SPIRITUALITY, QUALITY OF LIFE AND INTENSIVE CARE: IS THERE ROOM FOR EMPATHY?

SURVIVING INTENSIVE CARE IS ESSENTIAL, SURVIVING POST INTENSIVE CARE IS EXISTENTIAL.

A MIXED METHOD STUDY

CHARISSA C. MOORREES (S2117134)
MASTERTHESIS THEOLOGY AND RELIGIOUS STUDIES: RELIGION, HEALTH, AND WELLBEING, SUBTRACK SPIRITUAL CARE

UNIVERSITY OF GRONINGEN
FACULTY THEOLOGY AND RELIGIOUS STUDIES

FIRST SUPERVISOR: DR. ANJA VISSER-NIERAETH
SECOND SUPERVISOR: DR. MECHTELD-HANNA DERKSEN
GRONINGEN, JUNE 2020

Empathy is even better than talking in one language

-Rumi

Abstract

Intensive care can be traumatic and patients can develop Post Intensive Care Syndrome, which includes long-lasting and persistent psychiatric, cognitive and physical impairments. Spirituality has been shown to contribute in positively coping with illnesses and drastic operations. This mixed-method study retrospectively explored the self-identified spirituality and spiritual needs of patients during the ICU, and how they relate to quality of life and meaning-making at 3-6 months after discharge. Participants were four female patients recruited between three to six months after leaving intensive care. They completed an online questionnaire and a structured email interview. The online questionnaire measured sociodemographic information, religiosity, spirituality, and quality of life. The interview investigated how participants experienced spirituality and (spiritual) care from healthcare professionals in the intensive care unit and how this affected their own quality of life. Results showed the emergence of a core theme (dealing with uncertainty) and three main themes (needs, loss of control, care professionals). The results further highlighted that spiritual care should be provided with expertise to help reduce uncertainty and promote better coping. Limitations of the study were a small sample size and methodological issues by using an email interview. Future research should focus on further investigating the specific mechanisms that relate spirituality to quality of life during the ICU, and what part spiritual care and care professionals communication can play in moderating that effect.

keywords: intensive care, spirituality, quality of life, meaning-making

Content

Introduction

''This man (an ICU patient) had a bible and glasses at the side of his bag and he asked if I (The ICU nurse) wanted to reassure him that these (the Bible and his glasses) were in his bag, and I said: Well man, (and the patient was catching his breath at that time), your bible is still in your bag. And to this man, having the Bible near him, was very important.'(Thijs, Intensive Care nurse).[1]

Until mid 2020, at least 80.000 people have already been admitted to the Intensive Care Unit (ICU) in the Netherlands and because of the current COVID-19 outbreak these numbers will only increase further. But not only in the Netherlands, all over the world young and old people are admitted to the Intensive Care Unit. While medical and scientific improvements increased the overall survival rate of ICU patients, being an ICU survivor comes with a price. The most common complications that can arise while surviving the ICU include physical, psychological and cognitive impairments, as well as decreased Quality of Life (QOL).[2]

The WHO defines religion and spirituality as important contributions to QOL and studies have shown that spirituality can contribute in positively coping with illnesses and drastic operations, as well as decrease the risk of developing depression.[3] Nonetheless, little is

---

[1]"Frontberichten", BNN VARA, 08:40-09:06, accessed April 12, 2020, https://www.npostart.nl/frontberichten/31-03-2020/BV_101398706

[2] J. Griffiths, R. A. Hatch, J. Bishop, K. Morgan, C. Jenkinson, B. H. Cuthbertson, and S.J. Brett, "An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: A 12-month follow-up study." *Critical Care* 17, no. 3 (2013). R100.http://dx.doi.org/10.1186/cc12745 C. F. L. V. Karnatovskaia, M. Johnson, R. P. Benzo and O.Gajic, "The spectrum of psycho cognitive morbidity in the critically ill: A review of the literature and call for improvement." *Journal of Critical Care* 30, (2015): 130–137.http://dx.doi.org/10.1016/j.jcrc.2014.09.024; C. F. D. M. Needham, J. Davidson, H. Cohen, R. O. Hopkins, C. Weinert, H. Wunsch, M. A. Harvey, M. A. "Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders Conference.", *Critical Care Medicine* 40, (2012): 502–509.http://dx.doi.org/10.1097/CCM.0b013e318232da75

[3] C. L. Park and S. J. Sacco. "Heart Failure Patients' Desires for Spiritual Care, Perceived Constraints, and Unmet Spiritual Needs: Relations with Well-Being and Health-Related Quality of Life.", *Psychology, Health & Medicine* 22, no. 9 (October 2017): 1011–20, DOI:10.1080/13548506.2016.1257813. C.F. N. T. Kearns, J. Becker, K. McMinn, M. M. Bennett, M. B. Powers, A. M. Warren, and J. Edgerton. "Increased Spiritual Well-Being Following Cardiovascular Surgery Influences One-Year Perceived Posttraumatic Growth.", *Psychology of Religion and Spirituality,* October 3, 2019, DOI:10.1037/rel0000291. C.F. D. B. Bekelman, D. M. Sydney, D. M.

known about how patients experience spirituality and spiritual care during their admission to the ICU. Most studies have a focus on the effect of spirituality and spiritual care on QOL after the patient leaves the ICU, which can possibly add more confounding factors, like the natural recovery from the injury or additional rehabilitation treatments. To increase scientific knowledge about this subject, this study focuses on spirituality and spiritual care during the ICU, which can possibly help to promote increased well-being for future ICU patients and relieve the negative effects of being admitted to the ICU. Therefore, the aim of the current study is to investigate how patients experience the effect of their own spirituality and spiritual care during the ICU on their QOL and meaning-making. Furthermore, because of the traumatizing and stressful effect of the ICU on some patients, which can affect their core beliefs and views on life, this study also looks into how patients experience the impacts of the ICU on their meaning-making process, and how this might have been impacted by a patient's met or unmet spiritual needs as well.

In the following paragraphs, I will first take a look at the ICU, and then delve into the existing literature about spirituality, spiritual needs and how it relates to QOL and meaning-making.

The Intensive Care Unit

According to Sandra Gijtenbeek, the ICU is only a piece of a larger care puzzle, that needs a multidisciplinary approach to promote better well-being of a patient.[4]

Marshall et al. mention in "What Is an Intensive Care Unit? A Report of the Task Force of the World Federation of Societies of Intensive and Critical Care Medicine" that

---

Becker, I. S. Wittstein, D. E. Hendricks, T. E. Yamashita, and S. H. Gottlieb, "Spiritual Well-Being and Depression in Patients with Heart Failure.", *Journal of General Internal Medicine* 22, no. 4 (April 2007): 47077, DOI:10.1007/s11606-006-0044-9.

[4] Sandra Gijtenbeek, "De kracht van de intensive care", accessed March 11, 2020, https://www.medischcontact.nl/tijdschrift/medisch-contact-thema/thema-artikel/de-kracht-van-de-intensive-care.htm.

ICU's became an important and integral part of the health care system in low and high-income countries.[5] They reviewed peer-reviewed and gray literature in order to bring together contemporary models for ICU stratification. Their definition and classification of ICU' is: "*An ICU is an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of life-threatening organ system insufficiency.".[6]* The literature makes further distinctions between a Level 1 ICU, Level 2 ICU, and Level 3 ICU. A level 1 ICU has the capability to provide oxygen and non-invasive monitoring. Besides that, nurses can provide more intensive care in comparison to the care given on a ward. The level 2 ICU provides invasive monitoring and provides basic life support for a shorter period. A level 3 ICU differs from the first mentioned in that it provides a full spectrum of life support technologies and monitoring. Additionally, it serves as a regional resource for the care of patients that are critically ill, but it can also serve as a research and education centre for students to develop the specialty of Intensive Care.[7]

In scientific literature there are many studies that document the negative lasting effects of the ICU on patients. According to a study by Merbitz et al. patients can commonly suffer for months or even years from persistent anxiety, depression, acute stress disorder, and/or post-traumatic stress disorder symptoms.[8] This study by Merbitz et al. highlights the

---

[5] John C. Marshall et al., "What Is an Intensive Care Unit? A Report of the Task Force of the World Federation of Societies of Intensive and Critical Care Medicine", *Journal of Critical Care*, no. 37, (Feb 2017):270-276, DOI: 10.1016/j.jcrc.2016.07.015 https://pubmed.ncbi.nlm.nih.gov/27612678/
[6] Marshall et al., "What Is an Intensive Care Unit?", 270-276.
[7] Marshall et al. mention that a formal definition and a descriptive framework for ICu's can be helpful because it can inform health care decision-makers in measuring the capacity and in planning the care. But it also provides professionals and patients with a benchmark to evaluate the level of resources that are available for clinical care.
[8] Nancy Hansen Merbitz, Katharine Westie, Jennifer A. Dammeyer, Lester Butt, and Jessica Schneider, "After Critical Care: Challenges in the Transition to Inpatient Rehabilitation.", *Rehabilitation Psychology in Critical Care* 61, no. 2, (May 2016): 186–200, DOI:10.1037/rep0000072.

challenges that patients face as a consequence of having been admitted to the ICU, and the importance of the psychological care to help patients transition to rehabilitation, while minimizing the risk of developing disorders such as anxiety, depression, acute stress disorder, and/or post-traumatic stress disorder symptoms.[9] The risk to develop these psychological disorders makes them a high priority group in need of more efficient care.[10]

After the ICU, patients go on to a regular care unit, a nursing home, a recovery center or apply for care at home.[11] Patients that were on the ICU usually continue to have a high need for physical, psychological and spiritual support to deal with primary (e.g. impaired neurological functions, such as memory or attention) and secondary (e.g. sleep disturbances or depression) consequences of their illness or injury. Usually these illnesses or injuries (e.g. COVID-19, severe head injury, stroke or serious infections[12]) come unexpected and sudden, and can even be life threatening, because they put the patient at risk for multiple organ failure. [13] Hence, ICU patients differ from regular patients, because of their critical and intense illness. The experience of ICU, especially factors like receiving mechanical ventilation and the overall length of stay, can have negative long-term consequences for many patients, leading to lower quality of life and increasing risk for psychological disorders, e.g. Post-Traumatic

---

[9] Nancy Hansen Merbitz, Katharine Westie, Jennifer A. Dammeyer, Lester Butt, and Jessica Schneider. "After Critical Care: Challenges in the Transition to Inpatient Rehabilitation.", *Rehabilitation Psychology in Critical Care* 61, no. 2, (May 2016): 186–200, doi:10.1037/rep0000072.

[10] Margaret S. Herridge, Catherine M. Tansey, Andrea Matté, George Tomlinson et al., "Functional disability 5 years after acute respiratory distress syndrome." *The New England Journal of Medicine* 364, (2011): 1293-304, DOI: 10.1056/NEJMoa1011802. C.F. George Fildissis, Vassilius Zidianakis, Efi Tsigou, Despina Koulenti, et. al. "Quality of life outcome of critical care survivors eighteen months after discharge from intensive care.", *Croatian medical journal* 48, no. 6, (2007): 814–821, https://doi.org/10.3325/cmj.2007.6.814

[11]Gijtenbeek, "De kracht van de intensive care".

[12]"Intensive care", Conditions NHS, last modified June 19, 2019, https://www.nhs.uk/conditions/intensive-care/.

[13] Patients with critical illness usually encounter failure of one or more of their body's organ systems e. g. the heart, lungs, kidneys, liver but also the brain. It is not a surprise that these patients can suffer from their critical illness. For more information see the cohort study of M. Terblanche, P. Kruger, S. di Gangi, et.al. ''Risk factors for acute organ failure in intensive care unit patients who receive respiratory support in the absence of non-respiratory organ failure: an international prospective cohort study'', *Critical care* 16, no. 2 (2012):1-10, https://doi.org/10.1186/cc11306

Stress Disorder, Anxiety, and Depression.[14] Although quality of life is an ambiguous term with a variety of definitions in literature, it is nonetheless a key-concept and focus in the current study, which will be discussed in more detail below.

Quality of life

The present study uses the World Health Organization definition of QOL: "*[...] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [...] it is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.*"[15] That definition highlights the subjective and multidimensional nature of the QOL construct, which includes physical, emotional, social and functional well-being. Many of these aspects of QOL are usually affected by circumstances or illnesses that lead a patient to be admitted to the ICU.

According to Svenningsen, the Intensive Care hospitalization is a traumatic experience that negatively affects a patient's quality of life.[16] The traumatic experience stems from the patients being directly confronted with their own mortality, because of being sedated and additionally often being intubated, which leaves them unable to communicate.[17] Choi et al.

---

[14]Jaquilene B. Da Costa, Sheila Taba, Julia Ricardi Scherer, Lucian Lucchesi F. Oliveira, Kelen Cristina Barros Luzzi, et al., "Psychological Disorders in Post-ICU Survivors and Impairment in Quality of Life.", *Psychology & Neuroscience* 12, no. 3, (2019: 391–406, doi:10.1037/pne0000170. C. F. Rawal Gautam, Yadav Sankalp & Kumar Raj, "Post-intensive Care Syndrome: an Overview", *Journal of translational internal medicine* 5, no. 2, (2017):90–92, https://doi.org/10.1515/jtim-2016-0016.

[15]The World Health Organization, "Health statistics and information systems", WHOQOL measuring quality of life, accessed april 19, 2020, https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

[16]Helle Svenningsen, "Associations between sedation, delirium and post-traumatic stress disorder and their impact on quality of life and memories following discharge from an intensive care unit.", *Danish Medical Journal 60*, no. 4, (2013):4. C.F. Fildissis et. al. found out that the quality of ICU patients' life was poor after their discharge. After 18 months of discharge, there was improvement. Nonetheless, the quality of life was still worse than in comparison to the admission. The factors that had the most impact on the quality of life during the admission and 18 months after patients' discharge were: age, male sex and the length of stay.

[17]Talha Khan Burki, "Post-traumatic stress in the intensive care unit.", *The Lancet Respiratory Medicine 7*, no. 10, (2019):843-844, https://doi.org/10.1016/S2213-2600(19)30203-6

showed that during the first four months after ICU discharge patients experienced additional symptoms of weakness, pain, fatigue and disturbance.[18] Da Costa et al. reported that irrespective of why a patient was admitted to the ICU, they had lower scores on any domain of QOL.[19]

Studies that looked at positive influences on the QOL of patients that dealt with serious illnesses found that in general spirituality had a positive relation with increased QOL, in comparison to patients that displayed less spiritual traits. This was shown by Abu et al., who did a systematic review of the existing literature on the effect of spirituality on patients suffering from cardiovascular disease and found that spirituality and spiritual well-being were positively correlated with global measures of QOL.[20] There are only few studies that look at the effect spirituality has on QOL with patients on the ICU. One study that did factor in patients that are admitted to the ICU was done by Bashar et al., who found no direct or indirect relation between spirituality and quality of life, but unfortunately did not offer an explanation.[21]

Spirituality and Spiritual Needs on the ICU

While there is a growing interest in research about the influence of spirituality on mental or physical health, there is still a lack of research about the effects of spirituality and

---

[18]Choi J, et al. "Self-reported physical symptoms in intensive care unit (ICU) survivors: pilot exploration over four months post-ICU discharge.", *Journal of Pain and Symptom Management* 47, no. 2, (2014):257–270.

[19] Da Costa, Sheila Taba, Jaquilene Barreto, Julia Ricardi Scherer, Lucian Lucchesi F. Oliveira, Kelen Cristina Barros Luzzi, Daniela Prochnow Gund, Gabriel Sartori, Itamar R. P. Porto, Amaury C. Jorge, and Péricles Almeida Delfino Duarte, "Psychological Disorders in Post-ICU Survivors and Impairment in Quality of Life.", *Psychology & Neuroscience* 12, no. 3 (September 2019): 391–406. doi:10.1037/pne0000170.

[20] Abu Hawa O, Christine Ulbricht, Eric Ding, Jeroan J. Allison, Elena Salmoirago-Blotcher, Robert J. Goldberg, and Catarina I. Kiefe, "Association of Religiosity and Spirituality with Quality of Life in Patients with Cardiovascular Disease: A Systematic Review.", Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, *Care & Rehabilitation* 27, no. 11 (November 2018): 2777–97. doi:10.1007/s11136-018-1906-4.

[21] Farshid R. Bashar and Amir Vahedian-Azimi, Mahmood Salesi, Mohammadreza Hajiesmaeili, Seyedpouzhia Shojaei, Behrooz Farzanegan, Reza Goharani, et al., "Spiritual Health and Outcomes in Muslim ICU Patients: A Nationwide Cross-Sectional Study.", *Journal of Religion and Health* 57, no. 6 (December 2018): 2241–57. doi:10.1007/s10943-017-0543-5.

spiritual care on patients that are on the ICU. The lack of research can be partially explained

by the difficulties to find a common definition of spirituality. This was also discussed in a

study by McSherry and Cash, who highlight that in nursing settings, a clear definition of

spirituality is often only implied between nurse and patient, but can actually differ greatly

based on individual interpretations.[22] Steinhauser et al. describe spirituality as a construct

consisting of multiple distinct dimensions, that should be holistically conceptualized to

encompass all aspects of being human.[23] Therefore, I will use the following definition from

Puchalski, which has earned an international consensus: *"Spirituality is a dynamic and*

intrinsic aspect of humanity that refers to the way individuals seek and express meaning,

purpose, and transcendence, and is often tied with the feeling of connectedness to the moment,

self, family, others, community, society, nature, and the significant or sacred."[24]

Spirituality and spiritual needs have been shown to affect well-being, as well as being

associated with better overall mental and physical health.[25] This was further supported by a

meta-analysis from Salsman et al., who reviewed 148 studies and found a moderate positive

relationship between religion and spirituality on mental health in cancer patients.[26] Though

because of widely differing definitions of spirituality in the reviewed study, the applicability

of the results to the present study should be seen with caution. Spirituality has also been

---

[22] McSherry, Wilfred, and Keith Cash. "The Language of Spirituality: An Emerging Taxonomy." *International Journal of Nursing Studies* 41, no. 2 (February 2004): 151–61. doi:10.1016/S0020-7489(03)00114-7.

[23] Steinhauser, Karen E., George Fitchett, George F. Handzo, Kimberly S. Johnson, Harold G. Koenig, Kenneth I. Pargament, Christina M. Puchalski, Shane Sinclair, Elizabeth J. Taylor, and Tracy A. Balboni. "State of the Science of Spirituality and Palliative Care Research: Part I: Definitions, Measurement, and Outcomes." *Journal of Pain and Symptom Management* 54, no. 3 (September 2017): 428–40. doi:10.1016/j.jpainsymman.2017.07.028.

[24] Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med 2014;17(6):642–56. https://doi.org/10.1089/jpm.2014.9427

[25] Harold G. Koenig, D. E. King, and V. B. Carson, Handbook of religion and health, (New York:Oxford University Press, 2012). C. F. Pranee C. Lundberg, Petcharat Kerdonfag, "Spiritual care provided by Thai nurses in intensive care units", *Journal of Clinical Nursing Volume* 19, no. 7-8, (2010): 1121-8

[26] John M. Salsman, James E. Pustejovsky, Heather S. L. Jim, Alexis R. Munoz, Thomas V. Merluzzi, Login George, Crystal L. Park, et al., "A Meta-Analytic Approach to Examining the Correlation between Religion/Spirituality and Mental Health in Cancer.", *Cancer* 121, no. 21 (November 1, 2015): 3769–78. doi:10.1002/cncr.29350.

shown to function as a source of strength for patients, helping them to cope with their hardships.[27] A study by Koenig showed that patients' spiritual beliefs and practices are a means of dealing with an illness or stressful life changes.[28] According to Koenig a large volume of research showed that patients who reported higher scores of religiosity or spirituality have better mental health and also adapt faster to health problems, in comparison to patients who scored lower on religiosity or spirituality.[29] For that research Koenig used a definition of spirituality, which focuses on finding meaning and connecting to the sacred within oneself and outside, and therefore can be partially compared with the definition of spirituality of the present study. Religious and spiritual beliefs can help patients to explain, understand, and provide a framework of meaning to the experience of negative events, such as the ICU.[30] Additionally, Koenig sees that these benefits to mental health and well-being also have physiological consequences, which in turn have an impact on physical health and affect the risk of disease, but also can influence response to treatment.[31] Therefore, spirituality and religion have an influence on the participants' self-reported quality of life.[32]

Spirituality is in the end only one side of the coin. While spirituality is more of a trait, spiritual needs are more of a state. Which means that spiritual needs are dependent on the situation and are probably more prominent in situations that are stressful and life-changing,

---

[27]C. M. Puchalski, "The role of spirituality in health care.", *Proceedings Baylor University Medical Center* 14, no. 4, (2001): 352-7, doi:10.1080/08998280.2001.11927788

[28]Harold G. Koenig, "Religion, spirituality, and health: the research and clinical implications." *ISRN psychiatry*, (2012), DOI:10.5402/2012/278730

[29] Koenig, "Religion, spirituality, and health".

[30]Samual R. Weber and Kenneth I. Pargament, "The Role of Religion and Spirituality in Mental Health.", *Current Opinion in Psychiatry* 27, no. 5, (2014): 358–63, doi:10.1097/YCO.0000000000000080.

[31]Idem.

[32]Willemse et al. mentioned that Spiritual Care can relieve distress of patients and their relatives. Additionally, Spiritual Care contributes to the quality of care by addressing the spiritual and emotional needs of patients and their relatives, secondly when spiritual comfort to the distressed patient is offered this can increase spiritual well-being of patients, but also their relatives. S. Willemse, W. Smeets, E. van Leeuwen T. Nielen-Rosier, L. Janssen N. Foudraine, "Spiritual care in the intensive care unit: An integrative literature research", *Journal of Critical Care 57*, (2020): 55-78, https://doi.org/10.1016/j.jcrc.2020.01.026

e.g. the ICU. According to Abu et al., having a patient's spiritual needs met is positively associated with higher physical, mental and emotional well-being, while spiritual constraint was related with poor physical QOL.[33] Nonetheless, studies have shown that while patients do have a need for spiritual care, most do not receive it.[34] That was also demonstrated in a recent dutch study by Willemse et al., who questioned 487 care professionals from 85 dutch hospitals, working on the ICU. The majority agreed that spiritual care has benefits (e.g. promoting mental well-being, increased patient and relative satisfaction), but only the minority felt up to the task of offering spiritual care without a dedicated spiritual caretaker.[35]

Meaning-making

When global meaning (which is an individual's general view on many events)[36] is disrupted or violated by any event, e.g. the ICU experience, the attempt to restore this global meaning can be labeled as meaning-making.[37] Furthermore, Park describes a meaning making model of adjusting to highly stressful events, which explains that the discrepancies between appraised and global meaning lead to distress and that individuals attempt to make meaning by reappraising their situation to reduce the discrepancy and thereby ease their distress.[38] Therefore, meaning-making is when a patient sees or understands a situation in a different

---

[33] Abu Hawa O, Christine Ulbricht, Eric Ding, Jeroan J. Allison, Elena Salmoirago-Blotcher, Robert J. Goldberg, and Catarina I. Kiefe, "Association of Religiosity and Spirituality with Quality of Life in Patients with Cardiovascular Disease: A Systematic Review.", Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, *Care & Rehabilitation* 27, no. 11 (November 2018): 2777–97. doi:10.1007/s11136-018-1906-4.

[34] M. J. Balboni, A. Sullivan, A. Amobi et al., "Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training.", *Journal of Clinical Oncology* 31, no. 4, (2001): 461–467.

[35] Suzan Willemse, Wim Smeets, Evert van Leeuwen, Loes Janssen, and Norbert Foudraine. "Spiritual Care in the ICU: Perspectives of Dutch Intensivists, ICU Nurses, and Spiritual Caregivers.", *Journal of Religion and Health* 57, no. 2 (April 2018): 583–95. doi:10.1007/s10943-017-0457-2.

[36] Crystal L. Park, The meaning making model: a framework for understanding meaning, spirituality, and stress–related coping.", *the European Health Psychologist* 15, no. 2,(2013):40-45, https://www.ehps.net/ehp/index.php/contents/article/view/ehp.v15.i2.p40/1041

[37] Global meaning is not always restored during meaning –making, but can also be changed. Assimilation (to take in and fully understand) versus accommodation (to adjust) is relevant.

[38] Crystal L. Park, "Testing the Meaning Making Model of Coping with Loss.", *Journal of Social and Clinical Psychology* 27, no. 9 (November 2008): 970–94. doi:10.1521/jscp.2008.27.9.970.

way and is able to reconsider her belief and goals. When appraised meaning is discrepant with global meaning, patients often try to change their view in order to incorporate the new outlook in their global meaning, and vice versa. By doing so, consistency among the situation, beliefs and goals can be kept.[39] The feeling and sense that one's world is comprehensible and life is worth living is restored. Meaning-making can also be seen as a coping mechanism, which includes cognitive strategies such as positive reinterpretation or acceptance that are used to reinterpret the meaning of a situation.[40]

Bulman et al. interviewed 29 individuals who had been paralyzed in serious accidents between the ages of 16 and 35 years. Their findings suggest blaming somebody else and having the feeling that they could have avoided the accident were a prediction of poor coping; self-blame on the other hand was a successful predictor of good coping. According to the researchers, the question "Why me?" was posed by all participants. And all of them, except for one, wanted to explain why the accident happened to them. Hence, Bulman et al. concluded that these responses showed the participants need for meaning in explaining the incidence of the accident.[41] As the study of Bulman shows, the ''Why me?'' is relevant for patients. These results further highlight the need to investigate meaning-making and spirituality in ICU patients, because they offer possible answers or explanations to the patients coping, i.e. asking "Why me?".

In most studies meaning-making is seen simply as an aspect of spirituality, while it can be a coping mechanism to deal with situations or life events that runs parallel with

---

[39]Christopher G. Davis and Danay C. Novoa, "Meaning-making following spinal cord injury: Individual differences and within-person change.", *American Psychological* Association 58, no. 2, (2013): 166. C. F. Crystal Park and Susan Folkman, "Meaning in the Context of Stress and Coping.", Review of General Psychology 1, no. 2, (1997): 115–44, DOI:10.1037//1089-2680.1.2.115.

[40] S. Folkman, and J. T. Moskowitz, "Coping: Pitfalls and promise.", *Annual Review of Psychology* 55, no. 1, (2004): 745-774.

[41]Ronnie J. Bulman, U. Massachusetts, Amherst Wortmann, B. Camille. "Attributions of blame and coping in the 'real world': Severe accident victims react to their lot.", *Journal of Personality and Social Psychology* 35, no 5, (1977): 351-363.

spirituality. Meaning-making, especially if seen in global meaning, can also describe an overall worldview or ideology that serves as an explanation or reference for aspects of life, when one experiences demanding events. This worldview or ideology can even be secular and therefore be seen detached from spirituality, which is why the present study aims to analyze if participants experienced an influence on their meaning-making, depending on their spirituality and spiritual needs, while they were admitted to the ICU.

The Present Study

The goal of this research is to increase scientific knowledge about the role of spirituality and spiritual care in patients' ICU experiences and how patients perceive its influence on quality of life and meaning-making, in order for care professionals to provide better care during the ICU. ICU patients can have spiritual or religious needs and these needs should be met, but have to be identified first by the medical staff.[42] Therefore, this study aims to investigate the spiritual needs of female patients that have been out of Intensive Care for at least 3-6 months. Female patients were the focus in this study, because women have been shown to be "more religious" than men and have been reported to have a higher interest in spiritual issues as well.[43] Additionally, studies have indicated that women score higher on anxiety and that psychological problems after critical illness appear to be more common in

---

[42]Religious and spiritual beliefs and practices are used by patients to cope with illness or stressful life changes. According to Koenig a large volume of research has shown that patients who are more religious or spiritual have better mental health but also are able to adapt faster to health problems, in comparison to patients who are less religious or spiritual. And Koenig sees that these possible benefits to mental health and well-being also have physiological consequences, which in turn have an impact on physical health and affect the risk of disease, but also can influence response to treatment.

[43] E. Donelson, "*Psychology of religion and adolescents in the United States: Past to present", Journal of Adolescence* 22, no. 2, (1999):187-204. C.F. H. Streib and R. Hood, "*Semantics and psychology of spirituality. A cross-culturalanalysis", (*New York: Springer, 2016).

women.[44] The time frame was chosen to reduce the chance of the patients quality of life to be influenced by life events other than their stay on the IC.

The focus of this research is on the spiritual needs of post-ICU patients and the spiritual care they perceived after intensive care, in order to improve patient care in the future. This research thus contributes to the field of religion, health and wellbeing and in particular the field of spiritual care, because it focuses upon the perceived quality of life, the narrative and meaning making of the patients. Hence, it might also contribute to the field of psychology and medical care, because the answers of the patients on the questions that are asked in the interview guide and questionnaire might lead to extensive data that does not merely fit in one field of research. Above all, the primary goal is that care professionals will benefit from the collected data and results as well. My assumption is that this can even help them to understand the patient's needs better, which could improve patient care. As mentioned above, besides the psycho-somatic complaints after their stay in the ICU, there can be biomedical complaints and explanations as well. Therefore, it is my assumption that this research will have some overlap with other fields of research.

Research Question and Sub-questions

How do female patients between 20 and 35 years of age experience the impact of their self-identified spirituality, their spiritual needs, and the spiritual care provided during the intensive care on their quality of life and meaning-making three to six months after leaving the intensive care unit?

Sub Questions

---

[44] C. Herrmann, "International experiences with the Hospital Anxiety and Depression Scale — a review of validation data and clinical results", Journal of Psychosomatic Research 42, no. 1, (1997):17-41. C. F. Schandl A, M. Bottai, E. Hellgren, O. Sundin, P. Sackey, "Gender differences in psychological morbidity and treatment in intensive care survivors - a cohort study", Critical Care 16, no. 3, (2012), https://doi.org/10.1186/cc11338

1. How does the Post Intensive Care patient rate and describe the spiritual care they received?

2. How does the patient define positive spiritual care and how does she describe negative spiritual care?

3. What was the function of spirituality during the patient's ICU experience?

4. How does the patient describe her current quality of life and how is it influenced by the intensive care experience?

5. In what way do patients give meaning to their life according to them?

6. What spiritual needs did the patients have during the ICU?

7. Were these spiritual needs met during the ICU?

8. What was the role of the care professional in meeting these spiritual needs?

Method

In this mixed method study, I made use of relevant scientific literature, with a focus on Post Intensive Care Syndrome, Intensive Care, spirituality, meaning making and coping by patients. This research had a cross-sectional non-comparative study design. The tool used for data collection were email interviews and online questionnaires. Because of the outbreak of COVID-19 and the instated measures to prevent spreading, the initially planned method (i.e. face-to-face interviews in close proximity to the participants) was replaced with interviews done per email.

Combining interviews with questionnaires was chosen to promote "participant enrichment", which is the optimization of a sample by increasing the gathering of relevant

data through multiple tools.[45] Optimization would mean in this case that the validity of the answers given by the participants would increase (e.g. a participant indicates during the interview and on the questionnaire that she is only moderately spiritual). By separating the questions about the participants' own identification with and definition of spirituality from the interview, I prevented the possibility of participants getting primed with "spirituality" and overestimated its occurrence during the intensive care.

Due to the time limit of approximately four months, the sample consisted of four Post Intensive Care (Syndrome) patients between the age of 20-35 year that were interviewed and asked to fill out the questionnaires. The interview guide was based on the interview guide used in the study Spiritual care by nurses in curative cancer care, because it had sufficient validity.[46]

Because my research was focused on IC patients, who had a higher chance of suffering from memory loss, the use of a storyline technique would be unfeasible. Therefore, I chose to neither integrate the storyline technique nor GT, due to the fact that GT is focused upon constructing theories immediately from data analysis, and because this research had a descriptive focus. Additionally, I decided against a longitudinal study, because it consists of various observations over time, in order to better understand developments and the temporal relationships. The time frame of this study was less than six months, which made this approach not feasible either. Therefore, I decided for a cross-sectional study with participant

---

[45]Nancy L. Leech and Anthony J. Onwuegbuzie, "Guidelines for Conducting and Reporting Mixed Research in the Field of Counseling and Beyond", *Journal of counseling and development* 88, (2010): 61, https://DOI.org/10.1002/j.1556-6678.2010.tb00151.x

[46]Groot, Marieke, Anne F. Ebenau, Helen Koning, Anja Visser, Carlo Leget, Hanneke W.M. van Laarhoven, René van Leeuwen, Riet Ruben, Marijke Wulp, and Bert Garssen, "Spiritual Care by Nurses in Curative Cancer Care: Protocol for a National, Multicentre, Mixed Method Study." *Journal of Advanced Nursing* 73, no. 9 (2017): 2201–7. https://DOI.org/10.1111/jan.13332.

enrichment.[47] That entailed that data collection happened during one point in time only. I deployed a convergent parallel design[48], i.e. I used qualitative and quantitative methods simultaneously, in order to verify the observed relationships and processes with the participants. To be precise, I started with quantitative and then with qualitative, in order to allow participants a bigger time frame and focus for the interview.

Participants

Participants were Post Intensive Care patients from an academic hospital in the Netherlands, recruited by an experienced recruiter from the academic hospital by telephone. The total sample consisted of four female patients between the ages 18 to 35. Females were chosen, because gender has been shown to be a risk factor with women having a higher chance to develop Post Traumatic Stress Disorder, depression and anxiety after ICU admittance.[49] Additionally, the data could be compared to the data of two other researchers in the same project, who simultaneously interviewed female participants and next of kin between the age of 40-70.[50] As compensation after completing the study the participants received a 5€

---

[47]Creswell mentions that there should be a good reason to mix methods, for more information see page 61 ''Prototypical Versions of the Six Major Mixed Methods Research Designs'', accessed May 14, 2020, https://www.sagepub.com/sites/default/files/upm-binaries/35066_Chapter3.pdf.
According to Leech and Onwuegbuzie, mixed methods provide participant enrichment and in this research participant enrichment is a necessity. See ''Guidelines for Conducting and Reporting Mixed Research in the Field of Counseling and Beyond.'', *Journal of counseling and development* 88, (2010): 61, https://DOI.org/10.1002/j.1556-6678.2010.tb00151.x
[48]Jessica Tomasi, Carly Warren, Lauren Kolodzey, Sonia Pinkney, Anne-Marie Guerguerian, et al., "Convergent parallel mixed-methods study to understand information exchange in paediatric critical care and inform the development of safety-enhancing interventions: a protocol study.", *British Medical Journal Volume* 8, no. 8, (2018): 1-11, DOI: 10.1136/bmjopen-2018-023691.
[49]Gautam Rawal, Sankalp Yadav and Raj Kumar, "Post-intensive Care Syndrome: an Overview.", *Journal of translational internal medicine* 5, no. 2, (30 June 2017):90-92, doi:10.1515/jtim-2016-0016
[50]Wintermann et al. have concluded in their research that the needs of younger patiënt-partner dyad should be investigated further as well. Besides that, 16% of the family members of chronically critically ill patients show clinically relevant symptoms of post-traumatic stress within up to 6 months following the ICU stay. Wintermann et al. "Impact of post-traumatic stress symptoms on the health-related quality of life in a cohort study with chronically critically ill patients and their partners: age matters.", *Critical care* 23, no 39, (2019):1-9, DOI:10.1186/s13054-019-2321-0

gift voucher per email. Study 201800422 was approved by the UMCG ethics committee and informed consent was obtained from each participant before the interviews.

Selection

The experienced recruiter started out with 173 female patients (50 patients passed away). 45 patients were in the ICU for more than 48 hours. Six patients were between 18 - 35 years. One patient was not selected for the study due to no steady living situation and one patient was not selected due to blindness, deafness and needing life support. Therefore, these patients were not contacted by the university hospital recruiter. Hence, the recruiter called the other three patients and later on contacted the fourth patient. The 4 selected female patients were released from the ICU in the months October, November and December 2019 and have been in the ICU for more than 48 hours. Patient 1 and 4 were admitted to ICU 2, Patient 2 and 3 were admitted to ICU 3.

Interview assessment

The present study used confirmatory and exploratory questions and started with closed questions about spirituality, quality of life, demographic data, ICU experience, and open questions about support, religion, spirituality, the role of the medical staff during their illness, sources of inspiration, and power.[51]

Procedure

The study was administered over the course of four individual email-interview moments. Participants received an email with instructions about the research steps and attached to the email an explanation of the procedure and informed consent. After reading the pdf, patients could click on the link and were sent to an online-questionnaire portal (Qualtrics), where they could sign the informed consent and start with the questionnaire.

---

[51] See Appendix I for the questions.

Participants were contacted by phone to inquire if they received the email with information, and if they agreed to participate in the study. All participants were willing to participate and signed the informed consent. After participants entered Qualtrics, filled out the informed consent, and the questionnaire, they received an email that informed them that the first part was finished and the next step would continue with the email-interview. After one week the response rate on the first send email questions was low (i.e. one out four participants), so participants were contacted by phone. A reminder was sent out after four days. After 48 hours of sending the reminder, the second question was sent. To increase the response rate an email with the remaining nine questions was sent out, which included an estimation of the time needed to answer the questions (approximately 45 minutes). Three of the participants were able to answer the interview questions and one participant needed a few more days due to health conditions. During this time, I started with the 'thematic synthesis'.[52]

Analysis

The thematic synthesis consisted of three stages. First, the transcripts were coded line by line. Second, descriptive themes were developed. Lastly, analytical themes were generated. [53] I made use of open coding, due to the fact that this is an explorative study. I waited with coding until all of the participants sent their responses via email, in this way I did not adjust nor influence the interview guide, but explored what the participants experienced at that moment in time, reflecting on their ICU experiences.

After the data collection, I made use of qualitative analysis for the interviews[54] and a descriptive analysis approach for patterns of differences in themes on the questionnaires between patients. I started coding the first interview and proceeded with the other interviews,

[52]James Thomas and Angela Harden, "Methods for the thematic synthesis of qualitative research in systematic reviews.", *BMC Medical Research Methodology*, Volume 8: no. 45 (2008): 4-10, https://DOI.org/10.1186/1471-2288-8-45
[53]Thomas andHarden, "Methods for the thematic synthesis.", 4-10.
[54]The interviews will be coded.

specifically using the codes of the first interview. I made use of open coding and axial coding with the first interview, then came up with categories and a code list to be used for the other interviews. Lastly, I made use of selective coding, by identifying a core category, which was the basis of comparing against all other categories. Open coding consisted of labeling fragments of text and Axial coding focused upon comparing fragments with the same code in order to find similarities and differences.[55] Selective coding focused upon finding concepts, elaborating more about these concepts and coming up with a theme by constantly comparing the data. After sentences were coded, these codes were categorized (e.g. the codes "being taken seriously" "respect" and "acknowledgment" were categorized as "Needs"). "humane" and "inhumane" were categorized as "Care professionals".[56]

Ethical considerations

The procedure for the ethical review of research plans by the Amsterdam Institute for social science research was reflected upon and taken into account during this study.[57] Ethical permission was granted by the ethical committee of the university hospital for this research about Post Intensive Care (Syndrome) patients. The patients were informed that participation in this research is voluntary and they have the right to withdraw at any given moment. I have mentioned this during phone calls with the patients and asked if the questions and information was clear, because their symptoms could lead to memory loss, as also mentioned by Helle Svenningsen.[58] The goal of this study was to explore the experiences of ICU patients in order

---

[55]Judy Kendall, "Axial coding and the grounded theory controversy.", *Western journal of nursing research* 21, no. 6, (1999): 743-757, https://DOI.org/10.1177/019394599902100603.
[56]See appendix for the codes.
[57]Amsterdam Institute for Social Science Research, "procedure for ethical review of research plans", accessed May   14,   2020, http://aissr.uva.nl/binaries/content/assets/subsites/amsterdam-institute-for-social-science-research/map-1/aissr-ethical-review-procedure-and-questions.pdf?14872346768230
[58]Helle Svenningsen, "Associations between sedation, delirium and post-traumatic stress disorder and their impact on quality of life and memories following discharge from an intensive care unit." *Danish Medical Journal* 60, no. 4, (2013):4.

to investigate possible benefits for patients in the future. Because this research was done with the collaboration of these patients, the four fundamental principles of ethics are relevant: autonomy, non-maleficence, beneficence and justice.

Non-maleficence was relevant because Post Intensive Care patients could have experienced a lot during their stay in the ICU, some might even have PICS, and they should not be psychologically harmed during the study. Additionally, precautions were taken to leave the patients in an emotional state no worse than before. These precautions were the informed consent form and debriefing. The possible risks of this research were that patients could experience distressing emotions by remembering and writing about their intensive care experiences. Therefore, aftercare was offered through phone contact with a care professional, if necessary.

Post Intensive Care patients can be traumatized due to previous experiences, which makes beneficence highly relevant. Patients should benefit from this research instead of being traumatized even further. They will potentially get a better understanding about their own spiritual processes and views on life. The information gathering will not psychologically harm participants, but can be taxing in terms of energy, depending on a participants health situation, as mentioned in the informed consent form. By giving participants the opportunity to contact two care professionals, to discuss any distress they could experience during the study, the risk of psychological harm was minimized.

After completing the data collection part, patients received a compensatory gift. The value was kept "small", to prevent undermining the participants intrinsic motivation to contribute to scientific research. Due to the risk of COVID 19 infection, a digital 5€ gift voucher was sent to the participants by email. The presumed state of the patients between 20-35 was taken into account in the questionnaire. Patients were treated with respect, dignity,

and their privacy and autonomy are important and valued. They were informed that the data was shared with the other researchers, but their names were anonymized.

Justice and autonomy were relevant in this research. Because Post Intensive Care patients experienced a lot of stress and some of the patients might also deal with PTSD, it was important for them to be treated just and fair by the researcher in order to have a positive experience during their hardships. That means that the researcher listened carefully to their stories and took them and their experiences seriously and respected the patient's autonomy. The purpose of this research was explained in the first email (including a PDF-file containing the informed consent) and the participants have been asked to consent after reading the information about the research and the impact it might have. If willing to consent, participants were able to sign a form via Qualtrics. These steps were taken due to COVID-19 health risks. I signed the form beforehand, in order for the participants to see I am committed to respect their privacy and autonomy. Participants could choose in Qualtrics whether their data might be used by researchers in foreign countries. Hence, data sharing was only possible with their permission.

To make sure to sufficiently attend to the interests and concerns of the participants, I informed them of the possibility to contact me by email and phone and that I would respond within 48 hours, unless an unforeseen situation prohibited me to do so, then I would inform them about that as soon as possible. Additionally, there was occasional phone contact with the participant to discuss the status and other considerations. This was done to continuously enable participants autonomy and reduce risk of maleficence due to the possible emotional impact of the study. Participants were debriefed after completing the study according to the debriefing form for participation in a research study. Anonymity was ensured due to the fact

that names were not mentioned and data was stored in a specific closed file at the University of Groningen.

Results

In the following paragraphs I will first discuss the main findings of the online questionnaire, then make a small connection of the quantitative and qualitative data, and then discuss the main findings of the email interview, i.e. the main themes that emerged through the coding process and how they relate to the research question.

Demographic Information

The sample consisted of four female participants between the ages 24 to 29 (mean= 26, SD = 2.16). Three participants were of Dutch and one of non-Dutch nationality. Three participants spent four days on the ICU and one participant five days. Three participants indicated living together with a partner and one was single living with her parents. None of the participants had any children. When asked if they experienced any other psychological complaints all participants indicated to not suffer from any. The participants' highest educational levels were: one participant had a university education, one had pre-university education, another participant had a vocational education, and the last one had higher vocational education. The religious affiliations were: one participant was catholic and three participants had no religious affiliation. Further descriptive statistics for the sample of demographic and non-demographic data can be found in Table 1.

Quality of life

The participants rated their quality of life on a 10 point scale ranging from 0 (very bad) to 10 (very good). The rating of their perceived quality of life before the admittance to the ICU had a mean of 7.5 , while the quality of life at 3-6 months after the ICU had a mean

of 7.75, which indicates on average a good quality of life before and after the ICU. Three participants reported a quality of life score above 7 (i.e. good quality of life), while one participant reported a quality of life score of 5 (i.e. average quality of life).

Religiosity and Spirituality

"I view myself as religious" and "I view myself as spiritual" were scored on a 4-point likert scale from 1 (not at all) to 4 (completely). The scores for the four participants were: participant 1 (religious: 3; spiritual: 3), participant 2 (religious: 2; spiritual: 2), participant 3 (religious: 1; spiritual: 3), participant 4 (religious: 2; spiritual: 3). Overall participants indicated to view themselves as more spiritual than religious. Participants gave the following definitions of spirituality: participant 1: "Balance of the soul and body." ; participant 2: "Strength you receive from someone who has passed away, someone I was very close to." ; participant 3: "More the inner experience." ; participant 4: "The same as with religion, only a religion is fixed; the Quran, Bible, etc. Spirituality has a freedom of belief.".

Spiritual Coping and Need for Spiritual Care

"Spirituality plays a role for me in dealing with my disease and treatment" was scored on a 4-point likert scale from 1 (not at all) to 4 (completely). Participants scored 3 (participant 1), 3 (participant 2), 3 (participant 3), and 2 (participant 4), with a mean score of 2.75 that indicates a high importance of spirituality in dealing with the disease and treatment.

"I discussed spiritual topics with care professionals" was scored on a 5-point likert scale from 1 (very often) to 5 (never). The scores were 5 (participant 1), 4 (participant 2), 3 (participant 3), and 3 (participant 4). The scores indicate that two participants only rarely or never spoke with care professionals about spiritual topics and the other two participants only once in a while. Furthermore, participants reported to be satisfied with how often they talked

with care professionals about spiritual care. Which also indicates that two participants had only minimal or no need for spiritual care from care professionals, and the other two participants had some need for spiritual care.

Table 1
Descriptives

	Minimum	Maximum	Mean	Standard Deviation
Quality of Life before ICU (10-point likert scale)	5	9	7.5	1.914
Quality of Life after ICU (10-point likert scale)	5	9	7.75	1.893
Self-reported religiosity (4-point likert scale)	1	3	2	0.816
Self-reported spirituality (4-point likert scale)	2	3	2.75	0.500
Spiritual coping (4-point likert scale)	2	3	2.75	0.500

Connection of qualitative and quantitative data

The definitions of the participants personal definition of spirituality, their low scores on need for spiritual care, and the unchanging quality of life scores were reflected from the emerging themes from the email interviews. The data were analysed and categorized with open code (148), axial codes (22), 5 sub-themes with 3 emerging main themes and one core theme.The core theme was "dealing with uncertainty" with three emerging themes: *loss of control, care professionals,* and *needs.*

Loss of Control

All participants described different negative experiences that were made during the ICU admittance or during the ICU stay that were about having no control. Participant 1 described the problem of not having any control anymore about what the care professionals were doing with her: "*They touched my body a lot without saying anything; sometimes they came and there was almost a needle in my leg before I even could make it clear that I did not want that or wanted to know what it was or why it had to be done*.".

The fear of losing control was, next to the direct experiences around the ICU, also described in a meta-cognitive manner, as the control one feels to have about one's own bodily health. Participant 1 demonstrated that with her coming to terms with the fact that she has no control over her own mortality anymore: "*Our old bodies are gone. With every setback there is a fear that it will be the last for one of us [sisters]*.".

Participant 2 describes how she lost control over her own future, by describing how she was not able to make decisions anymore based on what she wanted, but on what her body dictated: "*I often worry about how my future will look like. Due to my limitations I have not been able to follow the education I would like to have, I cannot find a job and I cannot live on my own, while I would very much like to.*"

Losing control was mostly themed around the participants feeling powerless about how they were admitted and treated on the ICU and how their bodies lost abilities and control of body functions (i.e. being unconscious, loss of sensation or memory). Additionally, participants felt having no control over their circumstances or their own destiny: "*A call was then made to my doctors and they decided to take me with the ambulance from my parents place to the UMCG*"

The instances where participants described issues about perceiving having lost control over a part of their life were always accompanied by an increase in uncertainty about what did happen, how something happened or what will happen. At the same time all participants also tried to reduce these feelings of uncertainty. During the interview different ways to cope emerged that ultimately gave participants back a feeling of control. One theme that emerged was that participants looked for ways or answers to accept the situation. Participant 3 accomplished this by focusing on the moment and being conscious about the present, which can be seen as a form of practicing mindfulness and is conform with part of the definition of spirituality I stated at the beginning (i.e. *Spirituality is the dynamic dimension of human life...,and the way they connect to the moment, to self, to others...*): "*I try to live in the here and now and enjoy every moment. I try not to think much about it because I have no power to change things. If anything happens, it's not my fault.*"

For Participant 1 a comparable theme of spiritual coping emerged by shifting her focus on the present and on surviving her current situation until she can receive a transplantation: "*But I think you need that [happy moments] in my case to survive. I am now fighting for a chance for a better and second life, I am focused on that and I am working for it now.*"

Participant 1 was at the same time the participant that reported the most explicit instances of experiencing a loss of control over her own body and the situation she was put into, when care professionals were not communicating with her about what they were doing. At the same time participant 1 reported the lowest quality of life, and was the least satisfied with the spiritual care that she received: "*In my experience, the attention for spiritual care by care professionals to intensive care patients is insufficient.*[…] *During the last IC stay they should have made more effort to listen to me and get to know m*e." With that participant 1

indicates that she was reliant on care professionals to initiate contact with her about her spiritual needs, to reduce her perception of having no control over her situation.

Care Professionals

Care professionals emerged as another important theme during the interviews. The care professionals and how they behaved and communicated had an important influence on how participants experienced their admittance and stay on the ICU. Each participant described her positive and negative experiences with care professionals. Empathy, support, open communication, and being treated as a human being were important categories. One participant described that the Care professionals served as a support during her admittance but also after her admittance, if she wanted: "*I think I was very well guided by them and I was even allowed to visit again.*"

Another participant indicated that empathy was beneficial for her well-being, instead of harsh words: "*To me, good care means that a care professional has empathy and understanding, tough love isn't helpful for me.*" She described an experience during her ICU admittance where she was treated inhumanely by care professionals, who did not acknowledge her pain but instead tried to relativize and trivialize it: *"During one of my admittances I had to lie on one side of my body, where I just had a drain in it and also a lot of scars. I was dying of the pain. But when I started crying due to the unbearable pain, the Care professionals told me I had to push through the pain, because they already had seen a lot of patients who were in worse situations compared to me, and these patients did not even cry once. When I cried due to the pain the Care professionals asked me: "You aren't weak, or perhaps you are?". "* This was a traumatic experience for the participant that could be prevented if her pain and discomfort were at least acknowledged during her admittance. If the Care professionals would have managed to show more empathy and support, the ICU

experience would still have been painful for the participant but less traumatic. She further indicated in the interview that this traumatic experience increased her anxiety and stress for future admittances and encounters with care professionals.

Another participant indicated that her care professional listened and understood her needs. This care professional had a holistic perspective by focusing on the mind and body, which was helpful for the patients recovery and self-esteem: *"Luckily, I have a care professional who is very positive. She also gives haptonomy and let's me know and feel that I am good the way I am. She does this by giving massages and particular exercises."* She elaborated further about the care professionals approach, and indicated that her situation was taken into account and the given advice was based on her current needs: *"At the beginning of each session we talk about what we experienced lately and how we are doing. She [the Care Professional] gives me advice, suitable for my situation."* What this participant appreciated specifically was the care professionals ability for empathy and caring for her well-being: *"After my stay at the hospital when I got back home, she visited me immediately and we had a great time just chatting."* The participant viewed this care professional as altruistic and understanding, for not even charging a fee when visiting the participant at home. This had a positive impact on the participants' experience with, and opinion about, care professionals: *"This care professional is retired now, but we still keep in touch. Last year she gave me a treatment, without even asking for a payment. This says enough about her!"* She indicated that a good care professional should have a certain expertise and skill set that enables him or her to interact with the patient: *"To me a good care professional is somebody who is honest, makes you feel comfortable, really takes her time and listens carefully, gives decent advice that is suitable for the situation and problem. The care professional I was talking about meets all of these demands."*

Another participant mentioned that a positive opinion and advice of care professionals about her health have an effect on her stress and anxiety: *"Care professionals have a small role in dealing with my illness and emotions. If I notice that they are positive [about my health] then I worry less. But they also mention that I can't control becoming ill again."*
An important concept about care professionals that came up with all participants was about care professionals expertise and professionalism: *"No one ever asked if I or my family needed spiritual care. Frankly, I did not expect that from the doctors and nurses. I do expect it more that someone else will give spiritual care, for example a (medical) psychologist."*

Another mentioned that it depends on the function of the care professional: "*A doctor has more to do with this [spiritual care] than a nurse, because he has to answer more life questions, how long do I have to live, for example, than a nurse. And a therapist should certainly be able to do this [spiritual care], but a nurse does not necessarily have to. Therapists should provide spiritual care and a doctor should be able to provide it as well, in comparison to a nurse.*"

Participants mentioned that a care professional should be able to provide spiritual care if needed and that asking questions could be helpful: "*Spiritual care should not be forced upon a patient. You can often tell if someone needs support. Don't push it, but do ask some good questions.*"

Another patient mentioned that spiritual care should be provided only when necessary: *"Spiritual care should be provided when the patient raises this subject or asks for it, but also when such questions arise during a conversation. Or when the patient is clearly not feeling well."* This means that care professionals should listen carefully to the needs of the patients, and if the patient is not able to talk, the CP should be attentive to non-verbal signals as well that might indicate a need for communication: "*During the last IC stay, they [the Care*

professionals] should have made more of an effort to listen to me and get to know me better. They also should have shown more empathy." The participant also mentions that she appreciated it when care professionals made an effort to communicate with her during her stay in the ICU: "*Although I was unable to speak, they arranged an iPad so that I could still communicate a bit, although it was very difficult.*"

Another participant also mentioned that care professionals should be able to listen to patients and help them deal with issues occurring during the ICU stay and afterwards: "*A good care professional is somebody who listens to the patient's and her relatives. If the patient has physical problems, the care professional has to help her, but she should also realize that patients can have mental issues, e.g. questions about the admittance or just emotions. The care professionals should take the time for these patients and help them with mental issues as well.*"

One participant mentioned that the support from her care professionals helped to get her through hardships during and after the ICU admittance: "*During the aftercare I had the chance to discuss what my condition would mean for my future. The care professionals supported me a lot, by making it feasible for me to cope with what happened and not to get stuck in what happend. The care professional gave me a lot of support during the brief period I was conscious during the ICU admittance. When I got back to the ward, there were two care professionals who sat down next to my bed when I had a hard time [dealing with my situation].*" Hence, a care professional that shows empathy and communicates with the patient even after the admittance leaves a lasting impression and is appreciated highly: "*One aftercare professional did an excellent job. She rushed over to see me in the ICU [after I was admitted there for the second time] and when I got back home she contacted me by phone a few times [to see how I was doing]. This was extremely meaningful to me.*" But sometimes

care professionals forget to make a connection and to have the patience to ask the right questions to the patient's: "*The care professional should make a connection with the patient and ask the right questions*". This patient also indicated that the spiritual care she received was insufficient, because she was never asked if she or her family wanted spiritual care. Another participant indicated that she did not talk about spirituality with her care professionals, but being part of the medical process was what she needed at that time: "*We didn't talk about spirituality, but they listened to what I needed: they made me part of the whole medical process.*"

One participant mentioned that the different needs of different patients should be taken into account by the care professional in order to provide good care: "*Sometimes the patient needs support, sometimes she needs a harsh wake up call, and sometimes the patient needs somebody that just listens without judging her directly.*"

Good care was for one participant also just care professionals trying their best and being empathetic care professionals that treat participants as humans: "*Good care means that the best possible care is given, in the most human way, with empathy.*"

Needs

A third emerging theme from the interview data was "needs". All patients had needs that had to do with self-esteem, autonomy and support. Participant 1 mentioned that she didn't have the chance, due to her condition, to experience what young adults experience in life: "*I have not been able to do many things that a normal young person experiences (...) I have always been more mature than peers because I have had to grow up quickly and deal with my medicines and take care of myself in an adult way.*" Because she had different experiences in life (e. g. her ICU admittances, recovery and future admittances) she also felt different then her peers: "*As a result, I am more mature than peers because I had to grow up*

quickly due to the situation." Due to this situation she is dependent and needs help with medication and care, but she also needs support from her family and boyfriend. She developed a special bond with her family and boyfriend which enabled her to express and share her feelings and worries with them whenever necessary: "*Nowadays we can handle it all, for each other but also with each other: we can share the pain and sorrow [...] we keep doing fun things, stay normal, but above all: we talk to each other.*" She mentioned receiving a lot of support and understanding from her family and boyfriend: "*My parents, sister and especially my boyfriend support me very well [...] they understand me, and when I'm too weak to explain something better, they will explain it for me and help me out.*" But besides support from her family she also met a girl who is in a similar situation and she can share experiences with. Hence, this girl and "fellow sufferer" functions as a role model, but she also serves as a source of inspiration and power to this participant: "*I find support in people who are in similar situations, because they understand what I am going through [...]. There is this girl [who experienced the same] that I have contact with. She is a role model for me in dealing with [my] illness and admittances.*" This participant moved from her home back in with her parents, due to her medical condition and this experience gave her the possibility to share hardships with her family on a daily basis if necessary: "*My boyfriend and I temporarily live with my parents because there is too much Corona in my town at this moment. So, I speak to my parents and boyfriend on a daily basis.*" She indicated that she needs a lot of help and her family supported her: "*Due to my condition I need a lot of help: with my medication, personal care and daily errants [...] at the moment, my boyfriend does a lot. He does the medical procedures such as changing the IV two times a day, making sure my medication is sorted out: he became sort of a nurse [due to the situation]. Besides that, he also helps out a lot in the house.*" Because her family and boyfriend helped her out as much as they could, she was

able to save some energy and this motivated her to do what she liked and helped her to stay human. Hence, she was able to find strength from this situation: "*This is very helpful for my energy level and for my self image, indirectly serves as a source of balance and resilience because I have more time and energy to focus on the things that matter to me, and not only do what has to be done: this enables me to stay human*".

Participant 2 indicated that she often worried about her future. Her limitations prevented her from having success in finding a suitable job or study. She needed these positive experiences to feel better about herself in a way: "*It is difficult that I suffer from fear of failure and a poor self-image* [...]. *This hinders me in daily life, it makes me very sad and very insecure*."

The chance for her to have positive experiences after her IC admittance seemed to be small, because she kept being rejected by employees due to her limitations and she felt insecure due to being treated different: "*Due to my limitations I have not been able to follow the education I would have liked to have, I cannot find a job and I cannot live on my own, while I would very much like to*." The need to "live on my own" means more than simply moving out of her parents house. That implied being able to make autonomous decisions as a young adult without being dependent on others. The job rejections caused feelings of being useless and having failed: "*I have finished a study, but I always get rejected because of my limitations. This makes me sad, it also makes me feel useless. In my opinion I have failed*." This participant indicated that she needed a job and a home to become independent and make autonomous decisions. In the end, the participant was able to find suitable work where she was appreciated for her capabilities, felt valuable and had a feeling she contributed to society. She reported this as a positive experience which had an impact on her self-esteem and motivated her. She mentioned that she shared hardships with her friend: "*I feel happy*

whenever I'm out with a good friend of mine and we are able to laugh, but also offer each other a shoulder to cry on."

Participant 3 indicated that she needed moments with her family, friends, boyfriend or pets, having conversations and time with them made her happy. She indicated that it also was important to her that she also could be valuable to others: "*Happiness means that I have fulfilled enough in life, and that I can help myself and others.*" She indicated it was important that she could still enjoy life and continue with the things that made her happy. In comparison to the other participants, she indicated to be satisfied with her life and most of her needs were met: "*I need nothing more than I already have at the moment.*"

Participant 4 mentioned she needed a balance between work, finances and family in order to experience quality of life: "*Good quality of life is when there is a balance between work, finances and family.*" She mentioned that she had a solid support system surrounding her: "*I have people around me that I can fall back on.*" She also indicated that besides support her health was more stable at this moment, hence she was more satisfied with that than before: "*Now that my health is more stable, I am more satisfied.*" But even though her health seemed to be stable, she still was afraid she would relapse in the future which made her feel insecure: "*In order for me to experience more quality of life I need that this situation remains stable. I'm still not sure if I can or won't have another attack. I have to learn to deal with that. If I'm successful in dealing with my situation, this will give me peace and more quality of life.*" But having found a respectable job at a new employer also was a positive experience to her and contributed to her self-esteem: "*I start at my new employer soon and that also offers me a better future perspective.*"

All of the participants indicated they had a need for communication with their families, parents, friends, and partners, because they allowed them to share their feelings and

find similarities with other people in similar situations. One participant indicated that she had therapy in the past and this also served as a source of support for her.

Discussion

While spirituality and spiritual needs seem to be linked with positive outcomes in Quality of Life (QOL) and meaning-making, the exact relationship between these concepts is still not well understood, or studied in patients in the intensive care unit (ICU). Therefore, in this mixed-method study I retrospectively explored the self-identified spirituality and spiritual needs of patients during the ICU, and how they relate to quality of life and meaning-making at 3-6 months after discharge. In the following paragraphs I will highlight the results found related to the research question, followed by unexpected results.

I found indications that self-identified spirituality was linked to QOL, and meaning-making, which surprisingly seemed to depend on the participants' individual definitions of spirituality. This was shown in the interviews with the emergence of a core theme "dealing with uncertainty", and three main themes: "loss of control", "needs", and "care professionals". While all participants were identifying themselves as being spiritual and also reported spirituality as playing a role in dealing with their illness, spirituality was shown to be mostly of use when it could help to reduce "uncertainty", e.g. to provide answers or to help focus on certain aspects like the present or the moment. Then spiritual care could help to reduce the negative experience of losing control over one's own body and the situation a patient is subjected to. Although all participants self-identified as spiritual, three of them reported comprehensive and distinct (from religiosity) definitions of spirituality, including facets such as transcendence and connecting to the self or the moment that fit with the definition of spirituality by Puchalski used in this study, and reported overall higher global QOL before and after the ICU. For them spirituality functioned as an internal factor that

helped to reduce feelings of uncertainty that they experienced because of their illness and

being in a situation (i.e. in the ICU) where they seemingly lost control of their body and life.

This was contrasted by one participant, who, although she was similar to the other participants

in identifying as being a spiritual person and that spirituality played a role in dealing with her

illness, had a consistent low global QOL before and after the ICU. There was a difference in

her use of spirituality which showed mainly in how she defined spirituality. Her definition

contained broader and global terms (i.e. "Spirituality is a free way of believing"), and did not

incorporate any of the substantial facets of spirituality that are essential in the definition by

Puchalski. Additionally, that participant reported the lowest QOL before and after the ICU,

and recalled more difficulties to re-appraise her ICU experiences and new life situation, being

unable to shift her focus away from her illness and fear of loss of control. Part of these

findings were in accordance with a study by McSherry and Cash, who also identified the issue

of the vagueness of spirituality in care settings, and emphasize the necessity to not only use

proper definitions that incorporate the right concepts, but also that patients and care

professionals need a common definition, in order to promote patients making use of actual

spiritual practices that offer benefits and at the same time minimise the miscommunication

between patients and care professionals, when they discuss a patient's spiritual needs.[59] A

definition of spirituality that is inspired by the current study and takes into account what the

participants mentioned to benefit from should emphasize spirituality as a way to find personal

strength from connecting with oneself, an appreciation of the present moment, and a

transcending connection with others.

The effects of the participants self-identified spirituality and spiritual needs on the

meaning-making process were less clear. As expected all participants showed some form of

---

[59] McSherry, Wilfred, and Keith Cash. "The Language of Spirituality: An Emerging Taxonomy." *International Journal of Nursing Studies* 41, no. 2 (February 2004): 151–61. doi:10.1016/S0020-7489(03)00114-7.

stress-related growth triggered from the discrepancy of needing to appraise their illnesses and

ICU experiences in light of their global meaning, which elicited positive changes, e.g. feeling

closer to partner and family, rethinking life philosophies.[60] According to Puchalski's

definition of spirituality used in this study, some participants also showed spiritual growth,

which they described as "acceptance of their circumstances" or "connecting to the moment".[61]

The processes that came forth in the interviews are in line with the meaning-making model

and supported by an article from Crystal L. Park about the role of spirituality in the

meaning-making model of cancer survivors.[62]

A study by Abu et al. reported that fulfilling patients spiritual needs was positively

associated with higher physical, mental and emotional well-being.[63] This was also hinted at in

the current study, where participants, that experienced more of their spiritual needs being met,

generally reported more positive opinions about the care professionals and the ICU

experience, and had higher measures of QOL. On the other hand, a participant that had none

of her spiritual needs met reported more instances of feeling out of control, and generally felt

more anxious about her contact with care professionals. What also emerged as an unexpected

finding during the interview was that "expectations to receive spiritual care" seemed to

influence how negative the impact of not having the spiritual needs met by care professionals

was for participants. While two participants reported receiving little to no spiritual care while

---

[60] Sumalla, Enric C., Cristian Ochoa, and Ignacio Blanco. "Posttraumatic Growth in Cancer: Reality or Illusion?" *Clinical Psychology Review* 29, no. 1 (February 2009): 24–33. doi:10.1016/j.cpr.2008.09.006.

[61] Cole, Brenda S., Clare M. Hopkins, John Tisak, Jennifer L. Steel, and Brian I. Carr. "Assessing Spiritual Growth and Spiritual Decline Following a Diagnosis of Cancer: Reliability and Validity of the Spiritual Transformation Scale." *Psycho-Oncology* 17, no. 2 (February 2008): 112–21. doi:10.1002/pon.1207.

[62] Park, Crystal L. "Spirituality and Meaning Making in Cancer Survivorship." In *The Psychology of Meaning.*, edited by Keith D. Markman, Travis Proulx, and Matthew J. Lindberg, 257–77. Washington, DC: American Psychological Association, 2013. doi:10.1037/14040-013.

[63] Abu Hawa O, Christine Ulbricht, Eric Ding, Jeroan J. Allison, Elena Salmoirago-Blotcher, Robert J. Goldberg, and Catarina I. Kiefe, "Association of Religiosity and Spirituality with Quality of Life in Patients with Cardiovascular Disease: A Systematic Review.", Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, *Care & Rehabilitation* 27, no. 11 (November 2018): 2777–97. doi:10.1007/s11136-018-1906-4.

in the ICU, one of them had more expectations about being offered spiritual care and perceived the lack thereof as a bigger negative impact on her ICU experience. Participants defined spiritual care in terms of care professionals trying to "being present", offering advice, or attempting to communicate with a patient. This highlights the need for care professionals to be able to clearly communicate with patients about what they can and cannot expect, to decrease the negative effect of the ICU.

Spiritual care provided by care professionals was mostly seen as insufficient or even unwanted unless offered by someone with expertise. This was also driven by the idea that there should be a separation in care provided by care professionals, which is most likely due to the negative experiences some of the participants had with the care professionals they engaged with on a daily basis. Therefore, having a care professional on the ICU that is more focused on providing spiritual care and less in the daily routine with patients might help them to voice their spiritual needs. An additional unexpected result was that communication not only played a big role in building a patient-care professional relationship, but could also help to increase a patient's perception of control even if the communication only comes from the care professional. The participants recalled when they were not able to communicate with the care professionals that being offered communication can already help in reducing stress, including spiritual topics. This was especially the case for participants that were not always able to initiate communication due to having an endotracheal tube. In these instances they would appreciate the offer of communicating through devices like a tablet with the care professionals, because just having the opportunity was a source of feeling more secure and in control.

While "dealing with uncertainty" was the core theme of the interviews, what it often tied together with the main themes "loss of control" and "needs" were the care professionals.

While being admitted to the ICU is usually caused by unexpected and serious events (e.g. sudden illness or accident) that change a person's life completely with long lasting effects, the care professionals were for all participants a big point of focus that determined how the participants experienced the ICU. In that perspective the ICU was almost synonymous with the care professionals. This was highlighted by one participant that mentioned lasting stress and anxiety from how she was treated from care professionals or another participant that mainly mentioned one care professional that was enough to positively impact her overall ICU experience. In that regard, spiritual care provided by care professionals might even have a bigger impact on participants' QOL than participants own individual spiritual identity and practices. Spiritual care that is provided by care professionals comes with further benefits for patients like communication, connecting with others, reducing uncertainty and increasing perceived control over the patient's body and treatment, which are beyond the limit of what spirituality can offer if left only for the patients to take care of.

Limitations

The following paragraph investigates the most prominent limitations. First, the study suffered from limitations due to the low sample size. Although the population of people that are admitted to the ICU is quite small, the sample size of the current study is still too low to confidently draw conclusions from, but there were still indications to be found for future research.

Second, there were many possible confounding factors that could have influenced the results. While participants were questioned about their spiritual needs, the spiritual care they received, and how satisfied they were about the spiritual care, they were amongst other things not controlled for other sources that offered spiritual care or support. This is related to the third point, which is that the current study was a retrospective study. Participants were

required to remember and recall their ICU experiences from 3-6 months before. Besides the obvious point that participants could have simply forgotten instances where care professionals did try to communicate with them, their memories can also be altered by the traumatic aspect of the experience or the quality of care they received at the point of the interview. Though this questions the validity of the results of the current study the participants' recollections are still representative of how they experienced the ICU and the care they received. A few positive or negative experiences could respectively reinforce a more positive or negative opinion about the ICU or care professionals, but nonetheless these experiences still offer insight into possible trends that emerged between spirituality and QOL or meaning-making, and are therefore still representative. Additionally, by carefully analyzing and interpreting the participants' answers through the lens of their complete experience, the impact of this limitation can still be controlled for.

A fourth point of discussion, which is related to the previous one, was the use of a structured email interview. While such an interview has many advantages, e.g. participants can take their own time to answer and there is less chance that the researcher can influence the results, there were also disadvantages, i.e. I was not always able to get more detailed answers on every point, or patients were less inclined to verify if they correctly understood a question. This offered a great variety of answers that often went in different directions depending on the individual, but were less easy to compare as well.

Recommendations

Due to the COVID-19 virus, I decided to make use of email interviews, instead of the planned face-to-face in-depth interview method at the start of this research (before the COVID-19 virus). Despite some negative aspects of not as easily being able to steer the conversation or emphasize certain questions, email interviews have proven to be a valid tool

that also offers many advantages. Especially for such a vulnerable population, the chance to individually and on their own terms go through the interview, makes it worth to consider. Additionally, participants were able to decide what they wanted to share and to what degree. Besides more autonomy, this also gave away more useful information about how to interpret a participant and their answers in comparison to face-to-face interviews, where the researcher can subconsciously lead the interviewed participant to give certain answers.

Although it was not the main focus, the results still lead to a clear recommendation for hospitals to invest in training healthcare professionals in "being present".[64] A spiritual caregiver with affinity for and knowledge of "being present" can further aid and train other ICU care professionals. Non-verbal and verbal communication should be improved by also including new methods and technologies, which can help to reduce participants' stress during the ICU admittance and any additional form of stress-reduction will consequently increase the effectiveness of all following treatments and rehabilitation efforts.

Conclusion

Intensive care can be a traumatic experience for patients, including long-lasting and persistent psychiatric, cognitive and physical impairments. The scientific literature so far showed that spirituality can contribute in positively coping with illnesses and drastic life events. This study retrospectively explored the self-identified spirituality and spiritual needs of patients during the ICU, and how they relate to quality of life and meaning-making at 3-6 months after discharge. They completed an online questionnaire and a structured email interview. The participants' ICU experiences were affected by uncertainty, a fear of loss of control, emerging of new needs and care professionals. Spirituality appeared to be linked to higher QOL by reducing uncertainty and giving participants a sense of control. This was

---

[64]Baart, "Een theorie van de presentie". C. F. Andries Baart, "Presentie", accessed June 1, 2020, https://www.andriesbaart.nl/presentie/

further impacted by how participants defined and used spirituality. There were indications that more effective meaning-making and re-appraisal was dependent on participants' use of spiritual practices (e.g. accepting their circumstances, connecting to the moment or the self). Furthermore, care professionals lack of spiritual care and communication did lead to increased uncertainty and was linked to more negative evaluations of the ICU experience, as well as lower QOL. These findings provide additional information that can help direct future research and highlight the importance of understanding the mechanism of spirituality in improving QOL for ICU patients.

Bibliography

Baart, A. *Een theorie van de presentie.* Utrecht: Boom Lemma Uitgevers, 2011.

Balboni, Michael, Adam Sullivan, Adaugo Amobi, Andrea Phelps, Daniel Gorman, Angelika Zollfrank. "Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training." *Journal of Clinical Oncology* 31 no. 4 (2013): 461–467.

Bekelman, David B., Sydney M. Dy, Diane M. Becker, Ilan S. Wittstein, Danetta E. Hendricks, Traci E. Yamashita, and Sheldon H. Gottlieb. "Spiritual Well-Being and Depression in Patients with Heart Failure." *Journal of General Internal Medicine* 22, no. 4 (April 2007): 470–77. doi:10.1007/s11606-006-0044-9.

Bulman, Ronnie J. and Camille Wortmann. "Attributions of blame and coping in the 'real world': Severe accident victims react to their lot." *Journal of Personality and Social Psychology* 35, no. 5, (1977): 351-363.

Burki K. Talha. "Post-traumatic stress in the intensive care unit." The Lancet Respiratory Medicine 7, nr 10, (2019):843-844. DOI:https://doi.org/10.1016/S2213-2600(19)30203-6.

Choi J, Leslie A Hoffman, Richard Schulz , Judith A Tate, Michael P. Donahoe, Dianxu Ren, Barbara A Given, Paula R Sherwood. "Self-reported physical symptoms in intensive care unit (ICU) survivors: pilot exploration over four months post-ICU discharge." *Journal of Pain and Symptom Management* 47, no. 2, (2014):257–270.

Cole, Brenda S., Clare M. Hopkins, John Tisak, Jennifer L. Steel, and Brian I. Carr. "Assessing Spiritual Growth and Spiritual Decline Following a Diagnosis of

Cancer: Reliability and Validity of the Spiritual Transformation Scale."
Psycho-Oncology 17, no. 2 (February 2008): 112–21. doi:10.1002/pon.1207.

Da Costa, Jaquilene Barreto, Sheila Taba, Julia Ricardi Scherer, Lucian Lucchesi F.
Oliveira, Kelen Cristina Barros Luzzi, Daniela Prochnow Gund, Gabriel
Sartori, Itamar R. P. Porto, Amaury C. Jorge, and Péricles Almeida Delfino
Duarte. 2019. "Psychological Disorders in Post-ICU Survivors and Impairment
in Quality of Life." *Psychology & Neuroscience* 12 no. 3, (2010):391–406.
doi:10.1037/pne0000170.

Davis, Christopher G., Danay C. Novoa. "Meaning-making following spinal cord
injury: Individual differences and within-person change." *Rehabilitation
Psychology, American Psychological Association* 58, no. 2, (2013): 166-177.

Donelson, Elaine. *Psychology of religion and adolescents in the United States: Past to
present. Journal of Adolescence* 22, no. 2, (1999):187–204.

Fildissis, George, Vassilius Zidianakis, Efi Tsigou, Despina Koulenti, Theofanis
Katostaras, Aikaterini Economou, & George Baltopoulos. "Quality of life
outcome of critical care survivors eighteen months after discharge from
intensive care." *Croatian medical journal* 48 no. 6, (2007): 814–821.
https://doi.org/10.3325/cmj.2007.6.814

Folkman, Susan, and Judith Tedlie Moskowitz. "Coping: Pitfalls and Promise."
Annual Review of Psychology 55 (February 2004): 745–74.
doi:10.1146/annurev.psych.55.090902.141456.

Gijtenbeek, Sandra. "De kracht van de intensive care". Accessed March 11, 2020,
https://www.medischcontact.nl/tijdschrift/medisch-contact-thema/thema-artikel
/de-kracht-van-de-intensive-care.htm

Griffiths, John, Robert A Hatch, Judith Bishop, Kayleigh Morgan, Crispin Jenkinson, Brian H Cuthbertson, and Stephen J Brett. "An Exploration of Social and Economic Outcome and Associated Health-Related Quality of Life after Critical Illness in General Intensive Care Unit Survivors: A 12-Month Follow-up Study." *Critical Care (London, England)* 17, no. 3 (May 28, 2013): R100. doi:10.1186/cc12745.

Farshid R. Bashar and Amir Vahedian-Azimi, Mahmood Salesi, Mohammadreza Hajiesmaeili, Seyedpouzhia Shojaei, Behrooz Farzanegan, Reza Goharani, et al., "Spiritual Health and Outcomes in Muslim ICU Patients: A Nationwide Cross-Sectional Study.", *Journal of Religion and Health* 57, no. 6 (December 2018): 2241–57. doi:10.1007/s10943-017-0543-5.

Groot, Marieke, Anne Ebenau, Helen Koning, Anja Visser, Carlo Leget, Hanneke W.M. van Laarhoven, Rene Leeuwen, Riet Ruben, Marijke Wulp en Bert Garssen. "Spiritual care by nurses in curative cancer care: Protocol for a national, multicentre, mixed method study". *Journal of advanced nursing* 73, no. 9, (2017):2201-2207. https://doi.org/10.1111/jan.13332.

Haraldstad, K., A. Wahl, R. Andenæs, J. R. Andersen, M. H. Andersen, E. Beisland, C. R. Borge, E. Engebretsen, M. Eisemann, L. Halvorsrud, T. A. Hanssen, A. Haugstvedt, T. Haugland, V. A. Johansen, M. H. Larsen, L. Løvereide, B. Løyland, L. G. Kvarme, P. Moons, T. M. Norekvål, L. Ribu, G. E. Rohde, K. H. Urstad, S. Helseth. "A systematic review of quality of life research in medicine and health sciences." *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation* 28, no. 10, (2019): 2641-2650. DOI:10.1007/s11136-019-02214-9

Herrmann, Christoph. "International experiences with the Hospital Anxiety and Depression Scale — a review of validation data and clinical results." Journal of Psychosomatic Research 42, no. 1, (1997):17-41.

Herridge, S. Margaret, Catherine M. Tansey, Andrea Matté, George Tomlinson, Natalia Diaz-Granados, Andrew Cooper, Cameron B. Guest, C. David Mazer, Sangeeta Mehta, Thomas E. Stewart, Paul Kudlow, Deborah Cook, Arthur S. Slutsky and Angela M. Chung. "Functional disability 5 years after acute respiratory distress syndrome." *The New England Journal of Medicine* 364, (2011): 1293-304, DOI: 10.1056/NEJMoa1011802.

Ho, Q. Jim., Christopher D. Nguyen, Richard Lopes, Stephen C. Ezeji-Okoye, Ware G. Kuschner. "Spiritual Care in the Intensive Care Unit: A Narrative Review." *Journal of Intensive Care Medicine* 33, no. 5, (2018):279–287, DOI:10.1177/0885066617712677.

Karnatovskaia, Lioudmila V., Margaret M. Johnson, Roberto P. Benzo, Ognjen Gajic. "The spectrum of psycho cognitive morbidity in the critically ill: a review of the literature and call for improvement." *J Crit Care*. 2015;30(1):130-137. doi:10.1016/j.jcrc.2014.09.024

Kearns, Nathan T., Josh Becker, Kenleigh McMinn, Monica M. Bennett, Mark B. Powers, Ann Marie Warren, and James Edgerton. "Increased Spiritual Well-Being Following Cardiovascular Surgery Influences One-Year Perceived Posttraumatic Growth." *Psychology of Religion and Spirituality*, (2019), doi:10.1037/rel0000291.

Kendall, J. "Axial coding and the grounded theory controversy." *Western journal of nursing research* 21 no. 6, (1999): 743-757. https://doi.org/10.1177/019394599902100603

Koenig, Harold G. "Religion, spirituality, and health: the research and clinical implications." *ISRN psychiatry* 278730, (2012). DOI:10.5402/2012/278730

Leech N. L. and A. J. Onwuegbuzie. "Guidelines for Conducting and Reporting Mixed Research in the Field of Counseling and Beyond". *Journal of counseling and*

development 88   no.   1,   (2010):   61-69,
https://doi.org/10.1002/j.1556-6678.2010.tb00151.x

Lundberg, C. Pranee and Petcharat Kerdonfag. "Spiritual care provided by Thai nurses
    in intensive care units". Journal of Clinical Nursing 19, no. 7‑8, (2010).
    https://doi.org/10.1111/j.1365-2702.2009.03072.x

Marshall, C. John, Laura Bosco, Neill K Adhikari, Bronwen Connolly, Janet V Diaz,
    Todd Dorman, Robert A Fowler, Geert Meyfroidt, Satoshi Nakagawa, Paolo
    Pelosi, Jean-Louis Vincent, Kathleen Vollman and Janice Zimmerman. "What
    Is an Intensive Care Unit? A Report of the Task Force of the World Federation
    of Societies of Intensive and Critical Care Medicine". *Journal of Critical Care*,
    (2017):270-276.
    DOI: 10.1016/j.jcrc.2016.07.015 https://pubmed.ncbi.nlm.nih.gov/27612678/

McSherry, Wilfred, and Keith Cash. "The Language of Spirituality: An Emerging
    Taxonomy." *International Journal of Nursing Studies* 41, no. 2 (February
    2004): 151–61. doi:10.1016/S0020-7489(03)00114-7.

Merbitz, Nancy Hansen, Katharine Westie, Jennifer A. Dammeyer, Lester Butt, and
    Jessica Schneider, "After Critical Care: Challenges in the Transition to
    Inpatient Rehabilitation.", *Rehabilitation Psychology in Critical Care* 61, no.
    2, (May 2016): 186–200, DOI:10.1037/rep0000072.

Needham, Dale M, Judy Davidson, Henry Cohen, Ramona O Hopkins, Craig Weinert,
    Hannah Wunsch, Christine Zawistowski, et al. "Improving Long-Term
    Outcomes after Discharge from Intensive Care Unit: Report from a
    Stakeholders' Conference." *Critical Care Medicine* 40, no. 2 (February 2012):
    502–9. doi:10.1097/CCM.0b013e318232da75.

Park, Crystal L. and Susan Folkman. "Meaning in the Context of Stress and Coping." *Review of General Psychology* 1, no. 2 (1997): 115–44. DOI:10.1037//1089-2680.1.2.115.

Park, Crystal L., "Testing the Meaning Making Model of Coping with Loss.", *Journal of Social and Clinical Psychology* 27, no. 9 (November 2008): 970–94. doi:10.1521/jscp.2008.27.9.970.

Park, Crystal L. "Spirituality and Meaning Making in Cancer Survivorship." In *The Psychology of Meaning.*, edited by Keith D. Markman, Travis Proulx, and Matthew J. Lindberg, 257–77. Washington, DC: American Psychological Association, 2013. doi:10.1037/14040-013.

Puchalski, C. M. "The role of spirituality in health care." *Baylor University Medical Center proceedings* 14, no. 4 (2001): 352-7. DOI:10.1080/08998280.2001.11927788

Puchalski, Christina M, Robert Vitillo, Sharon K Hull, and Nancy Reller. "Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus." *Journal of Palliative Medicine* 17, no. 6 (June 2014): 642–56. doi:10.1089/jpm.2014.9427.

Rawal Gautam, Yadav Sankalp & Kumar Raj. "Post-intensive Care Syndrome: an Overview." *Journal of translational internal medicine*, 5 no. 2, (2017): 90–92. https://doi.org/10.1515/jtim-2016-0016

Steinhauser, Karen E., George Fitchett, George F. Handzo, Kimberly S. Johnson, Harold G. Koenig, Kenneth I. Pargament, Christina M. Puchalski, Shane Sinclair, Elizabeth J. Taylor, and Tracy A. Balboni. "State of the Science of

Spirituality and Palliative Care Research: Part I: Definitions, Measurement, and Outcomes." *Journal of Pain and Symptom Management* 54, no. 3 (September 2017): 428–40. doi:10.1016/j.jpainsymman.2017.07.028.

John M. Salsman, James E. Pustejovsky, Heather S. L. Jim, Alexis R. Munoz, Thomas V. Merluzzi, Login George, Crystal L. Park, et al., "A Meta-Analytic Approach to Examining the Correlation between Religion/Spirituality and Mental Health in Cancer.", *Cancer* 121, no. 21 (November 1, 2015): 3769–78. doi:10.1002/cncr.29350.

Schandl, Anna, Matteo Bottai, Orjan Hellgren, Elisabeth Sundin, Peter Sackey. "Gender differences in psychological morbidity and treatment in intensive care survivors - a cohort study." Critical Care 16, no. 3, (2012). DOI:10.1186/cc11338

Streib, Heinz and Ralph Hood. *Semantics and psychology of spirituality. A cross-cultural analysis.* New York: Springer, 2016.

Svenningsen, Helle. "Associations between sedation, delirium and post-traumatic stress disorder and their impact on quality of life and memories following discharge from an intensive care unit." *Danish Medical Journal* 60, nr 4, (2013):4.

Terblanche, Marius, Peter Kruger, Stefania di Gangi, Sadiq Gearay, Lynn, Gilfeather, Niall Ferguson, Rupert Pearse, Richard Beale, Andrew Rhodes, Stephen Brett, & Daniel McAuley. "Risk factors for acute organ failure in intensive care unit patients who receive respiratory support in the absence of non-respiratory organ failure: an international prospective cohort study." *Critical care* 16, no. 2, (2017). https://doi.org/10.1186/cc11306.

Thomas, J. and Angela Harden. "Methods for the thematic synthesis of qualitative research in systematic reviews." *BMC Medical Research Methodology* 8, (2008):45. https://doi.org/10.1186/1471-2288-8-45

Tomasi, J. C. Warren, L. Kolodzey, S. Pinkney, A.M. Guerguerian, R. Kirsch, C. Sperling, P. Sutton, P. Laussen, J. Hubbert and P. Trbovich. "Convergent parallel mixed-methods study to understand information exchange in paediatric critical care and inform the development of safety-enhancing interventions: a protocol study." *British Medical Journal* 8, (2018). DOI: 10.1136/bmjopen-2018-023691. PubMed PMID: 30173162.

Samual R. Weber and Kenneth I. Pargament, "The Role of Religion and Spirituality in Mental Health.", *Current Opinion in Psychiatry* 27, no. 5, (2014): 358–63, doi:10.1097/YCO.0000000000000080.

Sumalla, Enric C., Cristian Ochoa, and Ignacio Blanco. "Posttraumatic Growth in Cancer: Reality or Illusion?" *Clinical Psychology Review* 29, no. 1 (February 2009): 24–33. doi:10.1016/j.cpr.2008.09.006.

Willemse, S. W. Smeets, E. van Leeuwen T. Nielen-Rosier, L. Janssen N. Foudraine. "Spiritual care in the intensive care unit: An integrative literature research." *Journal of Critical Care* 57, (2020): 55-78. https://doi.org/10.1016/j.jcrc.2020.01.026

Suzan Willemse, Wim Smeets, Evert van Leeuwen, Loes Janssen, and Norbert Foudraine. "Spiritual Care in the ICU: Perspectives of Dutch Intensivists, ICU Nurses, and Spiritual Caregivers.", *Journal of Religion and Health* 57, no. 2 (April 2018): 583–95. https://doi:10.1007/s10943-017-0457-2.

Wintermann et al. "Impact of post-traumatic stress symptoms on the health-related quality of life in a cohort study with chronically critically ill patients and their

partners: age   matters."   *Critical   care*   23,   no.   1   (2019).
doi:10.1186/s13054-019-2321-0

Online sources

Amsterdam Institute for Social Science Research. "Procedure for ethical review of research plans". Accessed May 14 2020, http://aissr.uva.nl/binaries/content/assets/subsites/amsterdam-institute-for-socia l-science-research/map-1/aissr-ethical-review-procedure-and-questions.pdf?14 87234676823

Andries Baart, "Presentie". Accessed June 1 2020, https://www.andriesbaart.nl/presentie/

BNN VARA. "Frontberichten", BNN VARA, 08:40-09:06. Accessed April 12 2020, https://www.npostart.nl/frontberichten/31-03-2020/BV_101398706

NHS. "Intensive care". Conditions. Last modified June 19, 2019. Accessed April 12, 2020, https://www.nhs.uk/conditions/intensive-care/ .

Park, C. L. "The meaning making model: a framework for understanding meaning, spirituality, and stress–related coping". The European Health Psychologist. Accessed on May 21 2020, www.ehps.net/ehp.

The World Health Organization, "Health statistics and information systems", WHOQOL measuring quality of life, accessed april 19, 2020, https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

Creswell, "Prototypical Versions of the Six Major Mixed Methods Research Designs". Accessed on May 14 2020 https://www.sagepub.com/sites/default/files/upm-binaries/35066_Chapter3.pdf

Appendix I

Interview guide

1. Wilt u mij in grote lijnen vertellen wat er in de periode tijdens de IC opname is gebeurd?

    a. En hoe u dit heeft ervaren?

    b. Wilt u mij vertellen wat er gebeurd is na uw ontslag?

    c. En hoe u dit heeft ervaren?

    d. Wat betekent deze ervaring voor u?

2. Welke steun en inspiratiebronnen zijn voor u belangrijk?

    a. Spelen deze een rol in uw dagelijks leven?

    b. Zo ja, wat is deze rol?

    c. Zijn deze bronnen van belang voor balans en veerkracht?

3. Met welke levensvragen en gevoelens wordt u geconfronteerd?

    a. Zijn dit herkenbare vragen en gevoelens voor u?

    b. Hoe gaat u hiermee om?

    c. Bespreekt/deelt u dit met anderen?

        ■ Zo ja, met wie? op welke manier? en hoe vaak?

        ■ Zo nee, kunt u uitleggen waarom niet?

4. Spelen zorgverleners een rol in het omgaan met de ziekte en in het omgaan met deze emoties en vragen?

        ■ Zo ja, wat heeft de zorgverlener hierin voor u betekent?

        ■ Zo nee, had u wel wat van zorgverleners verwacht?

    b. Wat had een zorgverlener hierin kunnen betekenen voor u?

5. Wat doen zorgverleners precies en wat laten ze zien?

- ■ O aandacht in houding
- ■ O verkennen en in kaart brengen van emoties en vragen op bovengenoemde gebieden
- ■ O begeleiding
- ■ O crisis interventie
- ■ O doorverwijzen

6. Wilt u mij eens vertellen wat in uw ogen een goede zorgverlener is (of beter: goede zorg is) ?
    a. Wat betekent goede zorg voor u?
    b. Heeft u bij deze omschrijving ook een of meerdere specifieke zorgverleners voor ogen met wie u in de laatste maanden veel te maken heeft gehad?
        - ■ Zo ja, wie?

7. Wat betekent kwaliteit van leven voor u?
    a. Wat betekent gelukkig zijn voor u?
    b. Op welke momenten voelt u zich tevreden met uw huidige leven?
    c. Wat heeft u nodig om (meer) kwaliteit van leven te ervaren?

8. Spirituele zorg gaat om de begeleiding bij zingevings en levensvragen door een zorgverlener. Maar ook om de aandacht en erkenning die de ander voor u en uw vragen of wensen had toen u het moeilijk had.
    a. Ik vind dat het tot het vakgebied van de zorgverlener hoort om spirituele zorg te verlenen:
        - ■ O zeer mee eens
        - ■ O mee eens
        - ■ O ik twijfel daarover
        - ■ O mee oneens
        - ■ O absoluut mee oneens

9. Als een van de eerste vier opties aangekruist is:
    b. Wanneer vind u het dan gewenst en gepast om spirituele zorg te verlenen?

c. Hoe moet dat bepaald worden?

d. In mijn ervaring is de aandacht voor spirituele zorg door zorgverleners aan Intensive Care Patiënten

- ■ O onvoldoende
- ■ O voldoende
- ■ O erg goed

e. Indien er iets verbeterd kan worden: wat en hoe?

Appendix II

Themes, categories and codes

Core theme: dealing with uncertainty

Expectations:
1. competition
2. unfulfilled wishes
3. consequences
    a. going back
    b. failure
    c. difficulties
    d. relapse
4. well-being
5. future
    a. second chance
    b. recovery
    c. normality
    d. worries

Loss of control:
6. powerless
    a. life and death
    b. unconscious
    c. being handled
        i. traumatic
    d. decision by others
    e. being told
    f. being helped
    g. functioning
        i. Sickness
            1. stagnation
            2. no improvement
        ii. bodily functions
            1. loss of sensation
            2. impaired
            3. lack of energy
            4. memory loss
            5. unbearable
7. Coping
    a. expressing
    b. being inspired
    c. carry on
    d. self-protection
    e. reason
    f. survive
        i. resist

1. blame
   ii. trying
   iii. fighting
g. acceptance
   i. new meaning
   ii. realisation
      1. evidence
   iii. learning
   iv. adapting
   v. moving on
   vi. being conscious
      1. reflective awareness
      2. living in the moment
      3. focus
      4. recognition
      5. enjoying the moment
   vii. being content
8. circumstances
   a. unexpected
   b. sudden change
   c. admittance
   d. happening
   e. unfairness
   f. unknown
   g. emergency
   h. isolation
   i. hospital
      i. ambulance

Care professionals:
   j. expertise
      i. different expertise
      ii. inhuman
         1. incomprehension
         2. unheard
         3. unsympathetic
         4. unseen
         5. silence
         6. unanswered
         7. unusual behavior
         8. lack of communication
      iii. humane
         1. emotions
         2. trust
         3. attention
         4. empathy
         5. understanding
         6. negotiable
         7. altruism
      iv. advice
      v. professionalism
      vi. honesty
      vii. accompanying

        viii.   transparency

Needs:
9. self-esteem
    a. positive experiences
        i. first experiences
        ii. motivation
        iii. home
        iv. success
    b. insecurity
    c. being different
    d. being valuable
        i. appreciation
        ii. rejection
        iii. useless
        iv. contribute
10. autonomy
    a. being taken seriously
    b. strength
    c. respect
        i. acknowledgment
    d. needing help
    e. being dependant
    f. boundaries
    g. being true to oneself
        i. unawareness
11. support:
    a. positive communication
    b. therapy
    c. care
    d. social interaction:
        i. talking with each other
        ii. alone
        iii. family
        iv. partner
        v. parents
        vi. reaching out
        vii. contact:
            1. similarities
            2. sharing

Feeling:
12. unhappy
13. optimistic
14. guilt
15. hope
16. annoying
17. feeling cramped
18. pain
19. familiar
20. appreciation
21. outsider
22. anxiety

a. fear
b. stress