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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-014075
Article Type:	Research
Date Submitted by the Author:	30-Aug-2016
Complete List of Authors:	Van Keer , RL; Vrije Universiteit Brussel, Public Health Deschepper, Reginald; Vrije Universiteit Brussel, Public Health Huyghens, Luc; Universitair Ziekenhuis Brussel, Critical Care Bilsen, Johan; Vrije Universiteit Brussel, Public Health
Primary Subject Heading:	Intensive care
Secondary Subject Heading:	Mental health
Keywords:	MENTAL HEALTH, INTENSIVE & CRITICAL CARE, communication

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

Rose-Lima Van Keer[1], Reginald Deschepper [2], Luc Huyghens[3], Johan Bilsen[4]

(1) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rvkeer@vub.ac.be

(2) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rdeschep@vub.ac.be

(3) Critical care Department/Service of Intensive Care Medicine, Vrije Universiteit Brussel; Universitair Ziekenhuis Brussel
Laarbeeklaan 101 1090 Brussel
Brussels, Belgium
e-mail: Luc.Huyghens@uzbrussel.be

(4) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: johan.bilsen@vub.ac.be

Correspondence to: R. Van Keer rvkeer@vub.ac.be or +32 2 4774608

Word count: 3560 words

Key words: intensive care units, patients, cultural diversity, communication, mental health

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: All doctors and nurses at the ICU, 10 patients from ethnic-minority groups, and their visiting family members.

Results: The mental wellbeing of critically ill patients from ethnic minority groups is basically characterized by 'extreme emotional loneliness'. 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 alarming, and 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.
- A 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

During critical care, patients' mental wellbeing comes under threat in several ways.[1-2] Hallucinations, fear, and depression frequently occur among patients admitted to the intensive care unit (ICU).[3-6] Several risk factors are identified, including dependency and poor communication.[2,3,7,8] 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.[7,9]

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

In this study we therefore aim 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 in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among patients from ethnic minority groups can contribute to the development of recommendations to prevent such problems for these patients.

METHODS

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

Participants & setting

Ethnographic fieldwork was done in one ICU of a multi-ethnic urban hospital in Belgium over 6 months (January 2014-June 2014). 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. Patients and their family members were purposefully selected. 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 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 North Africa, Turkey, Central Africa, and Southern Europe, i.e. regions of origin of large ethnic minority groups in Belgium.[19]The patients were between 40 and 82 years old and consisted of 6 males and 4 females. The critical care team consisted of 80 nurses and 12 doctors, who were almost all white Caucasians from the dominant ethnic group.

Data collection

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

When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she transformed these notes into comprehensive descriptive field notes containing observations of participants' discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on her behaviour and feelings in the field.[17] Formal in-depth- interviews were held with nine healthcare professionals. These interviews were recorded. All data were collected by the first author (RVK), a trained ethnographer and sociologist.

Data analysis

The analysis started with a ‘thick description’ [20] of participants’ discourse, behaviour, and interaction and was followed by a grounded theory analysis.[21] In depth-interviews were transcribed, and data were conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly, an open coding phase was performed, involving the reading and rereading of the data. This resulted in the formation of different codes, for instance ‘physical contact’, ‘proximity’, and ‘fighting’. To find similarities and differences between these codes, new codes were constantly compared with already existing codes. Secondly, axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example ‘social contact’ and ‘saving patient’. Relationships between the categories were also established, for instance ‘basic needs’ and ‘care strategies’. Thirdly, selective coding was performed to determine the core category (‘emotional loneliness’) around which the related categories are clustered.[21,22]

Data collection and analysis were stopped when the point of saturation was reached.[21,23] Reliability was strengthened by the first author (RVK) doing the data analysis and two co-authors (RD & JB) doing a peer-revision of the analysis. The process of data collection and data analysis was also regularly discussed by members of the multidisciplinary academic research group in which these authors participate, consisting of a health scientist, a psychiatric nurse, 2 anthropologists, and 1 sociologist. To improve the reliability and accuracy of the study, the results were also read by an intensive care specialist who is part of the intensive care team at the hospital in which the researcher did her fieldwork.

Ethics

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

RESULTS

The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among patients. Patients had several 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 comprised 'the need for social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and to participate in end-of-life decision making'.

1) Need for social contact

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

Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting time, to come more often, or to take them back home (see appendix table 1). Some patients also wanted to phone home to request visits from relatives (see appendix table 2). Furthermore, patients wanted healthcare professionals to communicate more often with them. However, the rules concerning visits, the infrastructure/

accommodation (e.g. no telephone) and healthcare professionals’ focus on the patients’ disease made it difficult for staff to fully satisfy patients’ need for social contact. Moreover, pressure of work and time made it tough to communicate with patients. Furthermore language differences and misconceptions of healthcare professionals towards patients’ ability to communicate in the language of the host country, sometimes based on patients’ different skin colour, endangered the meeting of patients’ social needs. (see appendix table 3 and 4). Some patients also felt the urge to connect with other patients. This became indirectly apparent when patients stared at other beds and/or asked questions about other patients’ conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made communication between patients impossible. (see appendix table 5)

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 appendix table 6 and 7). Furthermore, nurses regularly did not communicate with patients or only communicated with them in a task-related manner (see appendix table 8).

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 appendix table 9). Also language differences made communication between patients and healthcare professionals about non-medical matters more difficult (see appendix table 10). 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 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 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely perceived language differences. Consequently, comfort and pain was often addressed based on healthcare professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients.

Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals because they were too occupied with medical care tasks (see appendix table 11). Apprehension by healthcare professionals of patients' verbal messages was sometimes hampered by language differences (see appendix table 12). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded inadequately or no communication occurred, in both cases sometimes grounded in healthcare professionals' misconceptions of patients' language proficiency (see appendix table 13 and 14).

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

4) Need to express desperation

Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the hospital, others wanted to completely give up treatment (see appendix table 17).

Patients felt the need to express and share these feelings with others. However, patients regularly felt obliged to suppress their hopelessness during critical care in front of healthcare professionals and relatives, resulting in frustration and sadness.

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

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

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

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

However healthcare professionals regularly acknowledged these patients' communication only minimally, neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central decision makers and wanted to continue treatment, when they believed that patients still had a chance to survive within the context of their specific pathology. Patients were seen as lacking the required expertise to make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or after taking anti-depressants (see appendix table 23). Further, healthcare professionals saw it as their mission to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by some healthcare professionals as a personal failure. (see appendix table 24 and 25)

DISCUSSION

This ethnographic study investigates 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 in a multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups is basically characterized by an 'extreme emotional loneliness'. 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. It concerned the need for social contact, for non-medical information exchange, 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 included patients were identified: firstly healthcare professionals' mainly biomedical approach to care, secondly the ICU context, and thirdly the patients' different ethno-cultural background.

The mental wellbeing of patients from ethnic minority groups in a critical care setting is an under-researched topic. Although a body of research has recently begun to grow that focuses on the lifeworld of patients in a critical care context [see for example:2,3,7,9], still very few of these studies focus on specific vulnerable patient groups, e.g. patients from ethnic minority groups. As far as we know, this is the first study where the mental wellbeing of these patients is investigated in depth by means of an ethnographic research design. A study design of this kind is the most appropriate way to gain nuanced/deep insight into complex themes e.g. mental wellbeing of patients from ethnic minority groups in a critical care setting. Ethnographic day-by-day observations on the ward allow the study of patients' mental wellbeing as it is 'genuinely expressed' and from the perspective of the different people involved, from a non-prejudiced perspective. A weakness 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. There is no specific reason to believe our findings are not valuable for other similar settings.

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

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

Staff, occupied with urgent lifesaving care tasks, were frequently unable to react effectively to patients' verbal and non-verbal communications, often expressed by patients who completely lacked knowledge of the language of the host country. However, adequately decoding ethno-culturally diverse patients' non-verbal communication is crucial for optimal pain management and shared medical decision making.[26,27] Furthermore, pressured healthcare professionals had little time to gain in-depth-knowledge of patients' level of skill in the language of the host society. Therefore the staff easily developed misconceptions of patients' language proficiency based, for example, on their general knowledge of the patient's country of origin or specific phenotypical features, which led to inadequate communication or a complete absence of communication with patients about their needs. Moreover, insufficiently satisfying specific needs which were ethno-culturally inspired led to high emotional loneliness among patients. For example, a failure to meet patients' needs for multiple types of social contact (e.g. proximity of others) strengthened by the collectivistic orientation of their minority cultures, led to high emotional suffering among patients. Moreover, because relatives shared ethno-cultural expectations towards patients to remain stoic and hopeful in difficult times, they did not pay enough attention to patients' specific unique basic needs, i.e. their need to express desperation and participate in end of life decisions, which made patients feel left behind. In line with this finding, previous research has shown that overt communication about pain and sorrow between patients from certain ethnic minority groups and their relatives is limited.[28] Additionally, relatives' high levels of hope triggered healthcare professionals, caring for patients with an uncertain prognosis, to continue life-saving treatments and reinforced their belief in their core responsibility to save patients' lives, while these patients' voices were largely unheard. Likewise, previous research demonstrates that more aggressive interventions occur at the end of the lives of patients from ethnic minority groups.[29] Relatives shared high levels of hope, which were associated with an ethno-cultural non-disclosure of negative information by some relatives towards other relatives, ethno-religious beliefs,[30] migration-related expectations towards an unlimited field of medical possibilities in western hospitals, and group pressure among the many relatives to remain hopeful.

CONCLUSION

This study shows that the mental state of patients from ethnic minority groups during critical care is alarming. These patients had specific basic needs for which they could not sufficiently turn to anybody, leaving them in a state of extreme emotional loneliness. Three interrelated risk factors for the development of mental health problems among these patients were identified: firstly, healthcare professionals' mainly biomedical care approach, secondly the ICU work context and thirdly the patients' different ethno-cultural background.

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) research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical care setting.

Abbreviations

ICU, intensive care unit

Contributors: All authors have met the four authorship criteria as stated in the International Committee of Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals.

Authors' contributions: RVK contributed to the research design, applied for the ethical approval, completed the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of

the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. All the authors read and approved the final manuscript.

Funding: This study was funded by a research grant from the FWO (Fonds Wetenschappelijk Onderzoek-Vlaanderen). The funding organization was not involved in the design of the study, collection, analysis and interpretation of the data and in writing the manuscript.

Ethics: The study (reference 2013/371) was approved by the ethics committee of the university Vrije Universiteit Brussel in December 2013.

Competing interests: The authors declare that they have no competing interests.

Data sharing: Extra data is available by emailing RVK.

REFERENCES

1 Van Keer RL, Deschepper R, Francke AL, et al. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. *Crit Care* 2015;19:441.

2 Lykkegaard K, Delmar C. Between violation and competent care--lived experiences of dependency on care in the ICU. *Int J Qual Stud Health Well-being* 2015;10:26603.

3 Moen EK, Naden D. Intensive care patients' perceptions of how their dignity is maintained: A phenomenological study. *Intensive Crit Care Nurs* 2015;31:285-93.

4 Sharma BG, Evs M, Ms K, et al. Psychological evaluation of patients in critical care/intensive care unit and patients admitted in wards. *J Clin Diagn Res* 2014;8:WC01-WC03.

5 Price AM. Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care* 2004;9:134-42.

6 Van Keer RL. Intensive Suffering. *Intensive Care Med* 2016;42:277.

7 Alasad JA, Abu Tabar N, Ahmad MM. Patients' experience of being in intensive care units. *J Crit Care* 2015;30:859.e7–e11.

8 Karlsson V. Being conscious during mechanical ventilator treatment-patients' and relatives' experiences in the intensive care units. Ghotenburg, Ghotenburg University 2012.

9 Stayt LC, Seers K, Tutton E. Patients' experiences of technology and care in adult intensive care. *J Adv Nurs* 2015;71:2051-61.

10 Leman J. The dynamics of emerging ethnicities. Immigrant and indigenous ethnogenesis in confrontation. Frankfurt, Peter Lang International Academic Publishers 2000.

11 Garrett PW, Dickson HG, Whelan AK, et al. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethn Health* 2008;13:479-96.

12 Zeilani R, Seymour JE. Muslim women's narratives about bodily change and care during critical illness: a qualitative study. *J Nurs Scholarsh* 2012;44:99-107.

13 Garrett PW, Dickson HG, Young L, et al. "The Happy Migrant Effect": perceptions of negative experiences of healthcare by patients with little or no English: a qualitative study across seven language groups. *Qual Saf Health Care* 2008;17:101-03.

14 Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain* 2009;10:1187-204.

15 Urden L, Stacy K, Lough M. Critical care nursing: diagnosis and management: 7th ed. St.Louis, Mosby-Elsevier 2014.

16 Wind G. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropol Med* 2008;15:79-89.

17 Esterberg KG. Qualitative methods in social research. Boston, The McGraw-Hill Companies 2002.

18 Sinuff T, Cook DJ, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *J Crit Care* 2007;22:104-111.

19 Hertogen J. Non-profit data. 2014. http://www.npdata.be/BuG/155-Vreemde-afkomst/. Accessed 04 Jan 2016.

20 Geertz C. The Interpretation of Cultures. New York, Basic Books 1973.

21 Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park CA, Sage 1990.

22 Hennink M, Hutter I, Bailey A. Qualitative research methods. London, Sage Publications 2011.

23 Creswell JW. Qualitative inquiry & research design. Choosing among five approaches. Lincoln, Sage Publications 2013.

24 Zeilani R, Seymour JE. Muslim women's experiences of suffering in Jordanian intensive care units: a narrative study. *Intensive Crit Care Nurs* 2010;26:175-184.

25 Alonso Y. The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Educ Couns* 2004;53:239-44.

26 Riess H, Kraft-Todd G. E.M.P.A.T.H.Y.: a tool to enhance nonverbal communication between clinicians and their patients. *Acad Med* 2014;89:1108-12.

27 Davidhizar R, Giger JN. A review of the literature on care of clients in pain who are culturally diverse. *Int Nurs Rev* 2004;51:47-55.

28 de Graaff FM, Mistiaen P, Devillé WL, et al. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliat Care* 2012;11:17.

29 Hanchate A, Kronman AC, Young-Xu Y, et al. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Arch Intern Med* 2009;169:493-501.

30 de Graaff FM, Francke AL, Van den Muijsenbergh ME, et al. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care* 2010;9:19.

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.

Researcher: And what do you think about that?

Patient: Leave the hospital.

[Field note, Norah]

Table 5

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 …*

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]

Table 6

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]

Table 7

I try to talk about his medical situation with him (patient) a bit and say: ‘Y*our 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 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]

Table 14

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

[Field note, Zacharia]

Table 15

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]

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…

[Field note, Norah]

Table 18

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: ‘D*on’t understand.’*

[Field note, Norah]

Table 19

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]

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* *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.

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-014075.R1
Article Type:	Research
Date Submitted by the Author:	18-May-2017
Complete List of Authors:	Van Keer , RL; Vrije Universiteit Brussel, Public Health Deschepper, Reginald; Vrije Universiteit Brussel, Public Health Huyghens, Luc; Universitair Ziekenhuis Brussel, Critical Care Bilsen, Johan; Vrije Universiteit Brussel, Public Health
Primary Subject Heading:	Intensive care
Secondary Subject Heading:	Mental health, Communication
Keywords:	MENTAL HEALTH, INTENSIVE & CRITICAL CARE, communication

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

Rose-Lima Van Keer[1], Reginald Deschepper [2], Luc Huyghens[3], Johan Bilsen[4]

(1) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of
Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rvkeer@vub.ac.be

(2) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of
Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rdeschep@vub.ac.be

(3) Critical care Department/Service of Intensive Care Medicine, Vrije Universiteit Brussel;
Universitair Ziekenhuis Brussel
Laarbeeklaan 101 1090 Brussel
Brussels, Belgium
e-mail: Luc.Huyghens@uzbrussel.be

(4) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty
of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: johan.bilsen@vub.ac.be

Correspondence to: R. Van Keer rvkeer@vub.ac.be or +32 2 4774608

Word count: 3560 words

Key words: intensive care units, patients, cultural diversity, communication, mental health

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 incpatientease 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

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

In this study we therefore aim 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 in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among patients from ethnic minority groups can contribute to the development of recommendations to prevent such problems for these patients.

METHODS

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

[22-24]

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' characteristics: see table)

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 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward. Therefore ‘negotiated interactive observation’ was chosen, meaning that before starting the observations the researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare professionals, relatives, and patients during visiting hours.

When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she transformed these notes into comprehensive descriptive field notes containing observations of participants’ discourse, behaviour, and interaction, informal conversations with them as well as researcher’s reflections on her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare professionals in two meeting rooms in the hospital. The 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. The interviews lasted between 50 minutes and 1h30 and were audio recorded. Interview transcripts were not returned to the research participants for comments or corrections. All data were collected by the first author (RVK), a trained ethnographer and sociologist (MSc) who was doing academic scientific research at university at the time of the study. She is extensively trained in qualitative research.

Data analysis

The analysis started with a ‘thick description’ [25] of participants’ discourse, behaviour, and interaction and was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly, an open coding phase was performed, involving the reading and rereading of the data. This resulted in the formation of different codes, for instance ‘physical contact’, ‘proximity’, and ‘fighting’. To find similarities and differences between these codes, new codes were constantly compared with already existing codes. Secondly, axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category ('emotional loneliness') around which the related categories are clustered.[26,27]

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

Ethics

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

RESULTS

The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among patients. Patients had several 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 comprised 'the need for social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and to participate in end-of-life decision making'.

1) Need for social contact

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

Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting time, to come more often, or to take them back home (see appendix table 1a). Some patients also wanted to phone home to request visits from relatives (see appendix table 1b). Furthermore, patients wanted healthcare professionals to communicate more often with them (see appendix table 1c). However, the rules concerning visits, the infrastructure/ accommodation (e.g. no telephone) and healthcare professionals' focus on the patients' disease made it difficult for staff to fully satisfy patients' need for social contact. Moreover, pressure of work and time made it tough to communicate with patients. Furthermore language differences and misconceptions of healthcare professionals towards patients' ability to communicate in the language of the host country, sometimes based on patients' different skin colour, endangered the meeting of patients' social needs. (see appendix table 1d). Some patients also felt the urge to connect with other patients. This became indirectly apparent when patients stared at other beds and/or asked questions about other patients' conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made communication between patients impossible. (see appendix table 1e)

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 appendix table 2a and 2b). Furthermore, nurses regularly did not communicate with patients or only communicated with them in a task-related manner (see appendix table 2c).

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 appendix table 2d). Also language differences made communication between patients and healthcare professionals about non-medical matters more difficult (see appendix table 2e). 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 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely perceived language differences. Consequently, comfort and pain was often addressed based on healthcare professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and irritation and insecurity occurred on both sides (see appendix table 3a).

Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients' verbal messages was sometimes hampered by language differences (see appendix table 3b). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded inadequately or no communication occurred. This was sometimes related to healthcare professionals' misconceptions of patients' language proficiency, based on the very quick and minimal moments of interaction they had with patients and relatives and patients' different skin colour. Also staff's general knowledge of patients' country of origin which they sometimes easily applied to all patients from that country contributed to these misconceptions (see appendix table 3c).

On the other hand, some patients who were at moments totally unable to communicate as a result of medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless (see appendix table 3d). When patients experienced discomfort for a longer time some of them did not want to ask healthcare professionals for help anymore and wanted to leave the ICU (see appendix table 3e).

4) Need to express desperation

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

Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for patients to express their negative feelings. And even when patients did express their hopelessness, healthcare professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless, tranquilizers/antidepressants were given (see appendix table 4b).

Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients (see appendix table 4c). Relatives' religious beliefs and high expectations for cure in western hospitals functioned as sources of hope. Furthermore, negative information was hidden for some family members by other relatives so as to not create unrest within their large transnational families, which affected relatives' positive outlook on the patients' situation (see appendix table 4d). Additionally, families' considerable size led to group pressure among its members to remain hopeful. Moreover, patients themselves presented their situation in a more positive manner towards visiting relatives coming from the home country so as to not worry their relatives there (see appendix table 4e).

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

Enduring physical and mental suffering triggered a need for some patients to participate in a decision to withdraw therapy. This need was verbally and non-verbally expressed at several points (see appendix table 5a).

However healthcare professionals regularly acknowledged these patients' communication only minimally, neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central decision makers and wanted to continue treatment, when they believed that patients still had a chance to survive within the context of their specific pathology. Patients were seen as lacking the required expertise to make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or after taking anti-depressants (see appendix table 5b). Further, healthcare professionals saw it as their mission to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by some healthcare professionals as a personal failure. (see appendix table 5c)

DISCUSSION

Health has

This ethnographic study investigates 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 in a multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups is basically characterized by an ‘extreme emotional loneliness’. 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. It concerned the need for social contact, for non-medical information exchange, 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 included patients were identified: firstly healthcare professionals’ mainly biomedical approach to care, secondly the ICU context, and thirdly the patients’ different ethno-cultural background.

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

The researcher might have had an impact on the field and the research findings as she herself has a non-Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic feature of qualitative ethnographic research [23]. A weakness 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. There is no specific reason to believe our findings are not valuable for other similar settings. Another weakness of this study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't allow other techniques, such as video recording and full participant observation, for ethical reasons.

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

Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems, caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine, although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks, making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the other hand, taking into account patients' emotions becomes even more complex and challenging when patients have a different ethno-cultural background. The included patients' different ethno-cultural backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care and suffering , communication forms and families' history of migration), and the level of patient-staff interaction (e.g. phenotypical features, language).

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

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

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) research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical care setting.

CONCLUSION

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

Abbreviations

ICU, intensive care unit

Contributors: All authors have met the four authorship criteria as stated in the International Committee of Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals.

Authors' contributions: RVK contributed to the research design, applied for the ethical approval, completed the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. All the authors read and approved the final manuscript.

Funding: This study was funded by a research grant from the FWO (Fonds Wetenschappelijk Onderzoek-Vlaanderen). The funding organization was not involved in the design of the study, collection, analysis and interpretation of the data and in writing the manuscript.

Ethics: The study (reference 2013/371) was approved by the ethics committee of the university Vrije Universiteit Brussel in December 2013.

Competing interests: The authors declare that they have no competing interests.

Data sharing: Extra data is available by emailing RVK.

REFERENCES

1 Mental health: strengthening our response. *Geneva: World Health Organisation* 2016. http://www.who.int/mediacentre/factsheets/fs220/en/.

2 Fassaert T, de Wit MAS, Tuinebreijer WC, et al. Acculturation and psychological distress among non western Muslim migrants-A population-based survey. *Int J Soc Psychiatry* 2011;57:132-143.

3 Van Keer RL, Deschepper R, Francke AL, et al. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. *Crit Care* 2015;19:441.

4 Lykkegaard K, Delmar C. Between violation and competent care--lived experiences of dependency on care in the ICU. *Int J Qual Stud Health Well-being* 2015;10:26603.

5 Moen EK, Naden D. Intensive care patients' perceptions of how their dignity is maintained: A phenomenological study. *Intensive Crit Care Nurs* 2015;31:285-93.

6 Sharma BG, Evs M, Ms K, et al. Psychological evaluation of patients in critical care/intensive care unit and patients admitted in wards. *J Clin Diagn Res* 2014;8:WC01-WC03.

7 Price AM. Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care* 2004;9:134-42.

8 Van Keer RL. Intensive Suffering. *Intensive Care Med* 2016;42:277.

9 Alasad JA, Abu Tabar N, Ahmad MM. Patients' experience of being in intensive care units. *J Crit Care* 2015;30:859.e7–e11.

10 Karlsson V. Being conscious during mechanical ventilator treatment-patients' and relatives' experiences in the intensive care units. Ghotenburg, Ghotenburg University 2012.

11 Griffin J. Forced dependency in the critically ill. *Dimens Crit Care Nurs* 1983;1:350-52.

12 Stayt LC, Seers K, Tutton E. Patients' experiences of technology and care in adult intensive care. *J Adv Nurs* 2015;71:2051-61.

13 Leman J. The dynamics of emerging ethnicities. Immigrant and indigenous ethnogenesis in confrontation. Frankfurt, Peter Lang International Academic Publishers 2000.

14 Derluyn I, Lorant V, Dauvrin M, Coune I, Verrept H. “Naar een interculturele gezondheidszorg: Aanbevelingen van de ETHEALTH-groep voor een gelijkwaardige gezondheid en gezondheidszorg voor migranten en etnische minderheden.” 2011 https://dial.uclouvain.be/pr/boreal/object/boreal:100991.

15 Garrett PW, Dickson HG, Whelan AK, et al. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethn Health* 2008;13:479-96.

16 Zeilani R, Seymour JE. Muslim women's narratives about bodily change and care during critical illness: a qualitative study. *J Nurs Scholarsh* 2012;44:99-107.

17 Cleveland LM. A Mexican American mother’s experience in the neonatal intensive care unit. *J Perinat Neonatal Nurs* 2009;23:178-85.

18 Lee SY, Weiss SJ. When East meets West: intensive care unit experiences among first-generation Chinese American parents. *J Nurs Scholarsh* 2009;41:268-75.

19 Garrett PW, Dickson HG, Young L, et al. "The Happy Migrant Effect": perceptions of negative experiences of healthcare by patients with little or no English: a qualitative study across seven language groups. *Qual Saf Health Care* 2008;17:101-03.

20 Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain* 2009;10:1187-204.

21 Urden L, Stacy K, Lough M. Critical care nursing: diagnosis and management: 7th ed. St.Louis, Mosby-Elsevier 2014.

22 Wind G. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropol Med* 2008;15:79-89.

23 Esterberg KG. Qualitative methods in social research. Boston, The McGraw-Hill Companies 2002.

24 Sinuff T, Cook DJ, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *J Crit Care* 2007;22:104-111.

25 Geertz C. The Interpretation of Cultures. New York, Basic Books 1973.

26 Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park CA, Sage 1990.

27 Hennink M, Hutter I, Bailey A. Qualitative research methods. London, Sage Publications 2011.

28 Creswell JW. Qualitative inquiry & research design. Choosing among five approaches. Lincoln, Sage Publications 2013.

29 de Graaff FM, Francke AL, Van den Muijsenbergh ME, et al. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care* 2010;9:19.

30 Zeilani R, Seymour JE. Muslim women's experiences of suffering in Jordanian intensive care units: a narrative study. *Intensive Crit Care Nurs* 2010;26:175-184.

31 Alonso Y. The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Educ Couns* 2004;53:239-44.

32 Riess H, Kraft-Todd G. E.M.P.A.T.H.Y.: a tool to enhance nonverbal communication between clinicians and their patients. *Acad Med* 2014;89:1108-12.

33 Davidhizar R, Giger JN. A review of the literature on care of clients in pain who are culturally diverse. *Int Nurs Rev* 2004;51:47-55.

34 de Graaff FM, Mistiaen P, Devillé WL, et al. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliat Care* 2012;11:17.

35 Hanchate A, Kronman AC, Young-Xu Y, et al. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Arch Intern Med* 2009;169:493-501.

APPENDIX

(Note: all the names are pseudonyms)

TABLE 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?

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 …*

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]

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: 'Y*our 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: ‘N*ow 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.

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 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: 'D*on'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. (..)

[..]

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]

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? *E.g. PhD, MD*	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? e.*g. personal goals, reasons for doing the research*	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. *Bias, assumptions, reasons and interests in the research topic*	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	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. *home, clinic, workplace*	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. demographic data, date*	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. participant number*	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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-014075.R2
Article Type:	Research
Date Submitted by the Author:	11-Jul-2017
Complete List of Authors:	Van Keer , RL; Vrije Universiteit Brussel, Public Health Deschepper, Reginald; Vrije Universiteit Brussel, Public Health Huyghens, Luc; Universitair Ziekenhuis Brussel, Critical Care Bilsen, Johan; Vrije Universiteit Brussel, Public Health
Primary Subject Heading:	Intensive care
Secondary Subject Heading:	Mental health, Communication
Keywords:	MENTAL HEALTH, INTENSIVE & CRITICAL CARE, communication

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

Rose-Lima Van Keer[1], Reginald Deschepper [2], Luc Huyghens[3], Johan Bilsen[4]

(1) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rvkeer@vub.ac.be

(2) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rdeschep@vub.ac.be

(3) Critical care Department/Service of Intensive Care Medicine, Vrije Universiteit Brussel; Universitair Ziekenhuis Brussel
Laarbeeklaan 101 1090 Brussel
Brussels, Belgium
e-mail: Luc.Huyghens@uzbrussel.be

(4) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: johan.bilsen@vub.ac.be

Correspondence to: R. Van Keer rvkeer@vub.ac.be or +32 2 4774608

Key words: intensive care units, patients, cultural diversity, communication, mental health

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

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

In this study we therefore aim 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 in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among patients from ethnic minority groups can contribute to the development of recommendations to prevent such problems for these patients.

METHODS

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

[22-24]

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)

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 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward. Therefore 'negotiated interactive observation' was chosen, meaning that before starting the observations the researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare professionals, relatives, and patients during visiting hours.

When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she transformed these notes into comprehensive descriptive field notes containing observations of participants' discourse, behaviour, and interaction, informal conversations with them as well as researcher's reflections on her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare professionals in two meeting rooms in the hospital. The 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 (Topic list in-depth interviews: see supplementary file). The interviews lasted between 50 minutes and 1h30 and were audio recorded. Interview transcripts were not returned to the research participants for comments or corrections. All data were collected by the first author (RVK), a trained ethnographer and sociologist (MSc) who was doing academic scientific research at university at the time of the study. She is extensively trained in qualitative research.

Data analysis

The analysis started with a 'thick description' [25] of participants' discourse, behaviour, and interaction and was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly, an open coding phase was performed, involving the reading and rereading of the data. This resulted in the formation of different codes, for instance 'physical contact', 'proximity', and 'fighting'. To find similarities and differences between these codes, new codes were constantly compared with already existing codes. Secondly, axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example 'social contact' and 'saving patient'. Relationships between the categories were also established, for instance 'basic needs' and 'care strategies'. Thirdly, selective coding was performed to determine the core category ('emotional loneliness') around which the related categories are clustered.[26,27]

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

Ethics

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

RESULTS

The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among patients. Patients had several 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 comprised 'the need for social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and to participate in end-of-life decision making'.

1) Need for social contact

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

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

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 (supplementary file 2a and 2b). Furthermore, nurses regularly did not communicate with patients or only communicated with them in a task-related manner (supplementary file 2c).

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 (supplementary file 2d). Also language differences made communication between patients and healthcare professionals about non-medical matters more difficult (supplementary file 2e). 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 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely perceived language differences. Consequently, comfort and pain was often addressed based on healthcare professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and irritation and insecurity occurred on both sides (supplementary file 3a).

Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients' verbal messages was sometimes hampered by language differences (supplementary file 3b). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded inadequately or no communication occurred. This was sometimes related to healthcare professionals' misconceptions of patients' language proficiency, based on the very quick and minimal moments of interaction they had with patients and relatives and patients' different skin colour. Also staff's general knowledge of patients' country of origin which they sometimes easily applied to all patients from that country contributed to these misconceptions (supplementary file 3c).

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

4) Need to express desperation

Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the hospital, others wanted to completely give up treatment (supplementary file 4a). Patients felt the need to express and share these feelings with others. However, patients regularly felt obliged to suppress their hopelessness during critical care in front of healthcare professionals and relatives, resulting in frustration and sadness.

Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for patients to express their negative feelings. And even when patients did express their hopelessness, healthcare professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless, tranquilizers/antidepressants were given (supplementary file 4b).

Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients (supplementary file 4c). Relatives' religious beliefs and high expectations for cure in western hospitals functioned as sources of hope. Furthermore, negative information was hidden for some family members by other relatives so as to not create unrest within their large transnational families, which affected relatives' positive outlook on the patients' situation (supplementary file 4d). Additionally, families' considerable size led to group pressure among its members to remain hopeful. Moreover, patients themselves presented their situation in a more positive manner towards visiting relatives coming from the home country so as to not worry their relatives there (supplementary file 4e).

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

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

However healthcare professionals regularly acknowledged these patients' communication only minimally, neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central decision makers and wanted to continue treatment, when they believed that patients still had a chance to survive within the context of their specific pathology. Patients were seen as lacking the required expertise to make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or after taking anti-depressants (supplementary file 5b). Further, healthcare professionals saw it as their mission to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by some healthcare professionals as a personal failure. (supplementary file 5c)

DISCUSSION

This ethnographic study investigates 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 in a multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups is basically characterized by an ‘extreme emotional loneliness’. 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. It concerned the need for social contact, for non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in end-of-life decision making. Insufficiently meeting patients’ basic needs endangered patients’ mental wellbeing as defined by the WHO, e.g. in the sense that they couldn’t cope adequately with stress and didn’t feel to contribute to their family/community anymore. Three interrelated risk factors for the development of mental health problems among the included patients were identified: firstly healthcare professionals’ mainly biomedical approach to care, secondly the ICU context, and thirdly the patients’ different ethno-cultural background.

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

The researcher might have had an impact on the field and the research findings as she herself has a non-Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic feature of qualitative ethnographic research [23]. A weakness 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. There is no specific reason to believe our findings are not valuable for other similar settings. Another weakness of this study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't allow other techniques, such as video recording and full participant observation, for ethical reasons.

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

Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems, caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine, although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks, making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the other hand, taking into account patients' emotions becomes even more complex and challenging when patients have a different ethno-cultural background. The included patients' different ethno-cultural backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care and suffering , communication forms and families' history of migration), and the level of patient-staff interaction (e.g. phenotypical features, language).

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

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

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) research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical care setting.

CONCLUSION

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

Abbreviations

ICU, intensive care unit

Contributors: All authors have met the four authorship criteria as stated in the International Committee of Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals.

Authors' contributions: RVK contributed to the research design, applied for the ethical approval, completed the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. All the authors read and approved the final manuscript.

Funding: This study was funded by a research grant from the FWO (Fonds Wetenschappelijk Onderzoek-Vlaanderen). The funding organization was not involved in the design of the study, collection, analysis and interpretation of the data and in writing the manuscript.

Ethics: The study (reference 2013/371) was approved by the ethics committee of the university Vrije Universiteit Brussel in December 2013.

Competing interests: The authors declare that they have no competing interests.

Data sharing: Extra data is available by emailing RVK.

REFERENCES

1 Mental health: strengthening our response. *Geneva: World Health Organisation* 2016. http://www.who.int/mediacentre/factsheets/fs220/en/.

2 Fassaert T, de Wit MAS, Tuinebreijer WC, et al. Acculturation and psychological distress among non western Muslim migrants-A population-based survey. *Int J Soc Psychiatry* 2011;57:132-143.

3 Van Keer RL, Deschepper R, Francke AL, et al. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. *Crit Care* 2015;19:441.

4 Lykkegaard K, Delmar C. Between violation and competent care--lived experiences of dependency on care in the ICU. *Int J Qual Stud Health Well-being* 2015;10:26603.

5 Moen EK, Naden D. Intensive care patients' perceptions of how their dignity is maintained: A phenomenological study. *Intensive Crit Care Nurs* 2015;31:285-93.

6 Sharma BG, Evs M, Ms K, et al. Psychological evaluation of patients in critical care/intensive care unit and patients admitted in wards. *J Clin Diagn Res* 2014;8:WC01-WC03.

7 Price AM. Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care* 2004;9:134-42.

8 Van Keer RL. Intensive Suffering. *Intensive Care Med* 2016;42:277.

9 Alasad JA, Abu Tabar N, Ahmad MM. Patients' experience of being in intensive care units. *J Crit Care* 2015;30:859.e7–e11.

10 Karlsson V. Being conscious during mechanical ventilator treatment-patients' and relatives' experiences in the intensive care units. Ghotenburg, Ghotenburg University 2012.

11 Griffin J. Forced dependency in the critically ill. *Dimens Crit Care Nurs* 1983;1:350-52.

12 Stayt LC, Seers K, Tutton E. Patients' experiences of technology and care in adult intensive care. *J Adv Nurs* 2015;71:2051-61.

13 Leman J. The dynamics of emerging ethnicities. Immigrant and indigenous ethnogenesis in confrontation. Frankfurt, Peter Lang International Academic Publishers 2000.

14 Derluyn I, Lorant V, Dauvrin M, Coune I, Verrept H. “Naar een interculturele gezondheidszorg: Aanbevelingen van de ETHEALTH-groep voor een gelijkwaardige gezondheid en gezondheidszorg voor migranten en etnische minderheden.” 2011 https://dial.uclouvain.be/pr/boreal/object/boreal:100991.

15 Garrett PW, Dickson HG, Whelan AK, et al. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethn Health* 2008;13:479-96.

16 Zeilani R, Seymour JE. Muslim women's narratives about bodily change and care during critical illness: a qualitative study. *J Nurs Scholarsh* 2012;44:99-107.

17 Cleveland LM. A Mexican American mother’s experience in the neonatal intensive care unit. *J Perinat Neonatal Nurs* 2009;23:178-85.

18 Lee SY, Weiss SJ. When East meets West: intensive care unit experiences among first-generation Chinese American parents. *J Nurs Scholarsh* 2009;41:268-75.

19 Garrett PW, Dickson HG, Young L, et al. "The Happy Migrant Effect": perceptions of negative experiences of healthcare by patients with little or no English: a qualitative study across seven language groups. *Qual Saf Health Care* 2008;17:101-03.

20 Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain* 2009;10:1187-204.

21 Urden L, Stacy K, Lough M. Critical care nursing: diagnosis and management: 7th ed. St.Louis, Mosby-Elsevier 2014.

22 Wind G. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropol Med* 2008;15:79-89.

23 Esterberg KG. Qualitative methods in social research. Boston, The McGraw-Hill Companies 2002.

24 Sinuff T, Cook DJ, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *J Crit Care* 2007;22:104-111.

25 Geertz C. The Interpretation of Cultures. New York, Basic Books 1973.

26 Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park CA, Sage 1990.

27 Hennink M, Hutter I, Bailey A. Qualitative research methods. London, Sage Publications 2011.

28 Creswell JW. Qualitative inquiry & research design. Choosing among five approaches. Lincoln, Sage Publications 2013.

29 de Graaff FM, Francke AL, Van den Muijsenbergh ME, et al. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care* 2010;9:19.

30 Zeilani R, Seymour JE. Muslim women's experiences of suffering in Jordanian intensive care units: a narrative study. *Intensive Crit Care Nurs* 2010;26:175-184.

31 Alonso Y. The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Educ Couns* 2004;53:239-44.

32 Riess H, Kraft-Todd G. E.M.P.A.T.H.Y.: a tool to enhance nonverbal communication between clinicians and their patients. *Acad Med* 2014;89:1108-12.

33 Davidhizar R, Giger JN. A review of the literature on care of clients in pain who are culturally diverse. *Int Nurs Rev* 2004;51:47-55.

34 de Graaff FM, Mistiaen P, Devillé WL, et al. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliat Care* 2012;11:17.

35 Hanchate A, Kronman AC, Young-Xu Y, et al. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Arch Intern Med* 2009;169:493-501.

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

(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?

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 …*

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: 'Y*our 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]

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: 'N*ow 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.

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]

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: 'D*on'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. (..)

[..]

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? *E.g. PhD, MD*	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? e.*g. personal goals, reasons for doing the research*	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. *Bias, assumptions, reasons and interests in the research topic*	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	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. home, clinic, workplace*	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. demographic data, date*	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. participant number*	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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2016-014075.R3
Article Type:	Research
Date Submitted by the Author:	03-Aug-2017
Complete List of Authors:	Van Keer , RL; Vrije Universiteit Brussel, Public Health Deschepper, Reginald; Vrije Universiteit Brussel, Public Health Huyghens, Luc; Universitair Ziekenhuis Brussel, Critical Care Bilsen, Johan; Vrije Universiteit Brussel, Public Health
Primary Subject Heading:	Intensive care
Secondary Subject Heading:	Mental health, Communication
Keywords:	MENTAL HEALTH, INTENSIVE & CRITICAL CARE, communication

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

Rose-Lima Van Keer[1], Reginald Deschepper [2], Luc Huyghens[3], Johan Bilsen[4]

(1) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rvkeer@vub.ac.be

(2) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: rdeschep@vub.ac.be

(3) Critical care Department/Service of Intensive Care Medicine, Vrije Universiteit Brussel; Universitair Ziekenhuis Brussel
Laarbeeklaan 101 1090 Brussel
Brussels, Belgium
e-mail: Luc.Huyghens@uzbrussel.be

(4) Mental Health and Wellbeing Research Group (MENT), Department of Public Health, Faculty of Medicine and Pharmacy,Vrije Universiteit Brussel
Laarbeeklaan 103 1090 Brussel
Brussels, Belgium
e-mail: johan.bilsen@vub.ac.be

Correspondence to: R. Van Keer rvkeer@vub.ac.be or +32 2 4774608

Key words: intensive care units, patients, cultural diversity, communication, mental health

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

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

In this study we therefore aim 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 in a multi-ethnic ICU'. In-depth understanding of occurrences of mental health problems among patients from ethnic minority groups can contribute to the development of recommendations to prevent such problems for these patients.

METHODS

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

[22-24]

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 records. In an ICU setting, typified among other things by time pressure and highly specialized lifesaving care tasks, it is very difficult for the researcher to fully participate in the core activities of social life on the ward. Therefore ‘negotiated interactive observation’ was chosen, meaning that before starting the observations the researcher always implicitly or explicitly asked permission for it to the research participants [22]. This technique enabled the researcher to gain the trust of the research participants easily. Negotiated interactive observation gave the researcher the opportunity to have 480 informal conversations with healthcare professionals, family members, and patients, attend 144 staff meetings, and witness 375 interactions between healthcare professionals, relatives, and patients during visiting hours.

When the researcher was in the ICU she made notes in a logbook. After the researcher had left the ICU, she transformed these notes into comprehensive descriptive field notes containing observations of participants’ discourse, behaviour, and interaction, informal conversations with them as well as researcher’s reflections on her behaviour and feelings in the field.[23] Formal in-depth- interviews were held with nine healthcare professionals in two meeting rooms in the hospital. The 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 (see supplementary file ‘Topic list interviews’). The interviews lasted between 50 minutes and 1h30 and were audio recorded. Interview transcripts were not returned to the research participants for comments or corrections. All data were collected by the first author (RVK), a trained ethnographer and sociologist (MSc) who was doing academic scientific research at university at the time of the study. She is extensively trained in qualitative research.

Data analysis

The analysis started with a ‘thick description’ [25] of participants’ discourse, behaviour, and interaction and was followed by a grounded theory analysis.[26] In depth-interviews were transcribed, and data were conceptualized by means of a three-step coding process, supported by NVIVO 8 (QSR International, 2008). This process resulted in the creation of a conceptual model, consisting of different themes and subthemes. Firstly, an open coding phase was performed, involving the reading and rereading of the data. This resulted in the formation of different codes, for instance ‘physical contact’, ‘proximity’, and ‘fighting’. To find similarities and differences between these codes, new codes were constantly compared with already existing codes. Secondly, axial coding took place. This led to the formation of groupings of similar codes, i.e. categories, for example ‘social contact’ and ‘saving patient’. Relationships between the categories were also established, for instance ‘basic needs’ and ‘care strategies’. Thirdly, selective coding was performed to determine the core category (‘emotional loneliness’) around which the related categories are clustered.[26,27]

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

Ethics

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

RESULTS

The patients included were admitted for complicated pneumonia (3), abdominal problems (1), heart problems (2), brain haemorrhage (2), cancer (1), and trauma (1). Mental health problems came overtly to the fore among patients. Patients had several 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 comprised ‘the need for social contact, non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and to participate in end-of-life decision making’.

1) Need for social contact

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

Patients wanted their relatives and friends to be close to them, felt the need to touch and/or kiss them and talk or write to them. Therefore, patients wanted their loved ones to stay longer than accepted during visiting time, to come more often, or to take them back home (see table 1a in supplementary file ‘Quotes’). Some patients also wanted to phone home to request visits from relatives (see table 1b in supplementary file ‘Quotes’). Furthermore, patients wanted healthcare professionals to communicate more often with them (see table 1c in supplementary file ‘Quotes’). However, the rules concerning visits, the infrastructure/ accommodation (e.g. no telephone) and healthcare professionals’ focus on the patients’ disease made it difficult for staff to fully satisfy patients’ need for social contact. Moreover, pressure of work and time made it tough to communicate with patients. Furthermore language differences and misconceptions of healthcare professionals towards patients’ ability to communicate in the language of the host country, sometimes based on patients’ different skin colour, endangered the meeting of patients’ social needs. (see table 1d in supplementary file ‘Quotes’). Some patients also felt the urge to connect with other patients. This became indirectly apparent when patients stared at other beds and/or asked questions about other patients’ conditions. Nonetheless, infrastructural constraints (e.g. remote beds) and language differences made communication between patients impossible. (see table 1e in supplementary file ‘Quotes’)

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 healthcare professionals' workload, time pressure, their focus on strictly medical care task and actual/falsely perceived language differences. Consequently, comfort and pain was often addressed based on healthcare professionals' unilateral assessment, sometimes leading to mistrust between themselves and patients and irritation and insecurity occurred on both sides (see table 3a in supplementary file 'Quotes').

Patients' non-verbal care requests were sometimes not seen or neglected by healthcare professionals because they were too occupied with medical care tasks. Apprehension by healthcare professionals of patients' verbal messages was sometimes hampered by language differences (see table 3b in supplementary file 'Quotes'). Moreover, when patients' non-verbal expressions of suffering were noticed, communication with patients sometimes unfolded inadequately or no communication occurred. This was sometimes related to healthcare professionals' misconceptions of patients' language proficiency, based on the very quick and minimal moments of interaction they had with patients and relatives and patients' different skin colour. Also staff's general knowledge of patients' country of origin which they sometimes easily applied to all patients from that country contributed to these misconceptions (see table 3c in supplementary file 'Quotes').

On the other hand, some patients who were at moments totally unable to communicate as a result of medical and linguistic barriers were automatically perceived as quiet patients who were comfortable/painless (see table 3d in supplementary file 'Quotes'). When patients experienced discomfort for a longer time some of them did not want to ask healthcare professionals for help anymore and wanted to leave the ICU (see table 3e in supplementary file 'Quotes').

4) Need to express desperation

Among some patients, feelings of desperation were observed at times. Some of them wanted to leave the hospital, others wanted to completely give up treatment (see table 4a in supplementary file 'Quotes'). Patients felt the need to express and share these feelings with others. However, patients regularly felt obliged to suppress their hopelessness during critical care in front of healthcare professionals and relatives, resulting in frustration and sadness.

Healthcare professionals did not stimulate expressions of desperation. They frequently presented patients with their situation in a hopeful manner and tried to motivate them to not give up, leaving little space for patients to express their negative feelings. And even when patients did express their hopelessness, healthcare professionals often did not respond. Moreover, when patients became very overtly anxious/hopeless, tranquilizers/antidepressants were given (see table 4b in supplementary file 'Quotes').

Additionally, family members remained hopeful and consequently also spoke in a hopeful tone to patients (see table 4c in supplementary file 'Quotes'). Relatives' religious beliefs and high expectations for cure in western hospitals functioned as sources of hope. Furthermore, negative information was hidden for some family members by other relatives so as to not create unrest within their large transnational families, which affected relatives' positive outlook on the patients' situation (see table 4d in supplementary file 'Quotes'). Additionally, families' considerable size led to group pressure among its members to remain hopeful. Moreover, patients themselves presented their situation in a more positive manner towards visiting relatives coming from the home country so as to not worry their relatives there (see table 4e in supplementary file 'Quotes').

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

Enduring physical and mental suffering triggered a need for some patients to participate in a decision to withdraw therapy. This need was verbally and non-verbally expressed at several points (see table 5a in supplementary file 'Quotes'').

However healthcare professionals regularly acknowledged these patients' communication only minimally, neglected it, forgot it or tried to change patients' opinions. Doctors mostly saw themselves as the central decision makers and wanted to continue treatment, when they believed that patients still had a chance to survive within the context of their specific pathology. Patients were seen as lacking the required expertise to make a decision to withdraw therapy. Furthermore, their wishes were perceived as irrational/fluctuating, as they could change after a hopeful conversation with a healthcare professional, after appropriate treatment or after taking anti-depressants (see table 5b in supplementary file 'Quotes'). Further, healthcare professionals saw it as their mission to save patients' lives, which was reinforced by their daily contact with many hopeful relatives of the patient who saw God as the ultimate decision maker. Consequently, not being able to save the patient was seen by some healthcare professionals as a personal failure. (see table 5c in supplementary file 'Quotes')

DISCUSSION

This ethnographic study investigates 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 in a multi-ethnic ICU in Belgium. We found that the mental state of critically ill patients from ethnic minority groups is basically characterized by an 'extreme emotional loneliness'. 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. It concerned the need for social contact, for non-medical information exchange, the need to increase comfort and alleviate pain, the need to express desperation, and participate in end-of-life decision making. Insufficiently meeting patients' basic needs endangered patients' mental wellbeing as defined by the WHO, e.g. in the sense that they couldn't cope adequately with stress and didn't feel to contribute to their family/community anymore. Three interrelated risk factors for the development of mental health problems among the included patients were identified: firstly healthcare professionals' mainly biomedical approach to care, secondly the ICU context, and thirdly the patients' different ethno-cultural background.

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

The researcher might have had an impact on the field and the research findings as she herself has a non-Belgian ethnic background and collected data for a long period which enabled her to gain a lot of trust from patients and their families and made the latter speak to her in a very open manner. This subjectivity is a basic feature of qualitative ethnographic research [23]. A weakness 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. There is no specific reason to believe our findings are not valuable for other similar settings. Another weakness of this study is that the researcher has only used a limited amount of ethnographic data collection techniques (in-depth interviews only with staff, negotiated interactive observation, consulting patients' medical files). This can be explained by the fact the specific ICU setting and the vulnerability of the patients and their relatives don't allow other techniques, such as video recording and full participant observation, for ethical reasons.

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

Healthcare professionals' care strategies were inspired by a biomedical model of care. According to this model, healthcare professionals primarily focus on the diagnosis, treatment, and cure of somatic problems, caused by biological processes and expressed in signs and symptoms.[31] Care is orchestrated by healthcare professionals who try to remove patients' disease as quickly as possible by applying evidence-based medicine, although 'trial and error' can play a role. Such care strategies go often together with enforcing regulatory frameworks (e.g. concerning visits) to safeguard patients' clinical condition, which is regarded as a central responsibility of healthcare professionals, a predominantly medical, unidirectional information flow interlaced with hope, little focus on psychosocial support, and minimal attention to patients' communication. These care strategies perfectly align with the ICU care context, characterized by the performance of life-saving tasks, making life and death decisions, a technological orientation, a specific regulatory framework and infrastructure (e.g. beds that are distant from each other, no telephone for patients), time pressure, uncertainty and professional stress. As a result, in ICUs, measurable, visual and auditable disease-related aspects are highly prioritized by staff, while less visible aspects, e.g. patients' emotions, are much less acknowledged.[7,9] On the other hand, taking into account patients' emotions becomes even more complex and challenging when patients have a different ethno-cultural background. The included patients' different ethno-cultural backgrounds entail specific characteristics on 3 interrelated levels: the patient's level (e.g. religious beliefs and collectivistic orientations), the family level (e.g. large and transnational family structures, specific views on care and suffering , communication forms and families' history of migration), and the level of patient-staff interaction (e.g. phenotypical features, language).

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

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

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) research is greatly needed to measure the specific impact of these recommendations in a multi-ethnic critical care setting.

CONCLUSION

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

Abbreviations

ICU, intensive care unit

Contributors: All authors have met the four authorship criteria as stated in the International Committee of Medical Journal Editors Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals.

Authors' contributions: RVK contributed to the research design, applied for the ethical approval, completed the data collection, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. RD applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data and wrote the manuscript. LH applied for the FWO grant, contributed to the research design and applied for the ethical approval, contributed to the interpretation of the data and wrote the manuscript. JB applied for the FWO grant, contributed to the research design, applied for the ethical approval, contributed to the data analysis, contributed to the interpretation of the data, wrote the manuscript and is the guarantor of the manuscript. All the authors read and approved the final manuscript.

Funding: This study was funded by a research grant from the FWO (Fonds Wetenschappelijk Onderzoek-Vlaanderen). The funding organization was not involved in the design of the study, collection, analysis and interpretation of the data and in writing the manuscript.

Ethics: The study (reference 2013/371) was approved by the ethics committee of the university Vrije Universiteit Brussel in December 2013.

Competing interests: The authors declare that they have no competing interests.

Data sharing: Extra data is available by emailing RVK.

REFERENCES

1 Mental health: strengthening our response. *Geneva: World Health Organisation* 2016. http://www.who.int/mediacentre/factsheets/fs220/en/.

2 Fassaert T, de Wit MAS, Tuinebreijer WC, et al. Acculturation and psychological distress among non western Muslim migrants-A population-based survey. *Int J Soc Psychiatry* 2011;57:132-143.

3 Van Keer RL, Deschepper R, Francke AL, et al. Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: an ethnographic study. *Crit Care* 2015;19:441.

4 Lykkegaard K, Delmar C. Between violation and competent care--lived experiences of dependency on care in the ICU. *Int J Qual Stud Health Well-being* 2015;10:26603.

5 Moen EK, Naden D. Intensive care patients' perceptions of how their dignity is maintained: A phenomenological study. *Intensive Crit Care Nurs* 2015;31:285-93.

6 Sharma BG, Evs M, Ms K, et al. Psychological evaluation of patients in critical care/intensive care unit and patients admitted in wards. *J Clin Diagn Res* 2014;8:WC01-WC03.

7 Price AM. Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care* 2004;9:134-42.

8 Van Keer RL. Intensive Suffering. *Intensive Care Med* 2016;42:277.

9 Alasad JA, Abu Tabar N, Ahmad MM. Patients' experience of being in intensive care units. *J Crit Care* 2015;30:859.e7–e11.

10 Karlsson V. Being conscious during mechanical ventilator treatment-patients' and relatives' experiences in the intensive care units. Ghotenburg, Ghotenburg University 2012.

11 Griffin J. Forced dependency in the critically ill. *Dimens Crit Care Nurs* 1983;1:350-52.

12 Stayt LC, Seers K, Tutton E. Patients' experiences of technology and care in adult intensive care. *J Adv Nurs* 2015;71:2051-61.

13 Leman J. The dynamics of emerging ethnicities. Immigrant and indigenous ethnogenesis in confrontation. Frankfurt, Peter Lang International Academic Publishers 2000.

14 Derluyn I, Lorant V, Dauvrin M, Coune I, Verrept H. “Naar een interculturele gezondheidszorg: Aanbevelingen van de ETHEALTH-groep voor een gelijkwaardige gezondheid en gezondheidszorg voor migranten en etnische minderheden.” 2011 https://dial.uclouvain.be/pr/boreal/object/boreal:100991.

15 Garrett PW, Dickson HG, Whelan AK, et al. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethn Health* 2008;13:479-96.

16 Zeilani R, Seymour JE. Muslim women's narratives about bodily change and care during critical illness: a qualitative study. *J Nurs Scholarsh* 2012;44:99-107.

17 Cleveland LM. A Mexican American mother’s experience in the neonatal intensive care unit. *J Perinat Neonatal Nurs* 2009;23:178-85.

18 Lee SY, Weiss SJ. When East meets West: intensive care unit experiences among first-generation Chinese American parents. *J Nurs Scholarsh* 2009;41:268-75.

19 Garrett PW, Dickson HG, Young L, et al. "The Happy Migrant Effect": perceptions of negative experiences of healthcare by patients with little or no English: a qualitative study across seven language groups. *Qual Saf Health Care* 2008;17:101-03.

20 Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. *J Pain* 2009;10:1187-204.

21 Urden L, Stacy K, Lough M. Critical care nursing: diagnosis and management: 7th ed. St.Louis, Mosby-Elsevier 2014.

22 Wind G. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropol Med* 2008;15:79-89.

23 Esterberg KG. Qualitative methods in social research. Boston, The McGraw-Hill Companies 2002.

24 Sinuff T, Cook DJ, Giacomini M. How qualitative research can contribute to research in the intensive care unit. *J Crit Care* 2007;22:104-111.

25 Geertz C. The Interpretation of Cultures. New York, Basic Books 1973.

26 Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park CA, Sage 1990.

27 Hennink M, Hutter I, Bailey A. Qualitative research methods. London, Sage Publications 2011.

28 Creswell JW. Qualitative inquiry & research design. Choosing among five approaches. Lincoln, Sage Publications 2013.

29 de Graaff FM, Francke AL, Van den Muijsenbergh ME, et al. 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care* 2010;9:19.

30 Zeilani R, Seymour JE. Muslim women's experiences of suffering in Jordanian intensive care units: a narrative study. *Intensive Crit Care Nurs* 2010;26:175-184.

31 Alonso Y. The biopsychosocial model in medical research: the evolution of the health concept over the last two decades. *Patient Educ Couns* 2004;53:239-44.

32 Riess H, Kraft-Todd G. E.M.P.A.T.H.Y.: a tool to enhance nonverbal communication between clinicians and their patients. *Acad Med* 2014;89:1108-12.

33 Davidhizar R, Giger JN. A review of the literature on care of clients in pain who are culturally diverse. *Int Nurs Rev* 2004;51:47-55.

34 de Graaff FM, Mistiaen P, Devillé WL, et al. Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliat Care* 2012;11:17.

35 Hanchate A, Kronman AC, Young-Xu Y, et al. Racial and ethnic differences in end-of-life costs: why do minorities cost more than whites? *Arch Intern Med* 2009;169:493-501.

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?

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 …*

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: 'Y*our 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]

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: 'N*ow 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.

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]

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: 'D*on'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. (..)

[..]

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? *E.g. PhD, MD*	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? e.*g. personal goals, reasons for doing the research*	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. *Bias, assumptions, reasons and interests in the research topic*	See 7
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Grounded theory was used. See p. 7, line 170
Participants selection			
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	The participants (patients and families) were selected purposefully. See p. 6, line 129-132
11	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	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. home, clinic, workplace*	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. demographic data, date*	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. participant number*	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