minutes and 1h30. See p. 7, line 162
22	Data saturation	Was data saturation discussed?	Data saturation was referred to. See p. 8, line 180
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. This was added to the revised manuscript (see p. 7, line 163)
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	3 researchers were involved in the coding of

			the data (RVK, RD, JB). See p. 8, line 180-182.
25	Description of the coding tree	Did authors provide a description of the coding tree?	The coding tree is described. See p. 7-8, line 170-179
26	Derivation of themes	Were themes identified in advance or derived from the data?	The themes were derived from the data. See p.7-8, line 170-179
27	Software	What software, if applicable, was used to manage the data?	NVIVO 8 (QSR International, 2008) was used to manage the data. See p. 7, line 170-171.
28	Participant checking	Did participants provide feedback on the findings?	Participant provided feedback on the findings. See p. 8 line 184-187.
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	In the appendix transcripts from fieldnotes and interviews are presented to illustrate the themes/findings. Each transcript was identified by stating the name of the case to which it belongs (fieldnotes) or by referring to the name of the interviewee (interviews). All names are pseudonyms. See appendix.
30	Data and findings consistent	Was there consistency between the data presented and the findings?	There was consistency between the data presented (see transcripts in the appendix) and the findings in the manuscript. This consistency is reflected in the title of each transcript which accords with the presented findings.
31	Clarity of major themes	Were major themes clearly presented in the findings?	Major themes are clearly presented in the results section. Each subtitle in the results sections refers to one of the 5 major themes.
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No

BMJ Open

MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A QUALITATIVE ETHNOGRAPHIC STUDY

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Primary Subject Heading:	Intensive care
Secondary Subject Heading:	Mental health, Communication
Keywords:	MENTAL HEALTH, INTENSIVE & CRITICAL CARE, communication

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3 1 **MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A**
4
5 2 **QUALITATIVE ETHNOGRAPHIC STUDY**
6

7
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56 26 **Key words:** intensive care units, patients, cultural diversity, communication, mental health
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3 27 **Abstract**

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5 28 **Objectives:** To investigate the state of the mental wellbeing of patients from ethnic minority groups
6
7 and possible related risk factors for the development of mental health problems among these
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9 patients during critical medical situations in hospital.
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13 31 **Design:** Qualitative ethnographic design.

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15 32 **Setting:** 1 intensive care unit (ICU) of a multi-ethnic urban hospital in Belgium.

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17 33 **Participants:** 84 ICU staff members, 10 patients from ethnic-minority groups, and their visiting family
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19 members.
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23 35 **Results:** Patients had several human basic needs for which they could not sufficiently turn to
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25 anybody, neither to their healthcare professionals, nor to their relatives, nor to other patients. These
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27 needs included the need for social contact, the need to increase comfort and alleviate pain, the need
28
29 to express desperation and participate in end-of-life decision making. Three interrelated risk factors
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31 for the development of mental health problems among the patients included were identified: Firstly,
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33 healthcare professionals' mainly biomedical care approach (e.g. focus on curing the patient, limited
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35 psychosocial support), secondly, the ICU context (e.g. time pressure, uncertainty, regulatory
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37 frameworks) and thirdly, patients' different ethno-cultural background (e.g. religious and
38
39 phenotypical differences).
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44 44 **Conclusions:** The mental state of patients from ethnic minority groups during critical care is
45
46 characterized by extreme emotional loneliness. It is important that staff should identify and meet
47
48 patients' unique basic needs in good time with regard to their mental wellbeing, taking into account
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50 important threats related to their own mainly biomedical approach to care, the ICU's structural
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52 context as well as the patients' different ethno-cultural background.
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50 **Article summary**

51 **Strengths and limitations of this study**

- 52 • As far as we know, this is the first study where the mental wellbeing of patients from ethnic
53 minority groups is profoundly investigated by means of an ethnographic research design.
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- 55 • By studying the mental wellbeing of these patients as is ‘genuinely expressed’, from multiple
56 perspectives and in a contextual manner, through ethnographic fieldwork in an intensive
57 care unit of a multi-ethnic urban hospital in Belgium, we have tried to develop a nuanced,
58 non-stereotypical and rich insight into such patients’ mental wellbeing.
59
- 60 • One limitation of this research could be the fact that the fieldwork was done in only one ICU.
61 Therefore transferability to other situations must be done with caution. However, by
62 spending a lot of time in a variety of situations (with 10 patients and their families, and all
63 their healthcare professionals) it was possible to gain a rich insight into our sensitive research
64 topic.

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69 INTRODUCTION

70 Having a good mental health/wellbeing means more than not having a mental disorder. The WHO defines
71 mental wellbeing as *'a state of well-being in which an individual realizes his or her own abilities, can cope with
72 the normal stresses of life, can work productively and is able to make a contribution to his or her community'*. It
73 is perceived as crucial to our capacity as people to think, communicate with others, earn money and enjoy life.
74 Risk factors include individual factors on e.g. the socio-economical level (e.g. being poor, having a low
75 educational level), cultural level (e.g. belonging to an ethnic minority group) and behavioural level (e.g. having
76 an unhealthy life style, having little sleep), contextual/structural factors (e.g. facing adverse work conditions,
77 discrimination) and biological/genetical factors (e.g. being physically ill) [1,2]. It is then no surprise that during
78 critical care patients' mental wellbeing comes under threat, and especially when other risk factors are involved,
79 e.g. when patients have a different ethno-cultural background [3,4].

80 Hallucinations, fear, and depression frequently occur among patients admitted to the intensive care unit
81 (ICU).[5-8] Several risk factors are identified, including invasive treatments, separation from family, physical
82 pain, immobility, dependency, lack of control, lack of privacy and poor communication.[4,5,9,10, 11] Although
83 disturbances in critically ill patients' mental health negatively affect their whole care process, healthcare
84 professionals working in a critical care setting lack adequate strategies to improve patients' mental health.
85 They are often not aware of patients' mental health problems as they mainly focus on the technological care
86 aspects and lack training in mental care. Many critical care nurses for example do not have enough insight in
87 the elements that might affect their patients' psychological state. [9,12] Furthermore in society at large,
88 mental health problems remain a sensitive issue as such problems are often difficult acknowledged and talked
89 about.

90 Additionally, healthcare professionals have to communicate increasingly with patients from ethnic minority
91 groups, i.e. persons of a different origin who share certain cultural characteristics to some extent [13], as a
92 result of societies' increased ethno-cultural diversity. In Belgium, healthcare for migrants is basically organized
93 in the same manner as for people from the ethnic majority group. However it is known that during the care for
94 migrants problems regularly arise which are situated on mainly 2 levels, namely firstly health differences
95 (ethnic minorities have less chance on a healthy life than people from the ethnic majority group) and secondly

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3 96 problems regarding the accessibility and use of healthcare services (ethnic minorities have lower access to
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5 97 healthcare services and receive less quality care than members of the ethnic majority group). Problems are
6
7 98 often very complex and related to different factors, such as linguistic and cultural differences. [14] We might
8
9 99 assume that critically ill patients from ethnic minority groups are at an even higher risk of mental health
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11 100 problems and that ethno-cultural differences render mental health problems more complex and multifaceted.
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13 101 Inattention by healthcare professionals to specific ethno-cultural habits (e.g. gender segregation),
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15 102 discrimination, unfamiliarity with the western healthcare system and different foodways can contribute to
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17 103 traumatic experiences for ethnic minorities.[15,16, 17, 18] Furthermore, language differences and ethno-
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19 104 cultural norms prescribing acceptance of physical suffering can lead to less adequate communication and pain
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21 105 relief[19,20], which can endanger such patients' psychological state.[7,15,21] Yet, although we increasingly live
22
23 106 in a multi-ethnic society, research about the mental wellbeing of patients from ethnic minority groups during
24
25 107 critical care is rather scarce and there are very few in-depth studies which try to understand this topic in its
26
27 108 specific context and from different angles.

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29 109 In this study we therefore aim to investigate 'the state of the mental wellbeing of patients from ethnic
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31 110 minority groups and possible related risk factors for the development of mental health problems among these
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33 111 patients in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among
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35 112 patients from ethnic minority groups can contribute to the development of recommendations to prevent such
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37 113 problems for these patients.

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41 42 115 **METHODS**

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45 116 Patients' mental wellbeing in a multi-ethnic critical care setting is a sensitive, complex, and novel topic of
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47 117 research. Therefore an ethnographic research design has been used, which gave the researcher the
48
49 118 opportunity to immerse herself into her study field and study the research topic for a long period on the
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51 119 workforce itself. By getting a feel of the lifeworld of the ICU, observing and interacting with different parties,
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53 120 the researcher was able to grasp the research topic in all its different facets and from different angles.

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3 122 **Participants & setting**
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8 124 Ethnographic fieldwork was done in one ICU of a multi-ethnic urban hospital in Belgium over 6 months (January
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10 125 2014-June 2014). 40 % of the ICU patients are estimated to belong to an ethnic minority group. Staff's,
11
12 126 patients', and relatives' behaviour, interactions, and experiences were studied for 360 hours. The selected
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14 127 patients and the family members who accompanied them, as well as their healthcare professionals, were
15
16 128 followed for the whole critical period. No relationship was established with the research participants prior to
17
18 129 the beginning of the study. Patients and their family members were purposefully selected and approached
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20 130 face-to-face. They were only eligible for inclusion in the study if the patient or at least one of his/her legal
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22 131 parents was born abroad, if at least one of the family members (patient/his or her relatives) was able to speak
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24 132 Dutch, French, or English, and if the patient was at least 18 years old. In total we selected 10 patients and their
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26 133 visiting family members, who were originally from Morocco, Algeria, Turkey, Congo and Portugal. No patients
27
28 134 and relatives refused to participate. The patients were between 40 and 82 years old and consisted of 6 males
29
30 135 and 4 females. They were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
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32 136 (2), brain haemorrhage (2), cancer (1), and a severe accident (1). All patients were sedated for some time, and
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34 137 as a result were unable to communicate or only had limited ability to communicate, depending on the level of
35
36 138 sedation. The critical care team consisted of 80 nurses and 12 doctors, who were almost all white Caucasians
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38 139 from the dominant ethnic group. 8 staff members refused to participate in the study. Of course also other
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40 140 people were present during the ethnographic fieldwork, e.g. doctors who mostly work in other wards.
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42 141 Research participants were aware of the researcher's reason for doing the research (improving intercultural
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44 142 communication in the ICU). (For further information about patients: see supplementary file)
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48 144 **Data collection**
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53 146 Data were collected through triangulation of several data collection strategies, namely negotiated interactive
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55 147 observation,[22] in-depth- interviews with healthcare professionals,[23] and the reading of patients' medical
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57 148 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care
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3 149 tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward.
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5 150 Therefore 'negotiated interactive observation' was chosen, meaning that before starting the observations the
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7 151 researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique
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9 152 enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation
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11 153 gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family
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13 154 members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare
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15 155 professionals, relatives, and patients during visiting hours.

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17 156 When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she
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19 157 transformed these notes into comprehensive descriptive field notes containing observations of participants'
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21 158 discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on
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23 159 her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare
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25 160 professionals in two meeting rooms in the hospital. The interview questions were based on an interview guide,
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27 161 which was discussed among experts before the actual data collection started and pilot tested among a limited
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29 162 number of persons (Topic list in-depth interviews: see supplementary file). The interviews lasted between 50
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31 163 minutes and 1h30 and were audio recorded. Interview transcripts were not returned to the research
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33 164 participants for comments or corrections. All data were collected by the first author (RVK), a trained
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35 165 ethnographer and sociologist (MSc) who was doing academic scientific research at university at the time of the
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37 166 study. She is extensively trained in qualitative research.

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41 42 168 **Data analysis**

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47 170 The analysis started with a 'thick description' [25] of participants' discourse, behaviour, and interaction and
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49 171 was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were
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51 172 conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This
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53 173 process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly,
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55 174 an open coding phase was performed, involving the reading and rereading of the data. This resulted in the
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57 175 formation of different codes, for instance 'physical contact', 'proximity', and 'fighting'. To find similarities and
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3 176 differences between these codes, new codes were constantly compared with already existing codes. Secondly,
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5 177 axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example
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7 178 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance
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9 179 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category
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11 180 ('emotional loneliness') around which the related categories are clustered.[26,27]
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13
14 181 Data collection and analysis were stopped when the point of saturation was reached.[26,28] Reliability was
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16 182 strengthened by the first author (RVK) doing the data analysis and two co-authors (RD & JB) doing a peer-
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18 183 revision of the analysis. The process of data collection and data analysis was also regularly discussed by
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20 184 members of the multidisciplinary academic research group in which these authors participate, consisting of a
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22 185 health scientist, a psychiatric nurse, 2 anthropologists, and 1 sociologist. To improve the reliability and accuracy
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24 186 of the study, the results were also read by an intensive care specialist who is part of the intensive care team at
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26 187 the hospital in which the researcher did her fieldwork. Furthermore the study results were presented to and
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28 188 discussed with the nurses who had participated in this study during a conference.
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31 32 33 190 **Ethics**

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35 191 The research protocol (reference 2013/371) was approved by the university ethics committee of the Vrije
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37 192 Universiteit Brussel. The privacy of the research participants and confidentiality of the data were respected,
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39 193 e.g. by using pseudonyms. Written consent to participation in the study was sought from healthcare
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41 194 professionals, family members, and patients who were still able to communicate. If the patient lacked the
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43 195 capacity to give consent, consent was sought from his/her legal representative.
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47 48 49 197 **RESULTS**

50
51 198 The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
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53 199 (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among
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55 200 patients. Patients had several basic needs for which they could not sufficiently turn to anybody, neither to their
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57 201 healthcare professionals, nor to their relatives, nor to other patients. These needs comprised 'the need for
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3 202 social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to
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5 203 express desperation, and to participate in end-of-life decision making’.

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10 205 **1) Need for social contact**

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13 206 Patients longed for social contact with relatives, healthcare professionals and other patients, and not only
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15 207 verbally but also non-verbally. This need became even more significant when patients were unable to
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17 208 communicate verbally as a result of their medical state and/or language differences. More specifically, patients
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19 209 longed for proximity of others, physical contact, and chatting.

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22 210 Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and
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24 211 talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting
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26 212 time, to come more often, or to take them back home (supplementary file 1a). Some patients also wanted to
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28 213 phone home to request visits from relatives (supplementary file 1b). Furthermore, patients wanted healthcare
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30 214 professionals to communicate more often with them (supplementary file 1c). However, the rules concerning
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32 215 visits, the infrastructure/ accommodation (e.g. no telephone) and healthcare professionals’ focus on the
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34 216 patients’ disease made it difficult for staff to fully satisfy patients’ need for social contact. Moreover, pressure
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36 217 of work and time made it tough to communicate with patients. Furthermore language differences and
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38 218 misconceptions of healthcare professionals towards patients’ ability to communicate in the language of the
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40 219 host country, sometimes based on patients’ different skin colour, endangered the meeting of patients’ social
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42 220 needs. (supplementary file 1d). Some patients also felt the urge to connect with other patients. This became
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44 221 indirectly apparent when patients stared at other beds and/or asked questions about other patients’
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46 222 conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made
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48 223 communication between patients impossible. (supplementary file 1e)

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3 227 **2) Need for non-medical information exchange with healthcare professionals**
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5 228 The information exchange between doctors and patients was primarily of a medical nature. When patients
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7 229 were conscious, doctors explained to patients their medical situation, which medical actions they had
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9 230 undertaken as well those they would undertake in the future, and which medical decisions had been taken.
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11 231 However, patients not only felt the need to get medical information regarding their physical state from
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13 232 healthcare professionals, but equally to exchange information with them on matters that were not strictly
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15 233 medical, e.g. practical issues, visual aspects (e.g. activities going on around them) and their family
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17 234 (supplementary file 2a and 2b). Furthermore, nurses regularly did not communicate with patients or only
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19 235 communicated with them in a task-related manner (supplementary file 2c).

20
21
22 236 Despite healthcare professionals' good intentions, they often perceived it as impossible to communicate
23
24 237 with patients about non-medical issues due to their prime task of safeguarding the patients' clinical state, time
25
26 238 pressure, and their workload (supplementary file 2d). Also language differences made communication between
27
28 239 patients and healthcare professionals about non-medical matters more difficult (supplementary file 2e). In
29
30 240 addition, communication with relatives about non-medical issues was limited as well. Relatives often focused
31
32 241 on their search for exhaustive medical information from doctors, which was reinforced by group pressure
33
34 242 within their families, during the restricted visiting hours.

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38
39 244 **3) Need to increase comfort and alleviate pain**
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41
42 245 Patients wanted to increase their comfort and be free from pain. This need was often expressed through verbal
43
44 246 and non-verbal communication. Patients verbally requested acts of care to increase comfort in the language of
45
46 247 the host society or in their own mother tongue. They also often indirectly requested comfort-increasing care by
47
48 248 expressing their suffering through non-verbal signs, e.g. pointing with their heads. However, sometimes these
49
50 249 expressions of patients' hardship were not noticed, minimally acknowledged, not apprehended or
51
52 250 misunderstood, even neglected, normalized or temporarily medically suppressed by giving tranquilizers, by
53
54 251 healthcare professionals. Inadequately meeting patients' need for comfort and pain alleviation was related to
55
56 252 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/false
57
58 253 perceived language differences. Consequently, comfort and pain was often addressed based on healthcare
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3 254 professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and
4
5 255 irritation and insecurity occurred on both sides (supplementary file 3a).
6

7 256 Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals
8
9 257 because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients'
10
11 258 verbal messages was sometimes hampered by language differences (supplementary file 3b). Moreover, when
12
13 259 patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded
14
15 260 inadequately or no communication occurred. This was sometimes related to healthcare professionals'
16
17 261 misconceptions of patients' language proficiency, based on the very quick and minimal moments of interaction
18
19 262 they had with patients and relatives and patients' different skin colour. Also staff's general knowledge of
20
21 263 patients' country of origin which they sometimes easily applied to all patients from that country contributed to
22
23 264 these misconceptions (supplementary file 3c).
24

25
26 265 On the other hand, some patients who were at moments totally unable to communicate as a result of
27
28 266 medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless
29
30 267 (supplementary file 3d). When patients experienced discomfort for a longer time some of them did not want to
31
32 268 ask healthcare professionals for help anymore and wanted to leave the ICU (supplementary file 3e).
33

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35 269

36 37 270 **4) Need to express desperation**

38
39
40 271 Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the
41
42 272 hospital, others wanted to completely give up treatment (supplementary file 4a). Patients felt the need to
43
44 273 express and share these feelings with others. However, patients regularly felt obliged to suppress their
45
46 274 hopelessness during critical care in front of healthcare professionals and relatives, resulting in frustration and
47
48 275 sadness.
49

50
51 276 Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients
52
53 277 with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for
54
55 278 patients to express their negative feelings. And even when patients did express their hopelessness, healthcare
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3 279 professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless,
4
5 280 tranquilizers/antidepressants were given (supplementary file 4b).
6
7

8 281 Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients
9
10 282 (supplementary file 4c). Relatives' religious beliefs and high expectations for cure in western hospitals
11
12 283 functioned as sources of hope. Furthermore, negative information was hidden for some family members by
13
14 284 other relatives so as to not create unrest within their large transnational families, which affected relatives'
15
16 285 positive outlook on the patients' situation (supplementary file 4d). Additionally, families' considerable size led
17
18 286 to group pressure among its members to remain hopeful. Moreover, patients themselves presented their
19
20 287 situation in a more positive manner towards visiting relatives coming from the home country so as to not worry
21
22 288 their relatives there (supplementary file 4e).
23
24

25 26 290 **5) Need to participate in end-of-life decision making**

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28
29 291 Enduring physical and mental suffering triggered a need for some patients to participate in a decision to
30
31 292 withdraw therapy. This need was verbally and non-verbally expressed at several points (supplementary file 5a).
32

33 293 However healthcare professionals regularly acknowledged these patients' communication only minimally,
34
35 294 neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central
36
37 295 decision makers and wanted to continue treatment, when they believed that patients still had a chance to
38
39 296 survive within the context of their specific pathology. Patients were seen as lacking the required expertise to
40
41 297 make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as
42
43 298 they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or
44
45 299 after taking anti-depressants (supplementary file 5b). Further, healthcare professionals saw it as their mission
46
47 300 to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient
48
49 301 who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by
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51 302 some healthcare professionals as a personal failure. (supplementary file 5c)
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305 **DISCUSSION**

306 This ethnographic study investigates the state of the mental wellbeing of patients from ethnic minority groups
307 and possible related risk factors for the development of mental health problems among these patients in a
308 multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups
309 is basically characterized by an 'extreme emotional loneliness'. Patients had several human basic needs for
310 which they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their
311 relatives, nor to other patients. It concerned the need for social contact, for non-medical information
312 exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in
313 end-of-life decision making. Insufficiently meeting patients' basic needs endangered patients' mental
314 wellbeing as defined by the WHO, e.g. in the sense that they couldn't cope adequately with stress and didn't
315 feel to contribute to their family/community anymore. Three interrelated risk factors for the development of
316 mental health problems among the included patients were identified: firstly healthcare professionals' mainly
317 biomedical approach to care, secondly the ICU context, and thirdly the patients' different ethno-cultural
318 background.

319 The mental wellbeing of patients from ethnic minority groups in a critical care setting is an under-
320 researched topic. Although a body of research has recently begun to grow that focuses on the lifeworld of
321 patients in a critical care context [see for example:4,5,9,12], still very few of these studies focus on specific
322 vulnerable patient groups, e.g. patients from ethnic minority groups, and mental health issues. Furthermore
323 some researchers that do focus on critically ill patients from ethnic minority groups study their experiences
324 mainly through interviews with patients, their relatives or staff [see for example: 15, 29]. So as far as we know,
325 this is the first study where specifically the mental wellbeing of patients from ethnic minority groups is
326 investigated in one particular context, namely the critical care context, by means of an ethnographic research
327 design. A study design of this kind is the most appropriate way to gain nuanced/deep insight into complex
328 themes e.g. mental wellbeing of patients from ethnic minority groups in a critical care setting. Ethnographic
329 day-by-day observations on the ward allow the study of patients' mental wellbeing as it is 'genuinely
330 expressed' and from the perspective of the different people involved, from a non-prejudiced perspective.

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3 331 The researcher might have had an impact on the field and the research findings as she herself has a non-
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5 332 Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from
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7 333 patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic
8
9 334 feature of qualitative ethnographic research [23]. A weakness of this research could be the fact that the
10
11 335 fieldwork was done in only one ICU. Therefore transferability to other situations must be done with caution.
12
13 336 However, by spending a lot of time in a variety of situations (with 10 patients and their families, and all their
14
15 337 healthcare professionals) it was possible to gain a rich insight into our sensitive research topic. There is no
16
17 338 specific reason to believe our findings are not valuable for other similar settings. Another weakness of this
18
19 339 study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-
20
21 340 depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can
22
23 341 be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't
24
25 342 allow other techniques, such as video recording and full participant observation, for ethical reasons.

26
27 343 Our study shows that the patients included felt extremely emotionally lonely because several of their basic
28
29 344 needs were insufficiently met. This seems to confirm previous research showing that ICU patients favour a
30
31 345 holistic care approach and thus value attention from healthcare professionals not only to their bio-
32
33 346 physiological needs but also to other general psycho-social and existential human needs, e.g. the need for
34
35 347 social contact, for non-medical information exchange, religious needs and participation in decision
36
37 348 making.[9,15,16,30]

38
39 349 Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this
40
41 350 model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems,
42
43 351 caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare
44
45 352 professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine,
46
47 353 although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory
48
49 354 frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central
50
51 355 responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced
52
53 356 with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care
54
55 357 strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks,
56
57 358 making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure

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3 359 (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and
4
5 360 professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly
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7 361 prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the
8
9 362 other hand, taking into account patients' emotions becomes even more complex and challenging when
10
11 363 patients have a different ethno-cultural background. The included patients' different ethno-cultural
12
13 364 backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and
14
15 365 collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care
16
17 366 and suffering, communication forms and families' history of migration), and the level of patient-staff
18
19 367 interaction (e.g. phenotypical features, language).

20
21 368 Staff, occupied with urgent lifesaving care tasks, were frequently unable to react effectively to patients'
22
23 369 verbal and non-verbal communications, often expressed by patients who completely lacked knowledge of the
24
25 370 language of the host country. However, adequately decoding ethno-culturally diverse patients' non-verbal
26
27 371 communication is crucial for optimal pain management and shared medical decision making.[32,33]
28
29 372 Furthermore, pressured healthcare professionals had little time to gain in-depth-knowledge of patients' level of
30
31 373 skill in the language of the host society. Therefore the staff easily developed misconceptions of patients'
32
33 374 language proficiency based, for example, on their general knowledge of the patient's country of origin or
34
35 375 specific phenotypical features, which led to inadequate communication or a complete absence of
36
37 376 communication with patients about their needs. Moreover, insufficiently satisfying specific needs which were
38
39 377 ethno-culturally inspired led to high emotional loneliness among patients. For example, a failure to meet
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41 378 patients' needs for multiple types of social contact (e.g. proximity of others) strengthened for some patients by
42
43 379 the collectivistic orientation of their minority cultures, led to high emotional suffering among particular
44
45 380 patients. Moreover, because relatives shared ethno-cultural expectations towards patients to remain stoic and
46
47 381 hopeful in difficult times, they did not pay enough attention to patients' specific unique basic needs, i.e. their
48
49 382 need to express desperation and participate in end of life decisions, which made patients feel left behind. In
50
51 383 line with this finding, previous research has shown that overt communication about pain and sorrow between
52
53 384 patients from certain ethnic minority groups and their relatives is limited.[34] Additionally, relatives' high levels
54
55 385 of hope triggered healthcare professionals, caring for patients with an uncertain prognosis, to continue life-
56
57 386 saving treatments and reinforced their belief in their core responsibility to save patients' lives, while these

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3 387 patients' voices were largely unheard. Likewise, previous research demonstrates that more aggressive
4
5 388 interventions occur at the end of the lives of patients from ethnic minority groups.[35] Relatives shared high
6
7 389 levels of hope, which were associated with an ethno-cultural non-disclosure of negative information by some
8
9 390 relatives towards other relatives, ethno-religious beliefs,[29] migration-related expectations towards an
10
11 391 unlimited field of medical possibilities in western hospitals, and group pressure among the many relatives to
12
13 392 remain hopeful.

14
15 393 Finally, another striking observation is that not only patients' mental health but also the mental state of
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17 394 healthcare professionals working in such interethnic critical medical situations can become severely threatened
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19 395 due to their experiences of powerlessness towards meeting some of their patients' human basic needs. This
20
21 396 can further negatively affect patients' mental state.

22
23 397 Our study results are certainly also of relevance to patients from majority ethnic backgrounds because we
24
25 398 found that the ICU context and staff's biomedical approach, factors to which all patients are exposed, hindered
26
27 399 the satisfaction of several human basic needs which are shared by all patients irrespective of their ethno-
28
29 400 cultural background. Patients from ethnic minority groups their different ethno-cultural background forms an
30
31 401 extra important risk factor for not meeting their basic needs. Of course the relative importance of this risk
32
33 402 factor is different for each patient.

34
35 403 Mental health problems among patients, irrespective of their ethno-cultural background, can primarily be
36
37 404 reduced by investing in patient-centred care, which requires the implementation of intervention measures
38
39 405 stimulating the coexistence of biomedical and more holistic views on health and care among staff, on the level
40
41 406 of daily work, training and education, and ICU policy/organization. Such structural measures include staff
42
43 407 training in mental health, flexible visiting policies, the presence of a social worker on the ward, questioning the
44
45 408 division of labour and working hours, close cooperation with a psychologist/psychiatrist, etc. Additionally, in a
46
47 409 multi-ethnic ICU context, extra measures are urgently required, e.g. cultural sensitivity training for staff and
48
49 410 students, language facilitation, and the presence of religious figures on the ward. Further (evidence-based)
50
51 411 research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical
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53 412 care setting.

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3 415 **CONCLUSION**

4
5 416 The followed patients had specific basic needs for which they could not sufficiently turn to anybody, leaving
6
7 417 them in a state of extreme emotional loneliness. Three interrelated risk factors for the development of mental
8
9 418 health problems among these patients were identified: firstly, healthcare professionals' mainly biomedical care
10
11 419 approach, secondly the ICU work context and thirdly the patients' different ethno-cultural background.

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16 421 **Abbreviations**

17
18 422 ICU, intensive care unit
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21
22 424 **Contributors:** All authors have met the four authorship criteria as stated in the International Committee of
23
24 425 Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly
25
26 426 Work in Medical Journals.

27 427
28
29 428 **Authors' contributions:** RVK contributed to the research design, applied for the ethical approval, completed
30
31 429 the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the
32
33 430 manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research
34
35 431 design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of
36
37 432 the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and
38
39 433 applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB
40
41 434 applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to
42
43 435 the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of
44
45 436 the manuscript. All the authors read and approved the final manuscript.

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52
53 440 interpretation of the data and in writing the manuscript.
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4
5 443 Universiteit Brussel in December 2013.
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9 445 **Competing interests:** The authors declare that they have no competing interests.
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13 447 **Data sharing:** Extra data is available by emailing RVK.
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Patients' characteristics

Number	Pseudonym	Country of origin	Medical condition
1	Amrani	Turkey	Complicated pneumonia
2	Fadila	Morocco	Heart problems
3	Norah	Morocco	Complicated pneumonia
4	Abdallah	Morocco	Complicated pneumonia
5	Zacharia	Morocco	Heart problems
6	Bilal	Algeria	Abdominal problems
7	Quintus	Congo	Brain haemorrhage
8	Onur	Turkey	cancer
9	Kabibe	Congo	Brain haemorrhage
10	Ali	Portugal	Severe accident

Topic list for formal in-depth interviews

- Pathology
- Experiences with communication (patient – relatives - intra-team)
 - Difficult communication/disagreements (if applicable)
- Decision making
 - Role - nurse - doctor - patient - relatives
 - Course
 - Difficult communication/disagreements (if applicable)
 - Final medical decision
- Care for patient
 - Positive and negative experiences
- Death of patient
 - Communication with relatives
- Prevention of difficult communication

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3 1 (Note: all the names are pseudonyms)
4
5

6 **1. NEED FOR SOCIAL CONTACT**

7 **a) Longer visits**

8
9 **Patient:** I've had enough... I've gone mad.

10
11 (..)

12
13 **Researcher:** But when your children are here, does that lift your spirits?
14

15
16 **Patient:** Yes, at the time...

17
18 **Researcher:** And at other times?

19
20 **Patient:** When they've gone? I'd like them to stay here longer.
21

22 [Field note, Norah]
23
24

25
26 **b) Phone home**

27
28 **Patient:** 'Telephone'.

29
30 **Researcher:** 'Do you want to use the telephone?'

31
32 **Patient:** 'Yes'.

33
34 **Researcher:** Who do you want to call?
35

36
37 (...)

38
39 **Patient:** 'Home'.

40
41 **Researcher:** 'Why?'

42
43 **Patient:** 'To say they have to come.'
44

45 [Field note, Zacharia]
46
47

48
49 **c) More communication with staff**

50
51 **Researcher:** So there aren't many people you can talk to?
52

53
54 **Patient:** Here in hospital?

55
56 **Researcher:** Nods, uh huh...

57
58 **Patient:** No... They don't answer you...

59
60 **Researcher:** Who?

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Patient: The nurses [...] They came when I had almost gone mad.

Researcher: And why?

Patient: I don't know.

Researcher: And what do you think about that?

Patient: Leave the hospital.

[Field note, Norah]

d) Misconceptions of staff towards patients' language proficiency

When I come in the patient, a dark-skinned man, is writing, along with his daughter Barbara. I notice that he is already able to write better than in the previous days during which he wrote a lot of indecipherable signs on the paper. He points to me and writes 'NAME' on the paper. So he is asking my name. Then he points to his daughter and writes 'Barbara' on the paper. I say my name and then write my name on the paper.

[...]

During the change of nursing shift, the following is said about the patient:

'The patient wants to write all the time'. A nurse remarks: '*But he writes in Arabic!*' (...). Annoyed, the nurse continues, saying: '*I'm not going to learn Arabic so that I can understand him! We can never get anything right*'. (...) The nurse storms angrily out of the meeting. Some of the other nurses look shocked but they continue with the meeting. Another nurse asks: '*How can he write? He can't even hold a glass, talk ...*'

However the patient does not know any Arabic and can talk French, an official language in Belgium.

Apparently the nurse wrongfully believed that the patient could only talk a foreign language because he has a different skin colour and has been writing a lot of unreadable signs lately.

[field note, Quintus]

e) Infrastructural constraints

Patient: *Is there a sick person over there?*

The patient lifts her head a little and looks curiously at the bed in the distance that is diagonally opposite her bed. She can only catch a glimpse of that bed ...

Patient: *She has been ill for a week ...*

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Researcher: *There are six beds here ...*

[...]

Patient: *Six in intensive care... Is it serious?*

Researcher: *Some are more seriously ill than others...*

[Field note, Norah]

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2. NEED FOR NON-MEDICAL INFORMATION EXCHANGE WITH HEALTHCARE PROFESSIONALS

a) Practicalities

The doctor gives a medical explanation to the patient. (...) During the doctor's explanation, the patient looks questioningly at the doctor. She asks the doctor: *'When can I go to the room?'* (Meaning: The patient asks the doctor when she can leave the ICU and go to a room in another ward). The doctor says: *'today'*.

[Field note, Norah]

b) Family

I try to talk about his medical situation with him (patient) a bit and say: *'Your cannula has gone'* and point to his throat. He says bluntly: *'I'm not interested in that'*. I'm shocked by what he says. I ask what does interest him. He says: *'My wife'*.

[Field note, Zacharia]

c) No communication from staff

The patient is lying with his eyes open. He has to gasp for air the whole time, is looking around which makes him seem very frightened (...) A nurse comes to aspirate the phlegm. He simply carries out his task and does not speak to the patient.

[Field note, Zacharia]

d) Time pressure and workload

Researcher: Erm, how did you experience your care for the patient? (..)

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3 **Nurse:** Very difficult! Erm, not always easy. Erm. He wasn't always easy to deal with himself. The patient.
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5 Which is sometimes understandable, of course, if you are that ill. Erm, but because of the, the pressure of
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7 work we're actually under, sometimes you can erm, with him, not as much, I mean sometimes we couldn't
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9 give him as much time as we would like to. Erm and sometimes I find that the most difficult part of your job,
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11 that you do want to stay in a room longer sometimes to, well, to be able to talk to your patient a bit more,
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13 or take your time a bit more with everything, but that sometimes that's not possible because you've got
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15 other things to do and you have to say "No, I have to go!" and, erm, yes, that's pretty much that. If I just look
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17 at the patient themselves, I mean.

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19 [Interview with nurse Vanessa]
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24 **e) Language differences**

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26 The nurse comes into quarantine without saying anything to the patient. She looks at the medication and
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28 does several things on the PC. The patient looks at the nurse and says: '*tranquil*', relax. I deduce from this
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30 that the patient wants to talk to the nurse. The nurse doesn't react to the patient's words. Then she pours
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32 the patient's urine into a plastic bottle. The patient asks me: '*What is she doing?*' I say to her: '*He's asking*
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34 *what you're doing*'. She replies in Dutch, a language the patient doesn't understand: '*I'm pouring his pee into*
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36 *a bottle*'. Then she leaves quarantine.

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38 [Field note, Zacharia]
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43 **3. NEED TO INCREASE COMFORT AND ALLEVIATE PAIN**

44 **a) Mistrust and irritation**

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46 10 minutes later, the patient is shivering with cold. He points to the blanket. He wants an extra blanket, but
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48 there are no nurses nearby. I leave quarantine again and go and ask the nurses for a blanket. One of them
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50 says: '*Now he's messing us around. I was with him just a moment ago.*' There was no response to his
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52 request.
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59 [Field note, Abdallah]
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b) Language differences

I sit down at the nurses' table. The patient sees us and calls out to us in Arabic. The nurses stay where they are and say: *'It is annoying, though, that we don't understand them'* (...). Apparently these carers feel powerless. The patient continues to call out and complain, and waves her arms in the air. She also bangs her arms against her head. Clearly she is trying to tell us something. None of the carers go over to her.

[Field note, Fadila]

c) Misconceptions of staff towards patients' language proficiency

I ask the nurses who are checking the parameters shown on the monitor by the patient's bed: *'Does he speak French?'* One nurse answers: *'Yes, because French is an official language in Algeria, isn't it.'* However the visitor told me that the patient only speaks Arabic. The patient is very distressed. 2 nurses stand around his bed after visiting hour and ask him in French: *'Can you breathe properly? Are you comfortable? Bilal, Bilal, are you comfortable?'* The patient is still very distressed and every time the nurses say something to him, he moves his head from left to right. (...) The carers therefore assume that this patient understands them on the basis of their presuppositions.

[Field note, Bilal]

d) Quiet comfortable patient

During the nurses' meeting in the unit, the patient's situation was discussed. Among other things, he is said not to be a difficult patient: *'He doesn't cause trouble, he's not in pain and he doesn't complain'*. It strikes me that the patient has little opportunity to 'complain' given that he had a cannula that rendered him unable to speak. Besides, according to the visitor, he does not speak Dutch, French or English, so he cannot speak to the nurses. It is also strange that the nurses decide he has no pain purely on the basis of the absence of verbal communication between the patient and the carers.

[field note, Bilal]

e) Wish to leave the ICU

Patient: I'm not going to stay in intensive care, this place is death.

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Researcher: Why?

Patient: I don't like it...Nobody comes, nobody listens... Even the nurses, one in ten glances your way for a moment, that's all ...(...) *'I can't manage yet, when I'm done'*...Anyway, I don't like it.

[...]

The patient looks sad and dejected. She says to her daughter that she wants to be moved because her back hurts. She says the nurses aren't friendly to her and that they don't often come when she asks them to.

Suddenly she starts to cry.

[Field note, Norah]

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4. NEED TO EXPRESS DESPERATION

a) Wish to give up treatment and leave the hospital

Patient: Nothing has changed...

Researcher: How does that feel?

(Silence; she's thinking)

Patient: It doesn't change anything.

Researcher: You don't think it changes anything? And why do you think that?

Patient: I'm disgusted with life.

Researcher: You're...?

Patient: Disgusted with life.

Researcher: Disgusted with life ... And that means?

Patient: I've no more hope.....I want to leave the hospital...

[Field note, Norah]

b) Tranquilizers

The nurse says that the patient is nervous and that that is why she is giving her a Xanax. The nurse speaks to the patient in Dutch, asking: *'Why are you nervous?!, You have to do your best, you know!!'*. I have the impression that the patient doesn't understand the nurse. (...) The patient says in French: *'Don't understand.'*

[Field note, Norah]

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c) Hopeful relatives

I hear from the nurses that the patient gets panic attacks, hyperventilates and that his heart rhythm has increased (...). During visiting hour the patient says to his wife: *'it's fucked,'* to which the wife replies hopefully: *'You'll get through it, you'll get better. The infection has gone down'*. The patient rolls his eyes at this.

[Field note, Abdallah]

d) Relatives hiding negative medical information for each other

In the meantime, the patient's daughter tells me her brother talked to another doctor the previous evening and that it was a 'good' conversation. The patient was apparently a bit better and they would see how he was later in the week. This has clearly given the daughter more hope today. However I witnessed the conversation the day before between the doctor and the patient's son from a distance and the news the doctor brought was not good news. I deduce from this that the patient's son is hiding the confronting information the doctor gave him from his sister and giving her a rosier picture of the patient's situation so that she would continue to hope.

[Field note, Onur]

e) Patient more positive towards relatives from his home country

Then the uncle says: *'Will you fight for your children?'* The patient nods. The uncle continues: *'You came out of the coma, that's a sign that you want to continue, that you want to fight. Your face looks better.'* Then the patient shakes his head and lowers his eyes. (...) Then the patient's brother comes into quarantine. He flew over yesterday from Morocco. When he asks the patient how he is, the tone is more cheerful. The patient lifts his hand into the air and makes small, successive striking motions in the air, with which he means to indicate that his medical situation is improving. The brother laughs and says he saw him a while ago in a coma and that he is pleased he is now awake and eating. So he says to the patient that he sees clear progress. It is striking that the patient says to his brother who has flown over from Morocco that he is better, whereas he tells his wife and uncle that he is not doing well. [field note, Abdallah (died in the ICU)]

5. NEED TO PARTICIPATE IN END-OF-LIFE DECISION MAKING

a) Verbal and non-verbal communication by patient

I ask him (the patient) if he is okay. He shakes his head, indicating 'no', then breathes in and out loudly. He looks like a fish gasping for air. He means by this that he has difficulty breathing, even with the machines. He points to the machines. He looks angry and very sad at the same time. (...) He strikes the air with his hand, a gesture that I believe means he wants to give up. He points to the machines again and says '*that's useless*'.

(...) The patient sighs and looks really contorted. I ask in French if he is in pain. '*Vous avez mal*'? He nods and points to his chest.

[Field note, Abdallah]

b) Patient seen as incompetent by staff

I see the doctor walking into the unit. I go over to him for a moment and tell him about the patient's panic attacks. He says: '*That is normal, because he has already been in here for three months... We can hardly tell his body it has to stop... And even if the patient or family wanted us to stop treatment, we couldn't comply with that....*' I ask him: '*Why not?*' He replies: '*The patient and his family are not competent to decide because they are in a phase of pain and emotion... If we say we are going to continue, we will continue...*'

[Field note, Abdallah]

c) Saving the patient as doctors' mission

Nurse: And I think he had indicated a couple of times himself that he had had enough.

Researcher: How did he indicate that?

Nurse: Yes, by actually, erm by saying, and by saying "It doesn't help, does it! Don't do that, it doesn't help!"

He said that very often at the end.

Researcher: And who did he say that to then?

Nurse: He said it to me a couple of times. (...) He definitely said to me: "Just leave it like this, it's not going to, you know..." Erm, but even helping to decide "We're going to stop!" I don't think he did that. (..)

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Researcher: Erm, and did you talk about that to other people, about the fact that the man told you he would prefer the treatment to stop?

Nurse: Yes. Yes. We do tell each other that. Yes, I did say it to my colleagues, and to the doctor as well, that he wanted, that those words had been said and that that... Well it's heartbreaking, isn't it, because, well, somehow you know he's right but, you still do it, don't you.

Researcher: Yes. And how did the doctors react to this?

Nurse: It wasn't easy. Because the doctor also had real difficulty with it, to take the decision to let him go. Yes. I think, well, at times like that, still not being able to admit it and saying anyway "We're going to keep going".

[Interview Nurse Vanessa]

7

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Answer (including page number where the item can be found)
Domain 1: Research team and reflexivity			
Personal characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	RVK conducted the entire data collection (including interviews): see p. 7 line 163-165.
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	The researcher is MSc in sociology and MSc in social and cultural anthropology. She is extensively trained in qualitative research. Researcher's credentials were added in the revised manuscript: see p. 7, line 163-165
3	Occupation	What was their occupation at the time of the study?	The researcher was doing academic scientific research at university as sociologist and anthropologist: see p. 7, line 163-165
4	Gender	Was the researcher male or female?	The researcher is female. In the section 'data collection' we refer to the researcher with 'she', e.g. see p. 7, line 156
5	Experience and training	What experience or training did the researcher have?	The researcher is trained in sociology and anthropology. She is extensively trained in quantitative and qualitative research techniques, which is added in the revised manuscript. See p. 7, line 163-165
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	No relationship was established with the research participants prior to study commencement. This was added in the revised manuscript: see p. 6, line 128-129
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Participants were aware of the researcher's reason for doing the research (improving intercultural communication in the ICU). This was mentioned by the researcher verbally and written in the forms on

			informed consent which the study participants had to sign. This information was added in the revised manuscript: See p. 6, line 141-142
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. <i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? e.g. <i>purposive, convenience, consecutive, snowball</i>	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.g. <i>face-to-face, telephone, mail, email</i>	Participants were approached face-to-face. This was added to the revised manuscript: See p. 6, line 129-130
12	Sample size	How many participants were in the study?	Our sample consisted of staff members (nurses and doctors), patients and their relatives. In total 144 participants were included in the study (observations and interviews). See p. 6, line 132-133 and line 138-139.
13	Non-participation	How many people refused to participate or dropped out? Reasons?	No patients and relatives refused to participate. 8 healthcare professionals refused to participate because they were not interested in the study topic. This was added to the revised manuscript, p. 6, line 133-134 and line 139.
Setting			
14	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>	The data was collected in the clinic (ICU). See p. 6, line 124-125
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	As common in ethnographic studies sometimes also non-participants were present during the data collection, e.g. doctors who mostly work in other wards, relatives of patients who were not included in the study. This was added in

			the revised manuscript: See p. 6, line 139-140
16	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>	Following important characteristics of the sample has been mentioned: ethno-cultural background (p. 6, line 131-132 and line 137-138), age (see p. 6, line 133), gender (see p. 6, line 133-134), medical condition (see p. 6, line 134-137). See also our included table on patients' characteristics.
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Interview questions were based on an interview guide, which was discussed among experts before the actual data collection started and pilot tested among a limited number of persons. This was added in the revised manuscript (see p. 7, line 160-162)
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	We don't know what is meant with the word repeat interviews.
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	The researcher used audio recording to collect the data (Interviews were audio recorded). This was added in the revised manuscript. See p. 7, line 162.
20	Field notes	Were field notes made during and/or after the interview or focus group?	Fieldnotes were made in 2 stages: firstly, in the field during the data collection (by making short notes in a logbook during observations and after interviews); secondly, after the researcher had left the field (by transforming the short notes in longer comprehensive descriptive field notes): see p. 7, line 156-159
21	Duration	What was the duration of the interviews or focus group?	The interviews lasted between 50 minutes and 1h30. See p. 7, line 162
22	Data saturation	Was data saturation discussed?	Data saturation was referred to. See p. 8, line 180
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. This was added to the revised manuscript (see p. 7, line 163)
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	3 researchers were involved in the coding of

			the data (RVK, RD, JB). See p. 8, line 180-182.
25	Description of the coding tree	Did authors provide a description of the coding tree?	The coding tree is described. See p. 7-8, line 170-179
26	Derivation of themes	Were themes identified in advance or derived from the data?	The themes were derived from the data. See p.7-8, line 170-179
27	Software	What software, if applicable, was used to manage the data?	NVIVO 8 (QSR International, 2008) was used to manage the data. See p. 7, line 170-171.
28	Participant checking	Did participants provide feedback on the findings?	Participant provided feedback on the findings. See p. 8 line 184-187.
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	In the appendix transcripts from fieldnotes and interviews are presented to illustrate the themes/findings. Each transcript was identified by stating the name of the case to which it belongs (fieldnotes) or by referring to the name of the interviewee (interviews). All names are pseudonyms. See appendix.
30	Data and findings consistent	Was there consistency between the data presented and the findings?	There was consistency between the data presented (see transcripts in the appendix) and the findings in the manuscript. This consistency is reflected in the title of each transcript which accords with the presented findings.
31	Clarity of major themes	Were major themes clearly presented in the findings?	Major themes are clearly presented in the results section. Each subtitle in the results sections refers to one of the 5 major themes.
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No

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MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A QUALITATIVE ETHNOGRAPHIC STUDY

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3 **MENTAL WELLBEING OF PATIENTS FROM ETHNIC MINORITY GROUPS DURING CRITICAL CARE: A**
4 **QUALITATIVE ETHNOGRAPHIC STUDY**
5

6
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56 **Key words:** intensive care units, patients, cultural diversity, communication, mental health
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Abstract

Objectives: To investigate the state of the mental wellbeing of patients from ethnic minority groups and possible related risk factors for the development of mental health problems among these patients during critical medical situations in hospital.

Design: Qualitative ethnographic design.

Setting: 1 intensive care unit (ICU) of a multi-ethnic urban hospital in Belgium.

Participants: 84 ICU staff members, 10 patients from ethnic-minority groups, and their visiting family members.

Results: Patients had several human basic needs for which they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their relatives, nor to other patients. These needs included the need for social contact, the need to increase comfort and alleviate pain, the need to express desperation and participate in end-of-life decision making. Three interrelated risk factors for the development of mental health problems among the patients included were identified: Firstly, healthcare professionals' mainly biomedical care approach (e.g. focus on curing the patient, limited psychosocial support), secondly, the ICU context (e.g. time pressure, uncertainty, regulatory frameworks) and thirdly, patients' different ethno-cultural background (e.g. religious and phenotypical differences).

Conclusions: The mental state of patients from ethnic minority groups during critical care is characterized by extreme emotional loneliness. It is important that staff should identify and meet patients' unique basic needs in good time with regard to their mental wellbeing, taking into account important threats related to their own mainly biomedical approach to care, the ICU's structural context as well as the patients' different ethno-cultural background.

Article summary

Strengths and limitations of this study

- As far as we know, this is the first study where the mental wellbeing of patients from ethnic minority groups is profoundly investigated by means of an ethnographic research design.
- By studying the mental wellbeing of these patients as is 'genuinely expressed', from multiple perspectives and in a contextual manner, through ethnographic fieldwork in an intensive care unit of a multi-ethnic urban hospital in Belgium, we have tried to develop a nuanced, non-stereotypical and rich insight into such patients' mental wellbeing.
- One limitation of this research could be the fact that the fieldwork was done in only one ICU. Therefore transferability to other situations must be done with caution. However, by spending a lot of time in a variety of situations (with 10 patients and their families, and all their healthcare professionals) it was possible to gain a rich insight into our sensitive research topic.

INTRODUCTION

Having a good mental health/wellbeing means more than not having a mental disorder. The WHO defines mental wellbeing as *'a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community'*. It is perceived as crucial to our capacity as people to think, communicate with others, earn money and enjoy life. Risk factors include individual factors on e.g. the socio-economical level (e.g. being poor, having a low educational level), cultural level (e.g. belonging to an ethnic minority group) and behavioural level (e.g. having an unhealthy life style, having little sleep), contextual/structural factors (e.g. facing adverse work conditions, discrimination) and biological/genetical factors (e.g. being physically ill) [1,2]. It is then no surprise that during critical care patients' mental wellbeing comes under threat, and especially when other risk factors are involved, e.g. when patients have a different ethno-cultural background [3,4].

Hallucinations, fear, and depression frequently occur among patients admitted to the intensive care unit (ICU).[5-8] Several risk factors are identified, including invasive treatments, separation from family, physical pain, immobility, dependency, lack of control, lack of privacy and poor communication.[4,5,9,10, 11] Although disturbances in critically ill patients' mental health negatively affect their whole care process, healthcare professionals working in a critical care setting lack adequate strategies to improve patients' mental health. They are often not aware of patients' mental health problems as they mainly focus on the technological care aspects and lack training in mental care. Many critical care nurses for example do not have enough insight in the elements that might affect their patients' psychological state. [9,12] Furthermore in society at large, mental health problems remain a sensitive issue as such problems are often difficult acknowledged and talked about.

Additionally, healthcare professionals have to communicate increasingly with patients from ethnic minority groups, i.e. persons of a different origin who share certain cultural characteristics to some extent [13], as a result of societies' increased ethno-cultural diversity. In Belgium, healthcare for migrants is basically organized in the same manner as for people from the ethnic majority group. However it is known that during the care for migrants problems regularly arise which are situated on mainly 2 levels, namely firstly health differences (ethnic minorities have less chance on a healthy life than people from the ethnic majority group) and secondly

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3 problems regarding the accessibility and use of healthcare services (ethnic minorities have lower access to
4 healthcare services and receive less quality care than members of the ethnic majority group). Problems are
5 often very complex and related to different factors, such as linguistic and cultural differences. [14] We might
6 assume that critically ill patients from ethnic minority groups are at an even higher risk of mental health
7 problems and that ethno-cultural differences render mental health problems more complex and multifaceted.
8 Inattention by healthcare professionals to specific ethno-cultural habits (e.g. gender segregation),
9 discrimination, unfamiliarity with the western healthcare system and different foodways can contribute to
10 traumatic experiences for ethnic minorities.[15,16, 17, 18] Furthermore, language differences and ethno-
11 cultural norms prescribing acceptance of physical suffering can lead to less adequate communication and pain
12 relief[19,20], which can endanger such patients' psychological state.[7,15,21] Yet, although we increasingly live
13 in a multi-ethnic society, research about the mental wellbeing of patients from ethnic minority groups during
14 critical care is rather scarce and there are very few in-depth studies which try to understand this topic in its
15 specific context and from different angles.

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29 In this study we therefore aim to investigate 'the state of the mental wellbeing of patients from ethnic
30 minority groups and possible related risk factors for the development of mental health problems among these
31 patients in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among
32 patients from ethnic minority groups can contribute to the development of recommendations to prevent such
33 problems for these patients.

34 35 36 37 38 39 40 41 42 **METHODS**

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45 Patients' mental wellbeing in a multi-ethnic critical care setting is a sensitive, complex, and novel topic of
46 research. Therefore an ethnographic research design has been used, which gave the researcher the
47 opportunity to immerse herself into her study field and study the research topic for a long period on the
48 workforce itself. By getting a feel of the lifeworld of the ICU, observing and interacting with different parties,
49 the researcher was able to grasp the research topic in all its different facets and from different angles.

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Participants & setting

Ethnographic fieldwork was done in one ICU of a multi-ethnic urban hospital in Belgium over 6 months (January 2014-June 2014). 40 % of the ICU patients are estimated to belong to an ethnic minority group. Staff's, patients', and relatives' behaviour, interactions, and experiences were studied for 360 hours. The selected patients and the family members who accompanied them, as well as their healthcare professionals, were followed for the whole critical period. No relationship was established with the research participants prior to the beginning of the study. Patients and their family members were purposefully selected and approached face-to-face. They were only eligible for inclusion in the study if the patient or at least one of his/her legal parents was born abroad, if at least one of the family members (patient/his or her relatives) was able to speak Dutch, French, or English, and if the patient was at least 18 years old. In total we selected 10 patients and their visiting family members, who were originally from Morocco, Algeria, Turkey, Congo and Portugal. No patients and relatives refused to participate. The patients were between 40 and 82 years old and consisted of 6 males and 4 females. They were admitted for complicated pneumonia (3), abdominal problems (1), heart problems (2), brain haemorrhage (2), cancer (1), and a severe accident (1). All patients were sedated for some time, and as a result were unable to communicate or only had limited ability to communicate, depending on the level of sedation. The critical care team consisted of 80 nurses and 12 doctors, who were almost all white Caucasians from the dominant ethnic group. 8 staff members refused to participate in the study. Of course also other people were present during the ethnographic fieldwork, e.g. doctors who mostly work in other wards. Research participants were aware of the researcher's reason for doing the research (improving intercultural communication in the ICU). (For further information about patients: see supplementary file 'Patients characteristics').

Data collection

Data were collected through triangulation of several data collection strategies, namely negotiated interactive observation,[22] in-depth- interviews with healthcare professionals,[23] and the reading of patients' medical

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3 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care
4 tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward.
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6 Therefore 'negotiated interactive observation' was chosen, meaning that before starting the observations the
7 researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique
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9 enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation
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11 gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family
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13 members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare
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15 professionals, relatives, and patients during visiting hours.
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19 When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she
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21 transformed these notes into comprehensive descriptive field notes containing observations of participants'
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23 discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on
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25 her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare
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27 professionals in two meeting rooms in the hospital. The interview questions were based on an interview guide,
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29 which was discussed among experts before the actual data collection started and pilot tested among a limited
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31 number of persons (see supplementary file 'Topic list interviews'). The interviews lasted between 50 minutes
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33 and 1h30 and were audio recorded. Interview transcripts were not returned to the research participants for
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35 comments or corrections. All data were collected by the first author (RVK), a trained ethnographer and
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37 sociologist (MSc) who was doing academic scientific research at university at the time of the study. She is
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39 extensively trained in qualitative research.
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45 **Data analysis**

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48 The analysis started with a 'thick description' [25] of participants' discourse, behaviour, and interaction and
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50 was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were
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52 conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This
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54 process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly,
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56 an open coding phase was performed, involving the reading and rereading of the data. This resulted in the
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3 formation of different codes, for instance 'physical contact', 'proximity', and 'fighting'. To find similarities and
4 differences between these codes, new codes were constantly compared with already existing codes. Secondly,
5 axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example
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7 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance
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9 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category
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11 ('emotional loneliness') around which the related categories are clustered.[26,27]
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15 Data collection and analysis were stopped when the point of saturation was reached.[26,28] Reliability was
16 strengthened by the first author (RVK) doing the data analysis and two co-authors (RD & JB) doing a peer-
17 revision of the analysis. The process of data collection and data analysis was also regularly discussed by
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19 members of the multidisciplinary academic research group in which these authors participate, consisting of a
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21 health scientist, a psychiatric nurse, 2 anthropologists, and 1 sociologist. To improve the reliability and accuracy
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23 of the study, the results were also read by an intensive care specialist who is part of the intensive care team at
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25 the hospital in which the researcher did her fieldwork. Furthermore the study results were presented to and
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27 discussed with the nurses who had participated in this study during a conference.
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35 Ethics

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37 The research protocol (reference 2013/371) was approved by the university ethics committee of the Vrije
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39 Universiteit Brussel. The privacy of the research participants and confidentiality of the data were respected,
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41 e.g. by using pseudonyms. Written consent to participation in the study was sought from healthcare
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43 professionals, family members, and patients who were still able to communicate. If the patient lacked the
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45 capacity to give consent, consent was sought from his/her legal representative.
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51 RESULTS

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53 The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems
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55 (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among
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57 patients. Patients had several basic needs for which they could not sufficiently turn to anybody, neither to their
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3 healthcare professionals, nor to their relatives, nor to other patients. These needs comprised 'the need for
4 social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to
5 express desperation, and to participate in end-of-life decision making'.
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10 11 12 **1) Need for social contact** 13

14 Patients longed for social contact with relatives, healthcare professionals and other patients, and not only
15 verbally but also non-verbally. This need became even more significant when patients were unable to
16 communicate verbally as a result of their medical state and/or language differences. More specifically, patients
17 longed for proximity of others, physical contact, and chatting.
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24 Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and
25 talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting
26 time, to come more often, or to take them back home (see table 1a in supplementary file 'Quotes'). Some
27 patients also wanted to phone home to request visits from relatives (see table 1b in supplementary file
28 'Quotes'). Furthermore, patients wanted healthcare professionals to communicate more often with them (see
29 table 1c in supplementary file 'Quotes'). However, the rules concerning visits, the infrastructure/
30 accommodation (e.g. no telephone) and healthcare professionals' focus on the patients' disease made it
31 difficult for staff to fully satisfy patients' need for social contact. Moreover, pressure of work and time made it
32 tough to communicate with patients. Furthermore language differences and misconceptions of healthcare
33 professionals towards patients' ability to communicate in the language of the host country, sometimes based
34 on patients' different skin colour, endangered the meeting of patients' social needs. (see table 1d in
35 supplementary file 'Quotes'). Some patients also felt the urge to connect with other patients. This became
36 indirectly apparent when patients stared at other beds and/or asked questions about other patients'
37 conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made
38 communication between patients impossible. (see table 1e in supplementary file 'Quotes')
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2) Need for non-medical information exchange with healthcare professionals

The information exchange between doctors and patients was primarily of a medical nature. When patients were conscious, doctors explained to patients their medical situation, which medical actions they had undertaken as well those they would undertake in the future, and which medical decisions had been taken. However, patients not only felt the need to get medical information regarding their physical state from healthcare professionals, but equally to exchange information with them on matters that were not strictly medical, e.g. practical issues, visual aspects (e.g. activities going on around them) and their family (see table 2a and 2b in supplementary file 'Quotes'). Furthermore, nurses regularly did not communicate with patients or only communicated with them in a task-related manner (see table 2c in supplementary file 'Quotes').

Despite healthcare professionals' good intentions, they often perceived it as impossible to communicate with patients about non-medical issues due to their prime task of safeguarding the patients' clinical state, time pressure, and their workload (see table 2d in supplementary file 'Quotes'). Also language differences made communication between patients and healthcare professionals about non-medical matters more difficult (see table 2e in supplementary file 'Quotes'). In addition, communication with relatives about non-medical issues was limited as well. Relatives often focused on their search for exhaustive medical information from doctors, which was reinforced by group pressure within their families, during the restricted visiting hours.

3) Need to increase comfort and alleviate pain

Patients wanted to increase their comfort and be free from pain. This need was often expressed through verbal and non-verbal communication. Patients verbally requested acts of care to increase comfort in the language of the host society or in their own mother tongue. They also often indirectly requested comfort-increasing care by expressing their suffering through non-verbal signs, e.g. pointing with their heads. However, sometimes these expressions of patients' hardship were not noticed, minimally acknowledged, not apprehended or misunderstood, even neglected, normalized or temporarily medically suppressed by giving tranquilizers, by healthcare professionals. Inadequately meeting patients' need for comfort and pain alleviation was related to

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3 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely
4 perceived language differences. Consequently, comfort and pain was often addressed based on healthcare
5 professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and
6 irritation and insecurity occurred on both sides (see table 3a in supplementary file 'Quotes').
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11 Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals
12 because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients'
13 verbal messages was sometimes hampered by language differences (see table 3b in supplementary file
14 'Quotes'). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with
15 patients sometimes unfolded inadequately or no communication occurred. This was sometimes related to
16 healthcare professionals' misconceptions of patients' language proficiency, based on the very quick and
17 minimal moments of interaction they had with patients and relatives and patients' different skin colour. Also
18 staff's general knowledge of patients' country of origin which they sometimes easily applied to all patients from
19 that country contributed to these misconceptions (see table 3c in supplementary file 'Quotes').
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30 On the other hand, some patients who were at moments totally unable to communicate as a result of
31 medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless
32 (see table 3d in supplementary file 'Quotes'). When patients experienced discomfort for a longer time some of
33 them did not want to ask healthcare professionals for help anymore and wanted to leave the ICU (see table 3e
34 in supplementary file 'Quotes').
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43 **4) Need to express desperation**

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45 Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the
46 hospital, others wanted to completely give up treatment (see table 4a in supplementary file 'Quotes'). Patients
47 felt the need to express and share these feelings with others. However, patients regularly felt obliged to
48 suppress their hopelessness during critical care in front of healthcare professionals and relatives, resulting in
49 frustration and sadness.
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3 Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients
4 with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for
5 patients to express their negative feelings. And even when patients did express their hopelessness, healthcare
6 professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless,
7 tranquilizers/antidepressants were given (see table 4b in supplementary file 'Quotes').
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12 Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients
13 (see table 4c in supplementary file 'Quotes'). Relatives' religious beliefs and high expectations for cure in
14 western hospitals functioned as sources of hope. Furthermore, negative information was hidden for some
15 family members by other relatives so as to not create unrest within their large transnational families, which
16 affected relatives' positive outlook on the patients' situation (see table 4d in supplementary file 'Quotes').
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18 Additionally, families' considerable size led to group pressure among its members to remain hopeful.
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20 Moreover, patients themselves presented their situation in a more positive manner towards visiting relatives
21 coming from the home country so as to not worry their relatives there (see table 4e in supplementary file
22 'Quotes').
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34 **5) Need to participate in end-of-life decision making**

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36 Enduring physical and mental suffering triggered a need for some patients to participate in a decision to
37 withdraw therapy. This need was verbally and non-verbally expressed at several points (see table 5a in
38 supplementary file 'Quotes').
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43 However healthcare professionals regularly acknowledged these patients' communication only minimally,
44 neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central
45 decision makers and wanted to continue treatment, when they believed that patients still had a chance to
46 survive within the context of their specific pathology. Patients were seen as lacking the required expertise to
47 make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as
48 they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or
49 after taking anti-depressants (see table 5b in supplementary file 'Quotes'). Further, healthcare professionals
50 saw it as their mission to save patients' lives, which was reinforced by their daily contact with many hopeful
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3 relatives of the patient who saw God as the ultimate decision maker. Consequently, not being able to save the
4 patient was seen by some healthcare professionals as a personal failure. (see table 5c in supplementary file
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14 DISCUSSION

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17 This ethnographic study investigates the state of the mental wellbeing of patients from ethnic minority groups
18 and possible related risk factors for the development of mental health problems among these patients in a
19 multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups
20 is basically characterized by an ‘extreme emotional loneliness’. Patients had several human basic needs for
21 which they could not sufficiently turn to anybody, neither to their healthcare professionals, nor to their
22 relatives, nor to other patients. It concerned the need for social contact, for non-medical information
23 exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in
24 end-of-life decision making. Insufficiently meeting patients’ basic needs endangered patients’ mental
25 wellbeing as defined by the WHO, e.g. in the sense that they couldn’t cope adequately with stress and didn’t
26 feel to contribute to their family/community anymore. Three interrelated risk factors for the development of
27 mental health problems among the included patients were identified: firstly healthcare professionals’ mainly
28 biomedical approach to care, secondly the ICU context, and thirdly the patients’ different ethno-cultural
29 background.
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43 The mental wellbeing of patients from ethnic minority groups in a critical care setting is an under-
44 researched topic. Although a body of research has recently begun to grow that focuses on the lifeworld of
45 patients in a critical care context [see for example:4,5,9,12], still very few of these studies focus on specific
46 vulnerable patient groups, e.g. patients from ethnic minority groups, and mental health issues. Furthermore
47 some researchers that do focus on critically ill patients from ethnic minority groups study their experiences
48 mainly through interviews with patients, their relatives or staff [see for example: 15, 29]. So as far as we know,
49 this is the first study where specifically the mental wellbeing of patients from ethnic minority groups is
50 investigated in one particular context, namely the critical care context, by means of an ethnographic research
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3 design. A study design of this kind is the most appropriate way to gain nuanced/deep insight into complex
4 themes e.g. mental wellbeing of patients from ethnic minority groups in a critical care setting. Ethnographic
5 day-by-day observations on the ward allow the study of patients' mental wellbeing as it is 'genuinely
6 expressed' and from the perspective of the different people involved, from a non-prejudiced perspective.
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11 The researcher might have had an impact on the field and the research findings as she herself has a non-
12 Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from
13 patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic
14 feature of qualitative ethnographic research [23]. A weakness of this research could be the fact that the
15 fieldwork was done in only one ICU. Therefore transferability to other situations must be done with caution.
16 However, by spending a lot of time in a variety of situations (with 10 patients and their families, and all their
17 healthcare professionals) it was possible to gain a rich insight into our sensitive research topic. There is no
18 specific reason to believe our findings are not valuable for other similar settings. Another weakness of this
19 study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-
20 depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can
21 be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't
22 allow other techniques, such as video recording and full participant observation, for ethical reasons.
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36 Our study shows that the patients included felt extremely emotionally lonely because several of their basic
37 needs were insufficiently met. This seems to confirm previous research showing that ICU patients favour a
38 holistic care approach and thus value attention from healthcare professionals not only to their bio-
39 physiological needs but also to other general psycho-social and existential human needs, e.g. the need for
40 social contact, for non-medical information exchange, religious needs and participation in decision
41 making.[9,15,16,30]
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48 Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this
49 model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems,
50 caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare
51 professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine,
52 although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory
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3 frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central
4 responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced
5 with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care
6 strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks,
7 making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure
8 (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and
9 professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly
10 prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the
11 other hand, taking into account patients' emotions becomes even more complex and challenging when
12 patients have a different ethno-cultural background. The included patients' different ethno-cultural
13 backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and
14 collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care
15 and suffering, communication forms and families' history of migration), and the level of patient-staff
16 interaction (e.g. phenotypical features, language).

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31 Staff, occupied with urgent lifesaving care tasks, were frequently unable to react effectively to patients'
32 verbal and non-verbal communications, often expressed by patients who completely lacked knowledge of the
33 language of the host country. However, adequately decoding ethno-culturally diverse patients' non-verbal
34 communication is crucial for optimal pain management and shared medical decision making.[32,33]
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36 Furthermore, pressured healthcare professionals had little time to gain in-depth-knowledge of patients' level of
37 skill in the language of the host society. Therefore the staff easily developed misconceptions of patients'
38 language proficiency based, for example, on their general knowledge of the patient's country of origin or
39 specific phenotypical features, which led to inadequate communication or a complete absence of
40 communication with patients about their needs. Moreover, insufficiently satisfying specific needs which were
41 ethno-culturally inspired led to high emotional loneliness among patients. For example, a failure to meet
42 patients' needs for multiple types of social contact (e.g. proximity of others) strengthened for some patients by
43 the collectivistic orientation of their minority cultures, led to high emotional suffering among particular
44 patients. Moreover, because relatives shared ethno-cultural expectations towards patients to remain stoic and
45 hopeful in difficult times, they did not pay enough attention to patients' specific unique basic needs, i.e. their

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3 need to express desperation and participate in end of life decisions, which made patients feel left behind. In
4 line with this finding, previous research has shown that overt communication about pain and sorrow between
5 patients from certain ethnic minority groups and their relatives is limited.[34] Additionally, relatives' high levels
6 of hope triggered healthcare professionals, caring for patients with an uncertain prognosis, to continue life-
7 saving treatments and reinforced their belief in their core responsibility to save patients' lives, while these
8 patients' voices were largely unheard. Likewise, previous research demonstrates that more aggressive
9 interventions occur at the end of the lives of patients from ethnic minority groups.[35] Relatives shared high
10 levels of hope, which were associated with an ethno-cultural non-disclosure of negative information by some
11 relatives towards other relatives, ethno-religious beliefs,[29] migration-related expectations towards an
12 unlimited field of medical possibilities in western hospitals, and group pressure among the many relatives to
13 remain hopeful.

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25 Finally, another striking observation is that not only patients' mental health but also the mental state of
26 healthcare professionals working in such interethnic critical medical situations can become severely threatened
27 due to their experiences of powerlessness towards meeting some of their patients' human basic needs. This
28 can further negatively affect patients' mental state.

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Our study results are certainly also of relevance to patients from majority ethnic backgrounds because we
found that the ICU context and staff's biomedical approach, factors to which all patients are exposed, hindered
the satisfaction of several human basic needs which are shared by all patients irrespective of their ethno-
cultural background. Patients from ethnic minority groups their different ethno-cultural background forms an
extra important risk factor for not meeting their basic needs. Of course the relative importance of this risk
factor is different for each patient.

Mental health problems among patients, irrespective of their ethno-cultural background, can primarily be
reduced by investing in patient-centred care, which requires the implementation of intervention measures
stimulating the coexistence of biomedical and more holistic views on health and care among staff, on the level
of daily work, training and education, and ICU policy/organization. Such structural measures include staff
training in mental health, flexible visiting policies, the presence of a social worker on the ward, questioning the
division of labour and working hours, close cooperation with a psychologist/psychiatrist, etc. Additionally, in a
multi-ethnic ICU context, extra measures are urgently required, e.g. cultural sensitivity training for staff and
students, language facilitation, and the presence of religious figures on the ward. Further (evidence-based)

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3 research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical
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10 11 12 **CONCLUSION**

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15 The followed patients had specific basic needs for which they could not sufficiently turn to anybody, leaving
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17 them in a state of extreme emotional loneliness. Three interrelated risk factors for the development of mental
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19 health problems among these patients were identified: firstly, healthcare professionals' mainly biomedical care
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21 approach, secondly the ICU work context and thirdly the patients' different ethno-cultural background.
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25 26 **Abbreviations**

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28 ICU, intensive care unit
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33 **Contributors:** All authors have met the four authorship criteria as stated in the International Committee of
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35 Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly
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37 Work in Medical Journals.
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40 **Authors' contributions:** RVK contributed to the research design, applied for the ethical approval, completed
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42 the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the
43
44 manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research
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46 design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of
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48 the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and
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50 applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB
51
52 applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to
53
54 the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of
55
56 the manuscript. All the authors read and approved the final manuscript.
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5 interpretation of the data and in writing the manuscript.
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11 **Ethics:** The study (reference 2013/371) was approved by the ethics committee of the university Vrije
12 Universiteit Brussel in December 2013.
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17 **Competing interests:** The authors declare that they have no competing interests.
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21 **Data sharing:** Extra data is available by emailing RVK.
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Patients' characteristics

Number	Pseudonym	Country of origin	Medical condition
1	Amrani	Turkey	Complicated pneumonia
2	Fadila	Morocco	Heart problems
3	Norah	Morocco	Complicated pneumonia
4	Abdallah	Morocco	Complicated pneumonia
5	Zacharia	Morocco	Heart problems
6	Bilal	Algeria	Abdominal problems
7	Quintus	Congo	Brain haemorrhage
8	Onur	Turkey	cancer
9	Kabibe	Congo	Brain haemorrhage
10	Ali	Portugal	Severe accident

Topic list for formal in-depth interviews

- Pathology
- Experiences with communication (patient – relatives - intra-team)
 - Difficult communication/disagreements (if applicable)
- Decision making
 - Role - nurse - doctor - patient - relatives
 - Course
 - Difficult communication/disagreements (if applicable)
 - Final medical decision
- Care for patient
 - Positive and negative experiences
- Death of patient
 - Communication with relatives
- Prevention of difficult communication

Quotes

(Note: all the names are pseudonyms)

1. NEED FOR SOCIAL CONTACT**a) Longer visits**

Patient: I've had enough... I've gone mad.

(..)

Researcher: But when your children are here, does that lift your spirits?

Patient: Yes, at the time...

Researcher: And at other times?

Patient: When they've gone? I'd like them to stay here longer.

[Field note, Norah]

b) Phone home

Patient: 'Telephone'.

Researcher: 'Do you want to use the telephone?'

Patient: 'Yes'.

Researcher: Who do you want to call?

(...)

Patient: 'Home'.

Researcher: 'Why?'

Patient: 'To say they have to come.'

[Field note, Zacharia]

c) More communication with staff

Researcher: So there aren't many people you can talk to?

Patient: Here in hospital?

Researcher: Nods, uh huh...

Patient: No... They don't answer you...

Researcher: Who?

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Patient: The nurses [...] They came when I had almost gone mad.

Researcher: And why?

Patient: I don't know.

Researcher: And what do you think about that?

Patient: Leave the hospital.

[Field note, Norah]

d) Misconceptions of staff towards patients' language proficiency

When I come in the patient, a dark-skinned man, is writing, along with his daughter Barbara. I notice that he is already able to write better than in the previous days during which he wrote a lot of indecipherable signs on the paper. He points to me and writes 'NAME' on the paper. So he is asking my name. Then he points to his daughter and writes 'Barbara' on the paper. I say my name and then write my name on the paper.

[...]

During the change of nursing shift, the following is said about the patient:

'The patient wants to write all the time'. A nurse remarks: '*But he writes in Arabic!*' (...). Annoyed, the nurse continues, saying: '*I'm not going to learn Arabic so that I can understand him! We can never get anything right*'. (...) The nurse storms angrily out of the meeting. Some of the other nurses look shocked but they continue with the meeting. Another nurse asks: '*How can he write? He can't even hold a glass, talk ...*'

However the patient does not know any Arabic and can talk French, an official language in Belgium.

Apparently the nurse wrongfully believed that the patient could only talk a foreign language because he has a different skin colour and has been writing a lot of unreadable signs lately.

[field note, Quintus]

e) Infrastructural constraints

Patient: *Is there a sick person over there?*

The patient lifts her head a little and looks curiously at the bed in the distance that is diagonally opposite her bed. She can only catch a glimpse of that bed ...

Patient: *She has been ill for a week ...*

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Researcher: *There are six beds here ...*

[...]

Patient: *Six in intensive care... Is it serious?*

Researcher: *Some are more seriously ill than others...*

[Field note, Norah]

2. NEED FOR NON-MEDICAL INFORMATION EXCHANGE WITH HEALTHCARE PROFESSIONALS

a) Practicalities

The doctor gives a medical explanation to the patient. (...) During the doctor's explanation, the patient looks questioningly at the doctor. She asks the doctor: *'When can I go to the room?'* (Meaning: The patient asks the doctor when she can leave the ICU and go to a room in another ward). The doctor says: *'today'*.

[Field note, Norah]

b) Family

I try to talk about his medical situation with him (patient) a bit and say: *'Your cannula has gone'* and point to his throat. He says bluntly: *'I'm not interested in that'*. I'm shocked by what he says. I ask what does interest him. He says: *'My wife'*.

[Field note, Zacharia]

c) No communication from staff

The patient is lying with his eyes open. He has to gasp for air the whole time, is looking around which makes him seem very frightened (...) A nurse comes to aspirate the phlegm. He simply carries out his task and does not speak to the patient.

[Field note, Zacharia]

d) Time pressure and workload

Researcher: Erm, how did you experience your care for the patient? (..)

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3 **Nurse:** Very difficult! Erm, not always easy. Erm. He wasn't always easy to deal with himself. The patient.
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5 Which is sometimes understandable, of course, if you are that ill. Erm, but because of the, the pressure of
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7 work we're actually under, sometimes you can erm, with him, not as much, I mean sometimes we couldn't
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9 give him as much time as we would like to. Erm and sometimes I find that the most difficult part of your job,
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11 that you do want to stay in a room longer sometimes to, well, to be able to talk to your patient a bit more,
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13 or take your time a bit more with everything, but that sometimes that's not possible because you've got
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15 other things to do and you have to say "No, I have to go!" and, erm, yes, that's pretty much that. If I just look
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17 at the patient themselves, I mean.

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20 [Interview with nurse Vanessa]
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23 24 **e) Language differences**

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26 The nurse comes into quarantine without saying anything to the patient. She looks at the medication and
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28 does several things on the PC. The patient looks at the nurse and says: '*tranquil*', relax. I deduce from this
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30 that the patient wants to talk to the nurse. The nurse doesn't react to the patient's words. Then she pours
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32 the patient's urine into a plastic bottle. The patient asks me: '*What is she doing?*' I say to her: '*He's asking*
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34 *what you're doing*'. She replies in Dutch, a language the patient doesn't understand: '*I'm pouring his pee into*
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36 *a bottle*'. Then she leaves quarantine.

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39 [Field note, Zacharia]
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48 **3. NEED TO INCREASE COMFORT AND ALLEVIATE PAIN**

49 **a) Mistrust and irritation**

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51 10 minutes later, the patient is shivering with cold. He points to the blanket. He wants an extra blanket, but
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53 there are no nurses nearby. I leave quarantine again and go and ask the nurses for a blanket. One of them
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55 says: '*Now he's messing us around. I was with him just a moment ago.*' There was no response to his
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57 request.

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60 [Field note, Abdallah]

b) Language differences

I sit down at the nurses' table. The patient sees us and calls out to us in Arabic. The nurses stay where they are and say: *'It is annoying, though, that we don't understand them'* (...). Apparently these carers feel powerless. The patient continues to call out and complain, and waves her arms in the air. She also bangs her arms against her head. Clearly she is trying to tell us something. None of the carers go over to her.

[Field note, Fadila]

c) Misconceptions of staff towards patients' language proficiency

I ask the nurses who are checking the parameters shown on the monitor by the patient's bed: *'Does he speak French?'* One nurse answers: *'Yes, because French is an official language in Algeria, isn't it.'* However the visitor told me that the patient only speaks Arabic. The patient is very distressed. 2 nurses stand around his bed after visiting hour and ask him in French: *'Can you breathe properly? Are you comfortable? Bilal, Bilal, are you comfortable?'* The patient is still very distressed and every time the nurses say something to him, he moves his head from left to right. (...) The carers therefore assume that this patient understands them on the basis of their presuppositions.

[Field note, Bilal]

d) Quiet comfortable patient

During the nurses' meeting in the unit, the patient's situation was discussed. Among other things, he is said not to be a difficult patient: *'He doesn't cause trouble, he's not in pain and he doesn't complain'*. It strikes me that the patient has little opportunity to 'complain' given that he had a cannula that rendered him unable to speak. Besides, according to the visitor, he does not speak Dutch, French or English, so he cannot speak to the nurses. It is also strange that the nurses decide he has no pain purely on the basis of the absence of verbal communication between the patient and the carers.

[field note, Bilal]

e) Wish to leave the ICU

Patient: I'm not going to stay in intensive care, this place is death.

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Researcher: Why?

Patient: I don't like it...Nobody comes, nobody listens... Even the nurses, one in ten glances your way for a moment, that's all ...(...) *'I can't manage yet, when I'm done'*...Anyway, I don't like it.

[...]

The patient looks sad and dejected. She says to her daughter that she wants to be moved because her back hurts. She says the nurses aren't friendly to her and that they don't often come when she asks them to.

Suddenly she starts to cry.

[Field note, Norah]

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4. NEED TO EXPRESS DESPERATION

a) Wish to give up treatment and leave the hospital

Patient: Nothing has changed...

Researcher: How does that feel?

(Silence; she's thinking)

Patient: It doesn't change anything.

Researcher: You don't think it changes anything? And why do you think that?

Patient: I'm disgusted with life.

Researcher: You're...?

Patient: Disgusted with life.

Researcher: Disgusted with life ... And that means?

Patient: I've no more hope.....I want to leave the hospital...

[Field note, Norah]

b) Tranquilizers

The nurse says that the patient is nervous and that that is why she is giving her a Xanax. The nurse speaks to the patient in Dutch, asking: *'Why are you nervous?!, You have to do your best, you know!!'*. I have the impression that the patient doesn't understand the nurse. (...) The patient says in French: *'Don't understand.'*

[Field note, Norah]

c) Hopeful relatives

I hear from the nurses that the patient gets panic attacks, hyperventilates and that his heart rhythm has increased (...). During visiting hour the patient says to his wife: *'it's fucked,'* to which the wife replies hopefully: *'You'll get through it, you'll get better. The infection has gone down'*. The patient rolls his eyes at this.

[Field note, Abdallah]

d) Relatives hiding negative medical information for each other

In the meantime, the patient's daughter tells me her brother talked to another doctor the previous evening and that it was a 'good' conversation. The patient was apparently a bit better and they would see how he was later in the week. This has clearly given the daughter more hope today. However I witnessed the conversation the day before between the doctor and the patient's son from a distance and the news the doctor brought was not good news. I deduce from this that the patient's son is hiding the confronting information the doctor gave him from his sister and giving her a rosier picture of the patient's situation so that she would continue to hope.

[Field note, Onur]

e) Patient more positive towards relatives from his home country

Then the uncle says: *'Will you fight for your children?'* The patient nods. The uncle continues: *'You came out of the coma, that's a sign that you want to continue, that you want to fight. Your face looks better.'* Then the patient shakes his head and lowers his eyes. (...) Then the patient's brother comes into quarantine. He flew over yesterday from Morocco. When he asks the patient how he is, the tone is more cheerful. The patient lifts his hand into the air and makes small, successive striking motions in the air, with which he means to indicate that his medical situation is improving. The brother laughs and says he saw him a while ago in a coma and that he is pleased he is now awake and eating. So he says to the patient that he sees clear progress. It is striking that the patient says to his brother who has flown over from Morocco that he is better, whereas he tells his wife and uncle that he is not doing well. [field note, Abdallah (died in the ICU)]

5. NEED TO PARTICIPATE IN END-OF-LIFE DECISION MAKING

a) Verbal and non-verbal communication by patient

I ask him (the patient) if he is okay. He shakes his head, indicating 'no', then breathes in and out loudly. He looks like a fish gasping for air. He means by this that he has difficulty breathing, even with the machines. He points to the machines. He looks angry and very sad at the same time. (...) He strikes the air with his hand, a gesture that I believe means he wants to give up. He points to the machines again and says '*that's useless*'.

(...) The patient sighs and looks really contorted. I ask in French if he is in pain. '*Vous avez mal*'? He nods and points to his chest.

[Field note, Abdallah]

b) Patient seen as incompetent by staff

I see the doctor walking into the unit. I go over to him for a moment and tell him about the patient's panic attacks. He says: '*That is normal, because he has already been in here for three months... We can hardly tell his body it has to stop... And even if the patient or family wanted us to stop treatment, we couldn't comply with that....*' I ask him: '*Why not?*' He replies: '*The patient and his family are not competent to decide because they are in a phase of pain and emotion... If we say we are going to continue, we will continue...*'

[Field note, Abdallah]

c) Saving the patient as doctors' mission

Nurse: And I think he had indicated a couple of times himself that he had had enough.

Researcher: How did he indicate that?

Nurse: Yes, by actually, erm by saying, and by saying "It doesn't help, does it! Don't do that, it doesn't help!" He said that very often at the end.

Researcher: And who did he say that to then?

Nurse: He said it to me a couple of times. (...) He definitely said to me: "Just leave it like this, it's not going to, you know..." Erm, but even helping to decide "We're going to stop!" I don't think he did that. (..)

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Researcher: Erm, and did you talk about that to other people, about the fact that the man told you he would prefer the treatment to stop?

Nurse: Yes. Yes. We do tell each other that. Yes, I did say it to my colleagues, and to the doctor as well, that he wanted, that those words had been said and that that... Well it's heartbreaking, isn't it, because, well, somehow you know he's right but, you still do it, don't you.

Researcher: Yes. And how did the doctors react to this?

Nurse: It wasn't easy. Because the doctor also had real difficulty with it, to take the decision to let him go. Yes. I think, well, at times like that, still not being able to admit it and saying anyway "We're going to keep going".

[Interview Nurse Vanessa]

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Answer (including page number where the item can be found)
Domain 1: Research team and reflexivity			
Personal characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	RVK conducted the entire data collection (including interviews): see p. 7 line 163-165.
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	The researcher is MSc in sociology and MSc in social and cultural anthropology. She is extensively trained in qualitative research. Researcher's credentials were added in the revised manuscript: see p. 7, line 163-165
3	Occupation	What was their occupation at the time of the study?	The researcher was doing academic scientific research at university as sociologist and anthropologist: see p. 7, line 163-165
4	Gender	Was the researcher male or female?	The researcher is female. In the section 'data collection' we refer to the researcher with 'she', e.g. see p. 7, line 156
5	Experience and training	What experience or training did the researcher have?	The researcher is trained in sociology and anthropology. She is extensively trained in quantitative and qualitative research techniques, which is added in the revised manuscript. See p. 7, line 163-165
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	No relationship was established with the research participants prior to study commencement. This was added in the revised manuscript: see p. 6, line 128-129
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Participants were aware of the researcher's reason for doing the research (improving intercultural communication in the ICU). This was mentioned by the researcher verbally and written in the forms on

			informed consent which the study participants had to sign. This information was added in the revised manuscript: See p. 6, line 141-142
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. <i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? e.g. <i>purposive, convenience, consecutive, snowball</i>	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.g. <i>face-to-face, telephone, mail, email</i>	Participants were approached face-to-face. This was added to the revised manuscript: See p. 6, line 129-130
12	Sample size	How many participants were in the study?	Our sample consisted of staff members (nurses and doctors), patients and their relatives. In total 144 participants were included in the study (observations and interviews). See p. 6, line 132-133 and line 138-139.
13	Non-participation	How many people refused to participate or dropped out? Reasons?	No patients and relatives refused to participate. 8 healthcare professionals refused to participate because they were not interested in the study topic. This was added to the revised manuscript, p. 6, line 133-134 and line 139.
Setting			
14	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>	The data was collected in the clinic (ICU). See p. 6, line 124-125
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	As common in ethnographic studies sometimes also non-participants were present during the data collection, e.g. doctors who mostly work in other wards, relatives of patients who were not included in the study. This was added in

			the revised manuscript: See p. 6, line 139-140
16	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>	Following important characteristics of the sample has been mentioned: ethno-cultural background (p. 6, line 131-132 and line 137-138), age (see p. 6, line 133), gender (see p. 6, line 133-134), medical condition (see p. 6, line 134-137). See also our included table on patients' characteristics.
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Interview questions were based on an interview guide, which was discussed among experts before the actual data collection started and pilot tested among a limited number of persons. This was added in the revised manuscript (see p. 7, line 160-162)
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	We don't know what is meant with the word repeat interviews.
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	The researcher used audio recording to collect the data (Interviews were audio recorded). This was added in the revised manuscript. See p. 7, line 162.
20	Field notes	Were field notes made during and/or after the interview or focus group?	Fieldnotes were made in 2 stages: firstly, in the field during the data collection (by making short notes in a logbook during observations and after interviews); secondly, after the researcher had left the field (by transforming the short notes in longer comprehensive descriptive field notes): see p. 7, line 156-159
21	Duration	What was the duration of the interviews or focus group?	The interviews lasted between 50 minutes and 1h30. See p. 7, line 162
22	Data saturation	Was data saturation discussed?	Data saturation was referred to. See p. 8, line 180
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. This was added to the revised manuscript (see p. 7, line 163)
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	3 researchers were involved in the coding of

			the data (RVK, RD, JB). See p. 8, line 180-182.
25	Description of the coding tree	Did authors provide a description of the coding tree?	The coding tree is described. See p. 7-8, line 170-179
26	Derivation of themes	Were themes identified in advance or derived from the data?	The themes were derived from the data. See p.7-8, line 170-179
27	Software	What software, if applicable, was used to manage the data?	NVIVO 8 (QSR International, 2008) was used to manage the data. See p. 7, line 170-171.
28	Participant checking	Did participants provide feedback on the findings?	Participant provided feedback on the findings. See p. 8 line 184-187.
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	In the appendix transcripts from fieldnotes and interviews are presented to illustrate the themes/findings. Each transcript was identified by stating the name of the case to which it belongs (fieldnotes) or by referring to the name of the interviewee (interviews). All names are pseudonyms. See appendix.
30	Data and findings consistent	Was there consistency between the data presented and the findings?	There was consistency between the data presented (see transcripts in the appendix) and the findings in the manuscript. This consistency is reflected in the title of each transcript which accords with the presented findings.
31	Clarity of major themes	Were major themes clearly presented in the findings?	Major themes are clearly presented in the results section. Each subtitle in the results sections refers to one of the 5 major themes.
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No

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